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Unpacking Support Types in Online Health Communities: An Application of Attraction-Selection-Attrition Theory

Research-in-Progress

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Abstract

Online communities are increasingly becoming part of the healthcare ecosystem, as they allow patients, family members and carers to connect and support each other at any time and from any location. This support can take many forms, including information, advice, esteem support and solidarity. Prior research has identified the Attraction-Selection-Attrition Theory as a promising framework for modelling and explaining how participants join, participate, and leave organizations in general (and online communities specifically), and how the actions of individuals effect the organization as a whole. However, it has not previously been applied specifically to online health communities (i.e. those that focus on physical and/or mental health). We propose to gather empirical evidence from a large online community that provides support for Australians effected by cancer. In doing so, we hope to develop evidence-based policies and procedures for growing, maintaining and moderating these communities.

Keywords: Online health communities, ASA Theory, Online support, Cancer patients

Introduction

Online communities are increasingly becoming part of people's everyday lives, as they allow members of the community to connect, share information and experiences, and exchange social support online (Abedin, 2016). In particular, the popularity of online health communities has significantly increased in the past few years among cancer patients and their carers (Bender et al. 2011). Recent research in information systems as well as digital health literature shows that using these communities can have significant positive impacts on psychological wellbeing of users (Erfani et al., 2016), since users can meet like-minded people, exchange emotional and informational support, and even receive professional advice from community moderators (Erfani & Abedin, 2018). Using online communities can also have potential adverse outcomes such as overloading users with a lot of information, therefore carefully considering moderation as well as adopting plans for mitigating potential risks are very important. Online communities, and particularly online health communities, are emergent information systems that require researchers to use relevant theories for interpreting the interactions between the host organization, community members, and the community technology. A relevant theory enables researchers to articulate the value of the community for its members, and to describe how the interplay between various stakeholders with each other give rise to particular outcomes. Therefore, in this study we draw upon the Attraction-Selection-Attrition (ASA) theory. The theory assumes that attraction, selection and attrition determine the type of people who are attracted to an organization, select it and stay in that organization. The theory proposes that, over time, "organizations become defined by the people in them as a natural outcome of an attraction-selection-attrition (ASA) cycle" (Scheneider et al., 1995, p 747). Butler et al (2014) later extended this theory to the for-profit online community context and named it Attraction-Selection-Attrition (ASA) theory for Online Communities (OCASA). They did so with a premise that attraction of members to an online community, their selection to stay and engage in the community, and community attrition are central to the emergence of discussion community characteristics. Butler et al. (2014) recognize the limitation of their model for non-commercial purposes, and that a cost-benefit analogy based on tangible financial rewards may not be applicable to them. They acknowledge that "*the extent to which other factors drive member expectations and participation decisions in ways that are inconsistent with cost–benefit logic is a limit on the generalizability of the simulation model presented [in their proposed ASA theory for online communities]"*. They invite future studies to develop, test, and analyze, *"alternative operationalizations of the OCASA theory would strengthen its value as a foundational theory for describing the role of community platform technologies in community growth and sustainability*."

Thus, firstly we reviewed the literature to synthesize existing work on social support in online cancer support communities and to aggregate scattered work on various support exchanged in these communities. This led to development of a framework that depicts the most valued types of social support that are provided in the online cancer support communities, which elaborates why people may select and join an online health community. Next, this paper contributes to the second stage of the OCASA theory, 'Select'. We did this as we examined textual discussions in one of Australia's largest online health community for cancer patients, Cancer Council Online Community, and presented the preliminary empirical findings that show the types of support which are discussed in the Cancer Council Online Community. The community under study is hosted and managed by Cancer Council NSW. Cancer Council NSW hosts a set of active online forums for people with cancer as well as their family members and friends to exchange informational and emotional support with other community members. These forums have been organized based on several areas of interests, and increasingly are attracting more and more users from across Australia and overseas.

Background

Attraction-Selection-Attrition Theory for Online Communities (OCASA)

While some online communities can attract, and maintain a large number of members, research shows that most communities fail do to so and struggle to grow and retain members (Abedin et al., 2010), which in turn damages the dynamic engagements within the community and limits its sustainability. Butler et al. (2014) argue that the community size as well as its resilience are critical for its success and create a self-reinforcing loop: a small community that cannot retain its members limits members' engagement and contributions, which consequently brings down the benefits and outcome for its members.

The OCASA offers three stages for online communities Butler et al (2014):

- Attraction: members join a community when their initial fit expectations are high and when they trust joining the community has benefits for them. This, in turn, puts a stress on the match between new members' anticipated benefits of joining the community and their perception from the relevance and value of a particular online community (even though chances are they may in fact have made a wrong judgement about the true fit with their interests).

- Selection: when new members expose themselves to activities and discussions after joining the community, their fit expectations change. These expectations evolve as members use the community resources and exchange interactions with others. Over time, they gain a real understanding of the benefits they receive by staying engaged in the community. Members may experience a variety of benefits from using online communities, particularly online health communities, such as access to information and support (Erfani et al., 2016), sense of community (Abedin et al., 2010), and access to expert advice (Lampel and Bhalla 2007). Members' perceived value from their first-hand experience leads them to revise their expectations about the future availability of such benefits, and thus decide whether to stay in the community as well as how much they should stay active and engaged in the community.
- Attrition: the third stage of the theory focuses on when individuals leave an online community due to their perception that the community's future activities diverge from their own interests. When the number of people leaving the community is greater than new arrivals, the community size and characteristics will be impacted as the level and direction of members' contributions will be changed. These changes create a new cycle, in which other members' ongoing assessment of the community's benefit will be influenced, which in turn can lead to follow-on departures and even more topic changes. Butler et al (2014) argue that such changes collectively change the community's long-term trajectory, thereby affecting a community's relevance and sustainability over time.

In this paper, we specially address OCASA's 'Selection' stage, and review the literature for understanding support types that members are looking for in choosing and staying engaged in an online health community. We focus on this stage because if community owners fail to meet or effectively shape members' expectation during the 'Select' stage, the ASA theory then suggests members are very likely to leave the community or not participate. We then present initial empirical examples for each support type.

Overview of Online Cancer Support Communities

A cancer diagnosis is a life-changing event and takes a great toll on a person's psychological wellbeing and quality of life (Moyer et al. 2014; Erfani et al. 2017). Emotional support and informational support can reduce some of the distress cancer patients experience (Erfani et al. 2016), benefiting them in terms of mood (Bender et al., 2011), ways of handling potentially difficult situations (Thompson et al. 2016), and strategies for managing stress (Weinberg 1995; Janssen et al. 2016). Many patients are unable to get adequate support because the disease itself often closes off communication with family and friends (Dunkel-Schetter, 1984; Farmer et al. 2009). Friends or relatives are uncertain about what they should or should not discuss with the patients. Patients themselves may be unwilling to share their distress with their families because they do not wish to put further burdens on them and may look for other support channels, such as patients with similar diagnoses (Thompson et al. 2016). Online cancer support communities enable cancer-affected people – cancer patients, cancer survivors and cancer caregivers – to exchange health-related information and experiences, make contributions to discussions and comprehend the information they acquire, and promote changes in health-related behaviors and consequently experience improved quality of life (Hong et al. 2012; An et al. 2016). Communication occurring on online support groups may traverse a variety of topics. The content of messages posted to online health communities can be analyzed to reveal participants' use of the medium, the communications that members are exposed to and aspects of audience activity. Research into online cancer support communities would provide evidence of their effectiveness, and an understanding of the needs of patients and family members who participate in online communities would allow the development of policies to address those needs. To date, there has been little such work in this field.

Support Types in Online Cancer Support Communities

Patients and their families seek multiple sources of health information as well as to connect with other patients with the same or similar disease through online communities (Farmer et al. 2009; Rubenstein et al. 2015). Previous studies show that a key outcome for patients using online communities is social support, notably empathy, which has a direct impact on patients' satisfaction with care, the success of the treatment and the healing process (Nambisan, 2011). Discussions in online cancer support communities cover many topics (Bender et al. 2011). Gustafson et al. (1994, 2001, 2005) investigated the impact of the earliest web-based support resource, the Comprehensive Health Enhancement Support System (CHESS), on women with breast cancer. They found that community members actively used the discussion board section available in CHESS to find and provide information about their medical condition, medications and side effects of treatment, fatigue and diagnostic tests. Members also shared alternative treatments and nonmedical information such as information about their personal lives and interests (e.g., gardening, crafts, family, holidays, and church and community activities). These studies show that in addition to seeking and providing information, members exchanged valuable emotional support including understanding, support, empathy and motivation. Members often expressed emotions in relation to topics such as family concerns and recurrence of cancer. Similarly, Weinberg (1996) conducted a pilot study on breast cancer support community and patients' use of a computer bulletin board, and found that community members exchanged information about their medical conditions, diagnostic tests, receiving good care, finishing treatment, and gaining inner strength and a positive outlook. Non-medical topics, including jobs, family, friends, homes and social activities, were also discussed in the online cancer support community. The study revealed that patients exchanged emotional support hope, prayers, empathy and showed willingness to listen. Members wrote about their concerns and exchanged supportive statements, sympathy and encouragement.

Sharf et al. (1997) applied participant-observation analysis to communication occurring on the Breast Cancer List (an online breast cancer support community). They divided the posts into four categories: (i) treatment and disease information, such as the meaning of diagnostic information, side effects of chemotherapy, radiation and surgery, and alternative treatments; (ii) practical information, including books and literature on breast cancer; (iii) personal experiences of diagnosis and side effects of treatments; and (iv) emotional support, such as offering love, prayers, hope and inspiration.

Meier et al (2007) conducted content analysis of messages sent to the online cancer support community hosted by the Association of Cancer Online Resources. The most common topics were treatment information, side effects, clinical trials and how to communicate with health care providers. Members gave emotional support in the form of encouragement, empathy and sympathy, emotional coping strategies, esteem support, prayers and solidarity. Members encouraged each other to stay vigilant for recurrences, seek appropriate treatment and overcome obstacles. They wrote messages to show that they understood the feeling of their peers and shared descriptions of attitudes that they had found helpful. Their contributions built a sense of self-worth, inspiration and competence, and engendered a feeling of solidarity so members did not feel alone in their treatment hardships.

Wiljer et al. (2011) conducted a qualitative study of women with gynecological cancer who were using an online cancer support group based on supportive–expressive group therapy. The members exchanged information on types of gynecologic cancer, emotional challenges, sexuality and body image issues, communicating with family members and friends about cancer, dealing with early menopause, self-identity issues, and management of symptoms such as pain and fatigue. Along similar lines, Gill et al. (2012) analyzed transcripts of participant discussions available in an online ovarian cancer forum hosted by MedHelp.org. Findings revealed that cancer patients shared both technical and emotional knowledge and experience. They requested information about quality of life and lifestyle management (e.g. diet and activities), self-care during and after treatment, and the effects of treatment on their lifestyle. Patients shared their personal and disease-related information and provided brief answers; they voiced their frustrations and received empathy from their community members.

Campbell et al(2013) applied a deductive thematic analysis on messages from two prostate cancer online support groups and confirmed the existence of information provision', 'provision of emotional support', 'provision of esteem support', 'noting similarity of experiences', 'discussion of sensitive topics' and 'chit-chat' which can foster patient's empowerment process. Rubenstein et al (2015) showed that breast cancer sufferers participate in online cancer support communities to find health-related information, including information about vitamin therapy, anti-cancer diets, the side effects of tamoxifen, chemotherapy side effects of treatment, sleep disorders, and diagnostic tests that has been found to affect their decision-making (Rubenstein et al., 2015).A recent study used a mixed method approach and showed that cancer-affected people who use online cancer support communities, such as ovarian cancer Facebook groups, exchange informational and emotional support and consequently experience better psychological wellbeing (Erfani et al., 2017).

Since the late 1990s', evidence has accumulated to show that cancer-affected people consider online health communities as a valuable source of support, including informational support and emotional support (Klemm et al. 1999; Sharf 1997; Bender et al. 2011; Hong et al. 2012; Erfani et al., 2017). Informational support refers to guidance, advice, facts, stories of personal experience, opinions and referrals to other sources of data and information. Emotional support includes expression of caring, hope, empathy and sympathy (Cutrona and Suhr, 1992). Table 1 shows the most valued types of social support including informational and emotional support which are often exchanged and offered in online cancer support communities, based on the literature (Sharf et al. 1997; Gustafson et al. 2005; Meier et al 2007; Wiljer et al. 2011; Campbell et al. 2013; Rubenstein et al., 2015; Erfani et al., 2017).

Case Study

Cancer Council NSW is a member of Cancer Council Australia, and is an independent charity that is 94% community funded. Cancer Council NSW's main objective is to be "Australia's leading cancer charity, uniting the community, proving support, and investing in research and saving lives". They host a set of active online forums for people with or who have had cancer, as well as their family members and friends, to exchange information and emotional support with other community members. Different cancer support topics are discussed in this community and increasingly are attracting more users from across Australia and beyond (https://www.cancercouncil.com.au/OC). In 2016, Cancer Council NSW began a program to evaluate their online community in order to provide evidence of the reach and effectiveness of the community. As part of a bigger project for a comprehensive assessment of their online support community, we obtained ethics approval for collection and analysis of the community content after removing any identifiable and personal information. We then searched the online text discussions to identify the types of social support which are offered in the Cancer Council Online Community. The objective was to assist the community moderators to gain insights about topics being discussed in the community and to guide future moderation and interventions initiatives. Support types, discussed topics, and their corresponding examples also offer preliminary findings for the ASA's Select stage. Table 1 shows anecdotal examples for the presence of all support types in this community.

Table 1. Initial empirical examples for health supports from an online cancer community

Type of support	Discussed topics	Descriptions/ Examples
Informational Support	Cancer diagnosis	Information and symptoms about cancer diagnosis *If it was lymphoma your white cell count would not have been normal*
	Cancer treatment	Information about treatment options, and factors to consider when making treatment decisions. *Without chemo the Cancer would have spread more rapidly*
	Cancer recurrence	Information on procedures for regular self-monitoring, lifestyle changes such as dietary changes, to reduce the likelihood of recurrence of cancer *Stay watchful for early signs and of recurrence*

	Cancer care and coping	*Listen to music before chemo* *Focus attention on good memory during the chemo??*
	Cancer related events and news	Information on local and national events, books and literature on cancer *Melanoma have a lot of resources in immunotherapy*
Emotional support	Encouragement	Support in persistence in facing challenges; expressing hope that situations will improve *Keep fighting the good fight*
	Empathy and emotional validation	Validating the appropriateness of another's reactions to stressful circumstances *I understand how you feel*
	Sympathy	Expressing condolences *Sorry to hear this news*
	Prayers	Offering blessings to others in distress *I wish you get some progress*
	Esteem support	Appreciation for the value of an individual and his or her accomplishments *You inspire us with your courage*
	Solidarity	Expressions of team spirit so members would not feel alone in their treatment *We're all here with you*

Conclusions and Future Work

The web is becoming an increasingly influential part of healthcare, and offers vast opportunities to transform services and innovate (Abedin and Qahri-Saremi, 2018). Consumers of health services, including cancer affected people, use the web to enhance their ability to communicate with others, in order to obtain health-related information, emotional support, products, and services (Erfani et al. 2017). In this paper, we have reviewed existing theoretical frameworks that describe the lifecycles of individual participation in organizations in general (i.e. the ASA theory) and online communities specifically (i.e. the OCASA theory). We have also reviewed existing literature on how support is provided in online health communities, and shown how these can be broadly categorized into informational support and emotional support. Finally, we have identified a promising community of study—namely the online forums hosted by the Cancer Council NSW—and shown how the different support types are manifested there.

The theoretical frameworks described above identify the selection stage as a key period in which a member is continuously evaluating the community and their place within it. Within the health domain specifically, it is reasonable to expect that much of this evaluation will revolve around the support that is exchanged. What kinds of support are most valued? What kinds of support are best offered by clinicians, community owners, moderators, or peers? To what extent should community owners and moderators offer support and address needs directly, vs encouraging peers to support each other? How can we encourage peers to continue to participate in a community after their initial needs have been met, to transfer from requesting support to providing it? These are the kinds of questions we hope to explore empirically, through the lenses of the OCASA theory. In doing so, we hope to develop evidence-based policies and procedures that will help these valuable communities flourish.

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