

Online Health Communities: Benefits, Privacy Concerns
and a Shift in the Traditional Patient-Physician Dynamic

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Abstract

This paper discusses the growth and impact of Online Health Communities (OHCs) on the daily lives of people living with chronic health conditions. Drawing on research from diverse scholarly perspectives, this paper deliberates on the extent to which affordances of associated Web 2.0 technologies have enabled individuals to seek and share information, as well as leverage the collective wisdom of others in virtual health communities (VHCs) and on platforms such as PatientsLikeMe (PLM), to better manage their illness and improve medical outcomes. Further discussion comprises the socially mediated relationships that provide valuable benefits which play a key role in the strengthening of weak ties relationships formed in virtual communities (VCs). Whilst Web 2.0 technologies have enabled chronically ill individuals to take control of and better manage their health in OHCs, research also reveals that many disregard privacy concerns whilst attempting to improve or find solutions to their health problems. Moreover, Health 2.0 having empowered patients have inevitably contributed to a shift in the patient-physician dynamic and healthcare.

Keywords: Web 2.0, online health communities, virtual communities, chronic health, weak ties, privacy, patient-physician relationship, social support, empowerment, PatientsLikeMe, healthcare, social network

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Patient-Physician Dynamic

Virtual Health Communities (VHCs) or Online Health Communities (OHCs) have grown at an unprecedented rate since the advent of the internet and more interactive, collaborative and participatory online technologies, known as Web 2.0 applications (Colineau & Paris, 2010; Fischer & Soyez, 2015; Heaton, 2011; Johnston, Worrell, Di Gangi, & Wasko, 2013; Zhou, 2018; Zigron & Bronstein, 2019). As a result, social media and the affordances of associated Web 2.0 technologies are unquestionably transforming the way individuals progressively search for information and take control of their health, particularly those with chronic illnesses (Bradley, Braverman, Harrington, & Wicks, 2016; Fischer & Soyez, 2015). Accordingly, Web 2.0 technologies with healthcare-related content is termed: Health 2.0 (Fischer & Soyez, 2015; Zhou, 2018). Johnston, Worrell, Di Gangi, and Wasko (2013) contend that OHCs offer people access to unique resources irrespective of geographical boundaries, time, or privacy restrictions (p. 214). In Health 2.0, apomediation is the term used when people seek health information online and have removed intermediaries that have been traditionally used in the process of sourcing and accessing health information (Fischer & Soyez, 2015, p.199). Unsurprisingly, medical professionals are no longer the gatekeepers of medical knowledge; as intermediaries, they have been substituted or complemented by Web 2.0 technologies and peers in OHCs who now share and provide credible information (Fischer & Soyez, 2015, p. 199). As argued by Aguiton and Cardon (2007), Web 2.0 affordances can be characterised by the astounding upsurge of publicly social connections that are facilitated by communities on the internet, the expansion of contacts made, and the formation of a new kind of weak bond or relationship (Aguiton & Cardon, 2007, p. 55). This trend of “weak ties” relationships in communities

continues to accelerate (2007, p. 61), particularly in OHCs such as PatientsLikeMe (PLM), highlighting the importance of these social relationships created in mediated spaces. While Web 2.0 platforms have enabled individuals to better manage their chronic illness and strengthen weak ties in OHCs, this is not without risk to their privacy and the disruption to the traditional patient-physician relationship.

A 2014 survey conducted by the Pew Research Institute in the United States revealed that 70% of respondents were more interested in health-related issues than any other topic on the internet (Zigron & Bronstein, 2019, p. 131). Several studies on OHCs have corroborated the assertion that people are no longer wholly dependent on medical professionals for health information and treatment decisions (Broom, 2009; Camerini, Diviani, & Tardini, 2010; Colineau & Paris, 2010; Fischer & Soyez, 2015; Heaton, 2011; Johnston et al., 2013; Zigron & Bronstein, 2019). Furthermore, various academics claim that OHCs represent a key source for medical informational retrieval and support, particularly for chronically ill individuals (Bradley et al., 2016; Colineau & Paris, 2010; Fischer & Soyez, 2015; Heaton, 2011; Johnston et al., 2013; Zhou, 2018; Zigron & Bronstein, 2019). According to a 2013 Fox survey, more than 50% of American people with chronic illnesses actively managed blogs and engaged in discussions on OHCs (as cited in Zigron & Bronstein, 2019, p. 131). VHCs enable individuals with health challenges to participate in supportive communication with other people coping with similar medical issues that would otherwise be problematic or impossible to establish in the real world (Zigron & Bronstein, 2019, p. 130). PatientsLikeMe.com (PLM), is an example of a social networking platform in which “shared patient experiences contribute to improved health self-management and support clinical knowledge” (Fischer & Soyez, 2015, p. 197).

Web 2.0 technologies facilitate VHCs, shape social relationships that exist only online in their social interactions amongst those that connect with and share a common interest or problem (Zigron & Bronstein, 2019, p. 130). The notion of weak ties in virtual spaces arises from the community as a source of diverse information, and the type of social connections between community members that nurture a sense of belonging—a sense of community (as cited in Zigron & Bronstein, 2019, p. 130). The strength of a tie is described by renowned sociologist, Mark Granovetter, “as the combination of the amount of time, the emotional intensity, the intimacy (mutual confiding) and the reciprocal services which characterize the tie” (as cited in Zigron and Bronstein, 2019, p. 130). Strong ties are referred to the relationships with close friends or family members (Zigron & Bronstein, 2019, p. 132), whilst weak ties are the relationships people form with individuals that are beyond their “immediate social network” (2019, p. 130).

The “intimacy and reciprocal services” exchanged between members are restricted to the needs pertaining to the common health problem, and whilst these participatory networks tend to promote new online relationships—weak ties relationships (Zigron & Bronstein, 2019, pp. 130-131), family and friends were often not part of the VC (Colineau & Paris, 2010, p. 142). Research has evidenced that whilst family and friends (strong ties) can provide valuable support structures, chronic health sufferers may feel that they are unable to express their feelings to others who do not share the same illness, or, may experience the “withdrawal” of close friends and family members who are fatigued from supporting them long-term (as cited in Johnston et al., 2013, p. 216). Weak ties are the people that ultimately go on to provide support, often during times of crisis such as long-term illness, and when strong ties relationships are disrupted (Zigron & Bronstein, 2019, p. 130). Peers in OHCs are increasingly favoured because they can still

maintain a “comfortable emotional distance” whilst offering support (Colineau & Paris, 2010, p. 151), strengthening the weak ties relationship. OHCs are becoming a powerful instrument in managing chronic health conditions, and this is particularly significant when patients living with a socially stigmatising and isolating illness do not receive the same level of empathy and support from society as other diseases, such as cancer (Zigron & Bronstein, 2019, p. 138). VHCs help peers cope with stigmatising health ailments by offering a less critical and more impartial place to source and obtain information and coping strategies (2019, p. 137). It is evident that OHCs significantly broaden and strengthen weak ties relationships, and participants derive manifold benefits from these socially mediated relationships (Zigron & Bronstein, 2019, p. 138).

According to Zigron and Bronstein, numerous studies identify and corroborate five key benefits of OHCs (as cited in Zigron & Bronstein, 2019, p. 131). Firstly, OHCs permit easy access and availability of information, particularly to those living in isolated locations, or who may be restricted to their homes. Secondly, OHCs help minimise socio-economic differences. Thirdly, in OHCs, the fear of rejection is reduced when members choose to either remain anonymous, or control and partially disclose personal health information that they may otherwise feel awkward doing. Fourthly, the relevance of the type of information offered in VCs, such as experiential information and coping mechanisms, help other members experiencing a similar condition to make positive lifestyle changes. Lastly, VCs facilitate social interactions among members, which helps alleviate feelings of anxiety and loneliness especially amongst individuals suffering a stigmatising illness (as cited in Zigron & Bronstein, 2019, p. 131). The potential of OHCs can be evidenced utilising the unique, open-sharing, data-rich site, PatientsLikeMe (PLM).

PLM is a social networking platform to more than six hundred thousand patients who have access to at least 2800 health conditions such as cancer, rheumatoid arthritis, fibromyalgia, and diabetes (<https://www.patientslikeme.com/>). PLM provides tools to users to help self-track their health as they interact with and share detailed real-world experiences, side-effects of medications and outcomes with other individuals of the same illness to help improve their lives (<https://www.patientslikeme.com/>). Zigron and Bronstein (2019) argue that the weak ties relationships in VCs are, therefore, far more salient than the role of strong ties relationships (p. 132). This is because members in a VC do not belong to the same social circle of friends and relatives, are not geographically or physically constrained, and provide a much-needed point of comparison and diversified experiential information which is not necessarily available from a more intimate relationship (as cited in Zigron & Bronstein, 2019, p. 132). Medical professionals and researchers have realised the potential of OHCs such as PLM, as they harness Web 2.0 affordances to aggregate data from consenting PLM patients to streamline or improve treatments (Bradley et al., 2016; Colineau & Paris, 2010), and to conduct further clinical trials and patient-driven research (Bradley et al., 2016; Heaton, 2011).

Academic studies provide valuable insights into the beneficial impact of OHCs on people with chronic health challenges. A 2003 study conducted by Wright and Bell revealed that when people write about their health problems and share personal information on OHCs, it can be therapeutic (Heaton, 2011; Zigron & Bronstein, 2019). Heaton (2011) contends that a key coping strategy of patients is to become extremely well-informed about their illness, find ways to manage their daily lives and to be able to discuss their health knowledgeably with their physician (2011, p. 217). Interestingly, OHCs may enhance or even supplant traditional face-to-face patient support groups; members exchange technical information about new treatment options, engage in

discussions about their lived experiences, as well as motivate one another (Heaton, 2011, p. 217). Web 2.0 empowers individuals to make more informed choices by leveraging the collective wisdom of OHC members—trust and confidence are built as information in most communities are actively vetted and filtered for inaccuracies (Colineau & Paris, 2010, p. 149). Informed peers of OHCs also help clarify medical jargon used by health professionals that may be confusing and difficult to understand (Johnston et al., 2013, p. 226). In a peer-to-peer relationship, information is often communicated swiftly “without borders”, thus encouraging despairing patients to attempt a new treatment predicated on the triumphant anecdotes of other OHC members (Colineau & Paris, 2010, p. 157). Web 2.0 technologies have enabled members of some OHCs to advocate for more obscure and largely unknown diseases, not only amongst the VC, but also across the populace, and further still by campaigning for reforms to government policies (Heaton, 2011, p. 218). The internet and digital technologies have indisputably enabled chronically ill individuals to better manage their illnesses and improve medical outcomes, but this is not without risk to their privacy.

Zhou (2018) proclaims that once information is posted online, it is in the public domain and can have unintended consequences (p. 287). Posts in OHCs may contain sensitive information such as an individual’s personal contact details, demographic data, financial status, therapy sessions, or treatment archives—all of which can be easily accessed by anyone (Zhou, 2018, p. 288). Some patients in one study perceived this risk as a small drawback that is counterbalanced by the richness of their social interactions and the empathy people demonstrated in OHCs (Colineau & Paris, 2010, p. 155). Another study of OHCs in China validated that privacy concerns and financial risks were frequently disregarded by patients for more valuable information and intangible psychological and social benefits (Zhou, 2018, p. 293). This was

particularly evident when people were faced with a long-term or life-threatening illness; therefore, disease severity directly impacted patients' decisions (Zhou, 2018, pp. 293-294). However, a surfeit of information and misinformation can disempower patients and contribute to a shift in the traditional doctor-patient dynamic (Johnston et al., 2013, p. 215).

As patients become more informed and proactive about their chronic health illnesses due to an abundance of specialist knowledge online, this can disrupt the power traditionally held by the medical elites (Broom, 2009; Colineau & Paris, 2010; Fischer & Soye, 2015; Johnston et al., 2013; Weinhold & Gastaldi, 2015). A study conducted by Broom illustrates patients' feelings of disempowerment when some physicians displayed antagonistic attitudes towards the informed patient in the medical encounter (Broom, 2009). Some professionals felt their power and authority as an expert threatened when treatment options and medications were challenged by informed patients (Broom, 2009). Colineau and Paris (2010) assert that the doctor-patient relationship is also perceived as a "more clinical one" since most physicians lack lived experience and are, therefore, unable to express empathy towards the patient (pp. 156-157). Informed patients may also observe that their physicians are not fully cognisant of all the most current medical treatment options, or, have dealt with many cases of that particular illness which could result in significant delays before a treatment becomes available (2010, p. 157). Broom (2009) argues that even though the majority of medical professionals are receptive to the vital shift in "self-help culture" (2009, p. 34), Weinhold and Gastaldi concede that it is a slow process to effect change in the traditional patient-physician relationship (2015, p. 194). Nonetheless, healthcare is "shifting from physician towards patient-centredness" (2015, p. 186), and it is crucial for patients and medical professionals to enhance health processes and outcomes by effectively sharing information and engaging in unified decision-making (pp. 186-187).

Managing a health condition is an emotionally challenging and daunting undertaking for any individual. A plethora of academic research validates that online health communities are becoming an increasingly powerful tool in managing chronic health ailments. Easy access to Web 2.0 technologies has enabled people to become more engaged in their health and well-being. Chronically ill individuals experiencing similar health challenges benefit immensely by sharing diverse information, experiential knowledge and personal success stories with acquaintances formed in OHCs. These new social bonds play a crucial role in helping to reduce social stigma and isolation and the need for social support and empathy have further strengthened these new weak tie relationships. However, research has evinced that patients sometimes privileged intangible psychosocial benefits received from the support systems in OHCs over privacy concerns and financial risks. Whilst Web 2.0 technologies have enabled people to take control and better manage their chronic illnesses, this has inevitably contributed to a shift in the traditional power dynamics between patient and physician. By leveraging the collective wisdom of peers in OHCs, empowered individuals have disrupted traditional medical hierarchies and continue to challenge an antiquated model of healthcare. Health 2.0, however, is still relatively new and healthcare is slowly and continually reforming to become more patient-centred. OHCs possess the remarkable potential to change the course and speed of health research; therefore, further studies on OHCs are imperative. This can elucidate how patients involved in clinical trials and patient-driven research on social networking platforms such as PLM, are contributing to chronic health management and ameliorating healthcare in the process.

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