

Sharing and Caring: The Giving and Receiving of Information in Online Chronic Disease Communities

Rosemary Stockdale

Swinburne University of Technology, Australia
rstockdale@swin.edu.au

Craig Standing

Edith Cowan University, Australia
c.standing@ecu.edu.au

Susan Standing

Edith Cowan University, Australia
s.standing@ecu.edu.au

Abstract

Online chronic disease communities are part of a healthcare phenomenon that empowers people to self-manage their condition. This paper discusses the growth and structure of such communities to identify the ways in which the sharing of information contributes to improved health outcomes. We draw together findings to offer a research agenda that will inform further studies in this complex area.

Keywords: Online communities, information exchange, chronic diseases

1 Introduction

The fast growing diffusion of online communities for people with a medical condition has added to the many expressions of concern about the general public's use of the Internet for health purposes. In 2000, Preece reported on the hype over the question of how the Internet would change the way that doctors and patients interacted (2000). In the same year Burrows et al., (2000) emphasized the 'strong and unambiguous relationship between social support and both physical and mental health and well-being' (p.99), arguing that the potential of the 'cyber dimension' forms a necessary area for re-assessment of social policy to enhance health and wellbeing. Nevertheless, ten years on there remain many unanswered questions regarding the impact on medical services of

more informed patients and the ability of virtual communities to support and increase self management of individuals' medical conditions.

The very wealth of literature has led to a confused research field with studies published in a diversity of journals. While this paper draws on articles from different disciplines, it concentrates on the specific aspect of information exchange in online communities dedicated to chronic health conditions. We draw together the findings from both theoretical and empirical studies to contribute to a greater understanding of online chronic disease communities (OCDCs). This provides a basis to identify a research agenda for analyzing information exchange in online health communities and contributes towards improving the overall care of people with a chronic disease. Our aims are therefore to identify the factors and their relationships that contribute to effective OCDCs and to use these to develop a research agenda.

OCDCs, unlike many other communities, can fulfill both an informational and a social purpose. These two dimensions are important for both sufferers and their carers. OCDCs are part of a healthcare phenomenon, which empowers individuals to manage their illness, be better-informed and less reliant on professional healthcare workers whose job constraints allow little time for extensive information giving.

In this paper we first discuss the growth and structure of online communities and their role in the management of chronic disease, before examining the exchange of information to identify what is known about the ability of OCDCs to contribute to the care of people with chronic diseases. Finally, we draw on the findings to propose a research agenda that will contribute to a clearer view of the way forward in this complex and important area.

2 Online Chronic Disease Communities

As medical science has extended life expectancy and raised expectations of better health the pressure on healthcare services has become increasingly intense. The length of consultation with a doctor is estimated at 8 minutes (Sillence, et al., 2006) with patients' input averaging 16 seconds (Preece, 2000). The Internet provides a well-used alternative source of health related information (Eysenbach et al., 2004) as people seek to make sense of their medical symptoms; particularly those diagnosed with a chronic disease that is life altering and requires a degree of self-management to alleviate the onset of more serious medical problems.

Chronic diseases are those that:

'mostlydo not resolve spontaneously, and are generally not cured completely. Some can be immediately life-threatening..... Others can persist over time and can be intensive in terms of management' (<http://www.aihw.gov.au/cdarf/index.cfm>)

The use of OCDCs for building networks of people sharing a chronic disease has been growing and there is early evidence that membership can improve individuals' self-management (Johnson & Ambrose, 2006; Leimeister et al., 2008; Radin, 2006; Temesgen et al., 2006). This improves a patient's sense of self-efficacy with corresponding improvements in pain reduction, immunological functioning and social inclusion (Winkelman & Choo, 2003). Less than 10% of people join local support groups (McArthur et al., 2006) and there are many barriers to socializing in a local environment including geography, education, finance and embarrassment (Lasker, Sogolow, & Sharim, 2005; White & Dorman, 2001). The online environment promises

advantages for extending social networks, which broaden the scope of behaviour and extends support, information sharing and encouragement (Warren, 2006). Geography becomes less relevant and finance is often restricted to the ability to access the Internet. Personal embarrassment is overcome by the anonymity that is possible online and education is less of a barrier facilitated by the opportunities to seek information that is understandable and relevant to the individual (White & Dorman, 2001).

3 The Environment of an OCDC

A definition of 'online communities' remains imprecise (Lazar & Preece, 2003). We define them as social aggregations that emerge when enough people form personal relationships through maintained discussion (Rheingold, 1993) in an online, shared space with common obligations and responsibilities (Jones, 1997; Preece, 2000; Preece & Maloney-Krichmar, 2003).

An online community environment is complex. While ease of use is essential to participation, social groupings are fragile and reasons for contributing are many and varied (Wang & Fesenmaier, 2003). The dynamics of interaction are made more difficult by the lack of social clues familiar to those in face-to-face situations and therefore nurturing the right environment can be very difficult. Information retrieval is often the first reason for members to join (Wang & Fesenmaier, 2003). When this is enhanced by social elements and opportunities for networking, members identify with other participants, which transforms information seeking into the concept of community and ultimately to lasting identification that supports belonging, commitment to the community and satisfaction with the membership (Bauer & Grether, 2005).

With chronic disease, diagnosis often leads to a sense of isolation and an inability to function well within a social environment. Initial activity within an OCDC is to inform a life-changing and frightening diagnosis and gain understanding to engender a greater sense of control (Lasker, et al., 2005; Zrebiec, 2005). Assimilating information and interacting with members leads to greater participation as existing members seek to offer emotional support and understanding (Johnson & Ambrose, 2006; Josefsson, 2005).

Benefits of OCDC participation include interaction with people who can empathise from a position of experience. Interaction is asynchronous thereby enabling individuals to assimilate information and respond in their own time. The environment supports anonymity, which is particularly valuable in situations of socially taboo diseases and overcomes some of the barriers reported in joining a local support group (Leimeister, et al., 2008). Participation also encourages a larger and more varied membership than is possible in a local face-to-face environment. Research suggests that medical benefits accrue through increased self-management, which enhances a person's health and ability to function, delays onset of more severe symptoms and enhances their quality of life (Josefsson, 2005; Leimeister, et al., 2008; Stockdale, 2008; Warren, 2006).

Participation in online communities is not without risk. There is evidence to suggest that seeking medical information online can lead to misdiagnosis and misinformation (Ahmad et al., 2006) although Hart et al., (2004) found that concerns in this area tended to be more anecdotal than real. Eysenbach et al., (2004) cite instances where participation in an OCDC produces fewer results than more conventional methods of care, although they acknowledge that further research is required in this area. Similarly, Bull et al., (2005) note negative outcomes from sites that offered 'little interactive

technology, provided mostly didactic information of varying quality, and had high reading levels' (p.144). Other research suggests that such problems are perhaps overestimated and that despite a slowly changing dynamic in the patient/doctor relationship, online information can provide a valuable tool to health professionals and their patients (Hart et al., 2004).

Risk in terms of security and privacy are rarely addressed in the OCDC literature. Sillence et al., (2006) discuss the need for privacy policies on sites, but note that studies have found little evidence of participant awareness in terms of privacy. They highlight the disparity with medical professionals who display more concerns over privacy and are less influenced by the attractiveness or functionality of a site.

4 The Stakeholders

In an OCDC, stakeholders range from individuals and their carers, voluntary and profession health workers, and private and governmental bodies to social and medical researchers (Burrows, et al., 2000). All communities have a core of participants whose guidance and co-ordination is essential to the creation and maintenance of critical mass (Phang, Kankanhalli, & Sabherwal, 2009; Wasko & Faraj, 2005) and peripheral members with limited or no participation (lurkers) (Phang, et al., 2009). This paper aligns the stakeholders into two main categories:

4.1 Sponsors/Owners

Few studies examine the role of ownership in the development of an OCDC or contrast the motivations of the sponsors with the outcomes of the community. Ownership may be socially constructed (i.e. peer to peer), sponsored by a voluntary or healthcare organisation or be business orientated (e.g. a pharmaceutical company) (Stockdale, 2008). Sponsorship, and the accompanying motivations, is held to influence the social environment of the community and impact its culture (Josefsson, 2005). Although not explicitly stated, empirical studies support the concept of the strong influence of the sponsors/owners. Radin (2006) examines a peer-to-peer community for breast cancer that displays a high level of trust with a vibrant discussion board and strong evidence of self expression, sense of belonging and advocacy. A comparative level of activity is evident in Lasker et al.'s study of a socially constructed community (2005) while a similar culture of trust is found in a not-for-profit cancer community in Germany (Leimeister, Ebner, & Krcmar, 2005). In contrast a site sponsored by a pharmaceutical company has been slow to evolve and displays a conventional patient/clinician relationship in the exchange of information (Zrebiec, 2005), which may reflect negative connotations of bias associated with pharmaceutical sponsors (Leimeister, et al., 2005).

Eysenbach et al., (2004) call for more investigation of peer-to-peer communities on the basis that consumer-led self-help groups are the guiding principle of support groups. Further research is also required into resourcing issues for maintaining OCDCs and the costs associated with ongoing community activities. Another area of interest is the potential sponsorship by medical bodies where the benefits of ownership may include insights for research and practitioners (Johnson & Ambrose, 2006; White & Dorman, 2001).

4.2 Members

The majority of participants in the community are sufferers of the chronic disease and both seek and give help. The concept of reciprocity is very strong in online communities where reward is strongly associated with self-esteem (Wasko & Faraj, 2005). Additionally, there is a strong element of empathy where frequent postings such as “we know what you are going through” are common (Leimeister, et al., 2005; Leimeister, et al., 2008; Stockdale, 2008). This generosity extends to lurkers, who while seen as passive users not reciprocating in communities (Nonnecke & Preece, 1999; Phang, et al., 2009) are supported in their needs for ‘*gaining a general understanding*’ and ‘*getting answers to question*’ (Nonnecke, Andrews and Preece, 2006, p. 18).

Other characteristics of members that may affect participation are not well-known but influences on behaviour may include gender, nationality, culture, length of membership and personal characteristics (Josefsson, 2005). The nature of the disease may also predetermine characteristics of members such as age or gender (Leimeister, et al., 2005).

4.3 Other Stakeholders

The needs and actions of other stakeholders are rarely addressed in studies. They may include medical professionals and family members, who require information and emotional support in their role as carers (Leimeister, et al., 2008). In the same way, the potential benefits of OCDCs to support the provision of healthcare services are under-explored and government activity in this area seems negligible.

5 Sharing and Caring in OCDCs

The benefits of online communities appear to be particularly appropriate for information-rich industries such as travel and health (Hagel & Armstrong, 1997; Wang & Fesenmaier, 2003). The exchange of information is a primary activity in online communities, and is discussed here in terms of seeking and giving and the effects of sharing.

5.1 Receiving Information

Health issues are a primary search area on the Internet and the sheer scale of search results raises concerns about the appropriateness, applicability and quality of available information. Online communities give individuals access to an accumulated pool of specific, relevant knowledge (Josefsson, 2005). OCDC information is associated with guidance for members about preventative, diagnostic and treatment options which is based within personal experiences of the chronic disease (Stockdale, 2008).

Information can broadly be divided into specific medical and general lay person information (Josefsson, 2005), although in the latter there are distinctions between information that is simply presented and information that is a matter of debate and argument within the community (Burrows, et al., 2000). The provision of medical information appears to relate to the ownership style of the OCDC. Socially constructed communities have disclaimers against the provision of medical information and emphasis is placed on exchange of experiences. In other communities, medical experts may provide information along themes, as FAQs or in response to postings. This type of information provision has been noted to result in a more traditional clinician/patient relationship, which curtails many of the advantages of participation (Zrebiec, 2005).

The co-location of expert information and member support has been noted in not-for-profit communities (Leimeister, et al., 2008), which appear to bridge the gap between socially constructed and business sponsored communities. In some cases the provenance of the information is not always clear and in some OCDCs economic influences may come to bear, such as recommendations of treatments related to a sponsoring organisation and the lack of disclosure on alternative treatments (Leimeister, et al., 2008).

Once the basic need for information is satisfied, it is the interaction of people with a common interest that predominates and exchanges between peers most often relates to non-disease topics. Radin (2006) found that postings were primarily about seeking emotional support while queries and medical information were second and third. She refers to the collective intelligence of an online community where lay people can interact with others to “understand their situation in detail, compare notes with others, reconstruct knowledge” and thereby form opinions and find support (p.600). This view is evident in Leimeister et al.’s (2005) study of a German cancer community, which is provided by a specialist cancer organisation, where discussions move beyond the need for medical information. The factual information is supplemented by discussion forums, relationships are formed (i.e. sharing experiences and comparing notes) and sometimes transferred to face-to-face situations, and the sharing of experiences and information is seen as a means of support (i.e. reconstruct knowledge).

However, an interesting contradiction is found in a community for Primary Biliary Cirrhosis (PBC), where there is a greater seeking of ‘biomedical information’, although mixed within socio-emotional postings, such as where specific medical information is accompanied by comments of thanks or coping or other forms of emotion (Lasker, et al., 2005). This difference in balance of information and emotional support is attributed to the rarity of the disease (approximately 15000 people in the US) and consequent lack of knowledge, with doctors learning alongside the patient. Few medical professionals have experience of treating PBC and the community offers a substantial amount of information to its members, carers and families as well as being closely involved in research projects aimed at more understanding of the disease and its treatment.

The contradictions in these communities require further research to establish whether the forming of collective intelligence is a key role in the development of an OCDC. In some studies the building and sharing of ‘reconstructed knowledge’ and the understanding of the effects of the disease underpins the ability of the community to interact and develop a socio-emotional role. In other cases the socio-emotional needs predominate and the building of a knowledge sphere develops from the actions of members sharing information.

The requirement to satisfy biomedical information needs before progression to the socio-emotional is also found at an individual level. Recently diagnosed patients seek knowledge of their condition to reduce feelings of uncertainty and promote feelings of control and hope (Radin, 2006). Such people have a need to understand the implications of their diagnosis and to overcome the uncertainty to enable a level of control to be experienced in a new situation (Coulson, 2005). Members may then transition to the role of contributor as their management of their disease improves and move again to seeker of information as the disease becomes more developed (Lasker, et al., 2005). Within the different phases of participation there remain a more active group of members and Lasker et al., (2005) find that such core members may influence the

formation of discussions as they open new lists and post comments – leading the way into new topic areas. More research is required into the role of leaders as influencers of information seeking behaviour and what influences members to participate and share information.

5.2 Giving Information

There is extensive evidence of the motivations and willingness of people to contribute knowledge in a community that is formed online, without the expectation of immediate reward (Kollock & Smith, 1999; Rheingold, 1993; Toral, et al., 2009; Wasko & Faraj, 2005; Wellman & Gulia, 1997), but few studies specifically address OCDCs.

Wasko & Faraj (2000) identify the decision to share as primarily either economic or non-economic with different norms governing the behaviour. They found that when contributing knowledge as a public good, there was evidence that people acted ‘pro-socially’ (p.169) with the expectation of reciprocity. While exchange of information may be on person-to-person basis, the reciprocity refers to expectations from the collective community (Kollock & Smith, 1999; Rheingold, 1993; Wellman & Gulia, 1997). This accords with Ekeh’s term ‘generalized exchange’ that transforms individuals from self-seekers into members of a community who share interests, a common identity and a commitment to the common good (in Wang and Fesenmaier, 2004) and is underpinned by Wasko and Faraj’s (2005) finding that people participating in a community want to belong.

Such behaviour, that goes beyond information seeking or giving for personal gain, is reflected in the literature on OCDCs. Zreibiec’s (2005) study into a business sponsored diabetes community found that while members did access the professional medical information, by far the greatest activity was on the discussion forums where the information given and received was rarely medical, but rather directed at support and encouraging self-management of the diabetes. Access to information from other people with the same chronic disease appears to be a primary reason for membership of online communities (Coulson, 2005; Josefsson, 2005; Lasker, et al., 2005; Leimeister, et al., 2005; Radin, 2006). People appear to be intrinsically predisposed to help those in a similar situation as themselves, to create social capital within the community and to enhance their own self-esteem.

Wang & Fesenmaier (2003) discuss the theory of self-concept, where the ideal self is derived from undertaking the role expectations of a reference group. This in some ways accords with the identification of the desire for status and prestige although perhaps goes beyond this to the importance of one’s self-image as an efficacious person (Rheingold, 1993). This desire is not well recognized in OCDCs as people seek more to share their experiences and tend not to provide medical knowledge. This may be a result of the separation of medical information and the discussion forums with the former, when available, being the province of medical professionals, while the latter tends towards more exchange of social and emotional interactions. In OCDCs, accumulation of these exchanges builds a pool of valuable information and strengthens the social network ties of the community. These network ties may be seen as weak given the lack of situational cues, face-to-face information and the absence of human expression and touch. However, there are many advantages in this type of network where relative anonymity is often a motivator to contribute rather than a hindrance (Wellman & Gulia, 1997) and where there are opportunities for interaction with a very wide variety of people that broadens the experiences on which OCDC members can draw.

Further reasons for contributing information to an OCDC appear to be public opinion and hedonism. Public opinion includes the potential for advocating and informing, where the collective intelligence can be used, for example, to advance general knowledge of chronic disease or advocate for change in policies or treatment (Stockdale, 2008). The hedonistic element of online community membership lies in the ability to form friendships in the virtual space (Rheingold, 1993; Wellman & Gulia, 1997) and is evident in the strong sense of enjoyment in being part of the community. This hedonic element is strongly present in OCDCs as evidenced by the sharing of jokes, posting of non-health related information and conversational exchanges (Stockdale 2008).

5.3 Assessing Information

It is estimated that less than 50% of health information online is reviewed by a medical professional and the provenance of the information is rarely given (McKemmish et al., 2009; Sillence, et al., 2006). While there is no consensus on how to assess the quality of such information, western medicine remains evidence-based and thus accreditation via the controls of this process remains the 'gold standard' (McKemmish et al., 2009). Early concerns by medical professionals regarding the availability of incorrect information and bad advice have been well noted (Wellman & Gulia, 1997). But in an environment of costly healthcare and limited access to GPs, people continue to access health sites and must assess the reliability and applicability of unregulated information and make value judgments on its merits (Burrows, et al., 2000). Online communities offer some advantages in the assessing of health information, where members can post questions to others who have similar experiences. The asynchronous nature of the OCDC enables people to absorb information, overcome uncertainty and return for more clarification. This contrasts with face-to-face physician/patient consultations, which are constrained by time and where patients may have to absorb life changing news and listen to related information within minutes (Josefsson, 2005). Several postings in OCDCs begin with sentences such as "I have just been diagnosed with....." indicating that participants are often seeking clarification of an emotional event.

OCDC sponsors can invoke some level of assessment of the information provided on their sites by the use of experts as information providers and as moderators. The latter is well documented (Leimeister, et al., 2005; Phang, et al., 2009; Zrebiec, 2005) although rarely in studies related to socially constructed OCDCs where there are few reports of negative behaviour. In not-for-profit and business sponsored OCDCs moderation is more visible and has, in some cases, been seen to alter the types of relationships formed into a more traditional therapeutic model (Zrebiec, 2005). While professional moderation may influence trust in the medical information, there is a gradual move to less interest in professional interaction over time. This supports Lasker et al.'s (2005) view that assimilating medical information may precede peer-to-peer support activities.

Professional moderators may extend their role by including commentaries along with the moderation, and responding to current concerns expressed within the community (Burrows, et al., 2000). For example, Zrebiec (2005) reports the creation of a discussion board when participants began seeking information about nutrition (a key topic for self management of diabetes). Others see the role as less a method of assessing information and more as a balance in ensuring adherence to the community rules and behavioural norms (Phang, et al., 2009). Where the moderator is too lax or too stringent there is a risk to sociability, with a consequent impact on the flourishing of the

community. Moderators may also have a role in keeping topics on track so that relevant information is found in appropriate places with appropriate answers. This may be a facet of knowledge sharing and contributing in a more formal or economic environment (Wasko & Faraj, 2005) as no OCDC studies report this use in chronic disease sites.

6 Effects of Caring and Sharing

The effects of information exchange through OCDCs are apparent in four interlinked areas; empowerment, healthcare benefits, policy making and in education and research.

In a review of the benefits of online health communities Eysenbach et al., reported no conclusive evidence that participation was beneficial or detrimental to health (2004). However, the authors called for more research into the self-help arena of peer-to-peer communities, where greater empowerment had the potential to improve health management. This issue of bottom-up forms of self-help versus top-down professionally driven communities is becoming evident in research (Burrows et al., 2000) and introduces the notion of a challenge to medical authority. The replacing of traditional authoritative sources of information with those of lay people is challenging to conventional doctor/patient relationships. For example in a community for parents with young children participants were seen to challenge doctors' advice on immunization procedures (Burrows et al., 2000). The balance of patient/doctor relationship is changing as people gain greater understanding of their disease through access to information (McArthur, et al., 2006). Patient empowerment through the use of IT holds promise of great improvements in health care as patients become more involved as active partners in care planning, and in sharing lifestyle support information (Warren, 2006).

This raises concerns for clinicians unfamiliar with well-informed patients who may confront, discuss and disagree with medical advice. Further clinician concerns include patients' use of inaccurate or false information resulting in inappropriate action, based on misunderstanding of their own condition (Bull et al., 2005). Despite the changes that this shift in relationships requires in terms of time and training of healthcare staff, patients are being seen more as participants in their own care plans rather than as passive subscribers (Bull, et al., 2005; Warren, 2006). Wider acceptance of the efficacy of empowerment through greater participation in patients' own care, with correspondingly more positive changes in behaviour, were noted in Temesgen et al.'s (2006) study of HIV/Aids patients. Participation in CHESS (an OCDC) was seen to improve quality of life and promote more effective use of health care as individuals gained greater understanding of their condition. A further positive result is seen in improved interaction between patients and health professionals (Warren, 2006). The facility of OCDCs to enhance patient empowerment would therefore appear to be interlinked with communities' ability to bring benefits to healthcare in terms of improved outcomes.

A further consequence of empowerment and the collective intelligence that arises from a vibrant OCDC is the development of an activist role in the wider community. Participants have been seen to contribute their collective and reconstructed knowledge to underpin public campaigns (for example for drug adoption by health boards) and greater recognition of the patient as an individual (Radin, 2006). This type of activity may be far reaching and is virtually unexplored in the literature, raising several

questions about the potential for advocacy and informing public opinion by OCDC participants leading to more effective policy making.

Another potential outcome from the collective intelligence of OCDCs that remains largely unexplored relates to the opportunities for education and research. The accumulated information in the discussion boards of OCDCs has the potential to contribute to greater insights into specific chronic diseases. Such insights could be both medical and social leading to greater understanding of a more holistic view of chronic diseases and of how people can be educated to self manage their health.

7 Constructing a Research Agenda

Online communities cannot be ‘created’ (Leimeister & Krcmar, 2005), but with understanding of the underlying concepts it is possible to provide the right environment for community to flourish. There is growing evidence that participation in OCDCs has the potential to enhance people’s management of their medical condition and thereby contribute to improved healthcare. This paper raises far more questions than it has answered and identifies several areas when further research is required to more fully understand the implications of OCDCs. There is no structured development of these communities and little consistency in their intrinsic characteristics although there is appreciation of the extrinsic attributes of design (Johnson & Ambrose, 2006; Preece, 2000).

The key areas that we have identified as requiring further research within the scope of this study are shown in Figure 1 and are discussed below.

Community Characteristics

Research on OCDCs needs to examine how community characteristics influence the quality of benefits and outcomes. Determination of the characteristics that may influence the nature of the community requires understanding of the influence of the chronic disease on information sharing. Further research is required into the demographic profiles of communities and examination of cultural aspects such as nationality, language and even the medical systems within a country. Other cultural aspects include understanding the role of community leaders as influencers, the effects of moderation and the nature of advocacy as an aspect of community behaviour.

Stakeholders

The characteristics of an OCDC may in turn be influenced by the sponsors, who appear to be highly influential in development of the community culture (Josefsson, 2005). Are peer-to-peer communities the right format for encouraging self-help as posited by Eysenbach et al., (2004) or is there an argument for more medical presence in the form of health centres or other organizations taking the ownership role? (Leimeister, et al., 2005; Zrebiec, 2005). If governments are to play a role in promoting policies that encourage OCDCs, what are the implications for control, costs, administration and membership?

The actions and habits of the participants of OCDCs also require more in-depth scrutiny. How does participant behaviour affect the health experience of the individual? What is the influence of the specific disease, and its social, emotional and medical characteristics, on individuals and on the community? Another subject area that is rarely addressed is that of the other stakeholders and the effect of OCDCs on, for example,

carers, medical professionals and policy makers. Research is needed to explore how the involvement of different stakeholder groups results in different outcomes.

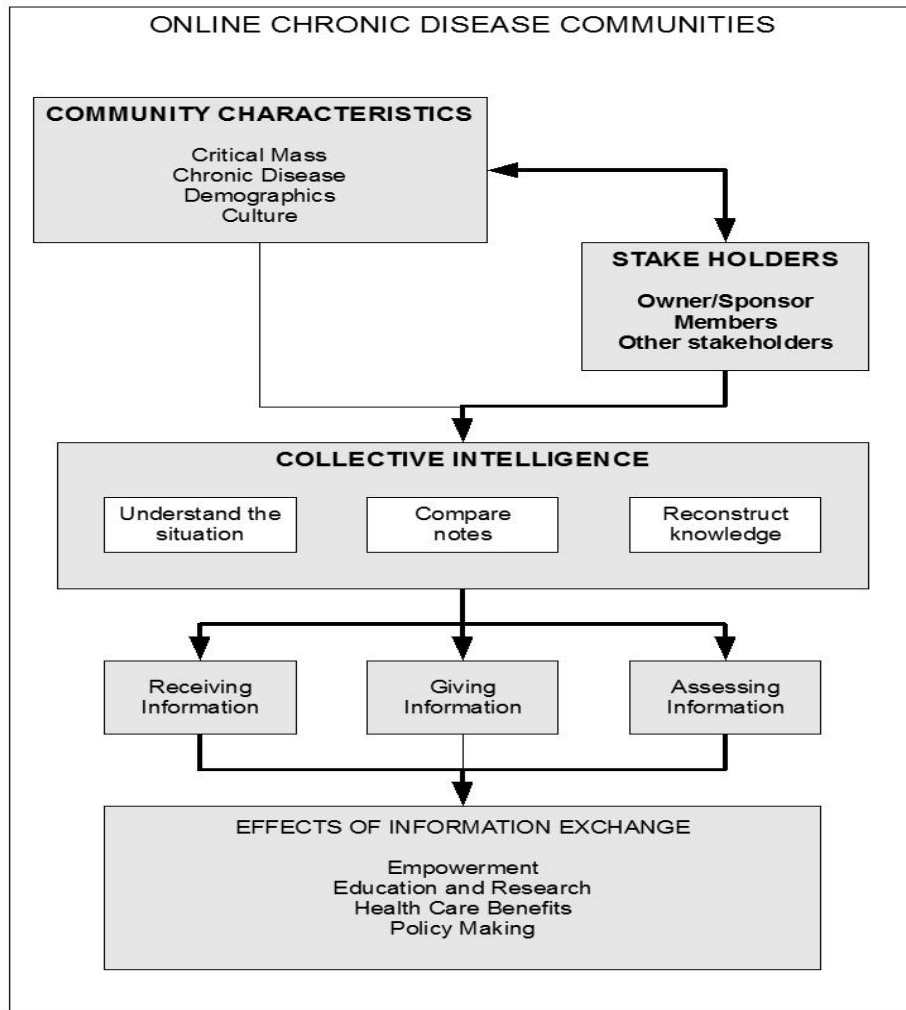


Figure 1: Key research areas for examining information exchange in OCDCs

Collective Intelligence & Information Exchange

The concept of collective intelligence (Radin, 2006) and the constructs of understanding of the situation, comparing notes and reconstructing knowledge relate well to the stages of giving, receiving and assessing information. This clearly links to work in knowledge management in relation to creation and sharing of knowledge. Nevertheless there is no detailed evidence of the stages of information sharing and whether the requirement for understanding precedes or co-exists with the need to compare and share information and experiences. Additionally, analysis of the construct of reconstruction of knowledge may lead to greater understanding of how OCDCs might influence public opinion, inform health professionals and offer opportunities for medical learning and research.

Effects of Information Exchange

The benefits of effective OCDCs are many. Importantly, they facilitate users into becoming more empowered in their health management, which often results in better overall health and wellbeing. However there are other potential benefits for stakeholders

that are not well understood and more research is required to examine the usefulness of OCDCs as a source of information for education, policy making and medical research. Further research is also required to understand the impact of the types of information being shared, how empowerment affects all the stakeholders and how information and emotional support are interlinked.

8 Limitations and Implications

This study of the theoretical and empirical evidence of OCDCs has been limited to examining the exchange of information. Although information seeking is held to be the first activity that drives prospective participants onto the Internet, online communities have the capacity to form social capital and offer emotional support. We have offered a research agenda in an attempt to consolidate existing work into online communities that specifically address chronic diseases to inform future work in this area.

The implications for practitioners of intensive research into OCDCs are extensive. There is the potential to provide insights into chronic disease management from a patient's perspective to improve future treatment plans. Opportunities to inform and improve clinician/patient relationships in a climate of greater patient empowerment are extensive and could lead to more cost effective management of chronic disease. Educational programmes and research studies could well benefit from access to a critical mass of people with a chronic disease who are well informed on their condition and familiar with sharing information.

References

- Ahmad, F., Hudak, P., Bercovitz, K., Hollenberg, E., & Levinson, W. (2006) Are Physicians Ready for Patients With Internet-Based Health Information? *Journal of Medical Internet Research* 8(3). Retrieved 3 Apr 10 from <http://www.jmir.org>
- Bauer, H., & Grether, M. (2005). Virtual community: Its contribution to customer relationships by providing social capital. *Journal of Relationship Marketing*, 4(1/2), 91-109.
- Bull, S., Gaglio, B., McKay, H. G., & Glasgow, R. E. (2005). Harnessing the Potential of the Internet to promote Chronic Illness Self-management: Diabetes as an Example of How Well We are Doing. *Chronic Illness*, 1, 143-155.
- Burrows, R., Nettleton, S., Pleace, N., Loader, B., & Muncer, S. (2000). Virtual Community Care? Social Policy and the Emergence of Computer Mediated Social Support. *Information, Communication & Strategy*, 3(1), 95-121.
- Coulson, N. (2005). Receiving Social Support Online: An Analysis of a Computer-Mediated Support Group for Individuals Living with Irritable Bowel Syndrome. *CyberPsychology & Behavior*, 8(6), 580-584.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health Related Virtual Communities and Electronic Support Groups: Systematic Review of the Effects of online Peer to Peer Interactions. *BMJ*, 328(15 May), 1166-1170.
- Hagel, J., & Armstrong, A. (1997). *Net gain. Expanding markets through virtual communities*. Cambridge, MA: Harvard Business School Press.
- Hart, A., Henwood, F., & Wyatt, S. (2004). The Role of the Internet in Patient-Practitioner Relationships: Findings from a Qualitative Research Study. *Journal*

- of *Medical Internet Research* 6(3). Retrieved 3 Apr 10 from <http://www.jmir.org>
- Johnson, G., & Ambrose, P. (2006). Neo-Tribes: The Power and Potential of Online Communities in Health Care. *Communications of the ACM*, 49(1), 107-113.
- Jones Q. Virtual communities, virtual settlements and cyber-archaeology: A theoretical outline. *Journal of Computer Mediated Communication*. 1997;3(3). Available from: <http://www.ascusc.org/jcmc/issue3/jones.htm>. Accessed 14 January 2007.
- Josefsson, U. (2005). Coping with Illness Online: The Case of the Patients' Online Communities. *The Information Society*, 21, 143-153.
- Kollock, P., & Smith, A. (1999). Communities in cyberspace. In P. Kollock & B. Smith (Eds.), *Communities in cyberspace*. London: Routledge.
- Lasker, J., Sogolow, E., & Sharim, R. (2005). The Role of an Online Community for People with a Rare Disease: Content Analysis of Messages Posted on a Primary Biliary Cirrhosis Mailinglist. *Journal of Medical Internet Research*, 7(1).
- Lazar J, Preece J. Social considerations in online communities: Usability, sociability, and success factors. In: H van Oostendorp, ed. *Cognition in a digital world*. Mahersh, NJ: Lawrence Erlbaum Assoc; 2003. p127-151.
- Leimeister, J. M., Ebner, W., & Krcmar, H. (2005). Design, Implementation, and Evaluation of Trust Supporting Components in Virtual Communities for Patients. *Journal of Management Information Systems*, 21(4), 101-135.
- Leimeister, J. M., & Krcmar, H. (2005). Evaluation of a Systematic Design for a Virtual Patient Community. *Journal of Computer Mediated Communication*, 10(4).
- Leimeister, J. M., Schweizer, K., Leimeister, S., & Krcmar, H. (2008). Do Virtual Communities Matter for the Social Support of Patients? Antecedents and Effects of Virtual Relationships in Online Communities. *IT and People*, 21(4), 350-374.
- McArthur, R., Bruza, P., Warren, J., & Kralik, D. (2006). *Projecting computational sense of self: a study of transition in a chronic illness online community*. Paper presented at the 39th Hawaii International Conference on System Sciences Hawaii.
- McKemmish, S., Manaszewicz, R., Burstein, F., & Fisher, J. (2009). Consumer Empowerment Through Metadata-Based Information Quality Reporting: The Breast Cancer Knowledge Online Portal. *Journal of American Society for Information Science and Technology*, 60(9), 1792-1807.
- Nonnecke, B., Andrews, D., & Preece, J. (2006). Non-Public and Public Online Community Participation: Needs, Attitudes and Behavior. *Electronic Commerce Research*, 6, 7-20.
- Nonnecke, B., & Preece, J. (1999). *Shedding Light on Lurkers in Online Communities*. Paper presented at the Ethnographic Studies in Real and Virtual Environments, Edinburgh.
- Phang, C. W., Kankanhalli, A., & Sabherwal, R. (2009). Usability and Sociability in Online Communities: A Comparative Study of Knowledge Seeking and Contribution. *Journal of the Association for Information Systems*, 10(10), 721-747.

- Preece, J. (2000). *Online Communities: Designing Usability, Supporting Sociability*. Chichester: John Wiley & Sons.
- Preece J, Maloney-Krichmar D. Online communities: focusing on sociability and usability. In: Jacko & Sears, eds. *Handbook of human-computer interaction*. Mahersh, NJ: Lawrence Erlbaum Assoc; 2003.
- Radin, P. (2006). "To me, it's my life": Medical Communication, Trust and Activism in Cyberspace. *Social Science & Medicine*, 62, 591-601.
- Rheingold, H. (1993). *The virtual community: homesteading on the electronic frontier*. Reading, MA: Addison-Wesley.
- Sillence, E., Briggs, P., Harris, P., & Fishwick, L. (2006). A Framework for understanding Trust Factors in Web-Based Health Advice. *International Journal of Human-Computer Studies*, 64, 697-713.
- Stockdale, R. (2008). Peer-to-peer Online Communities for People with Chronic Diseases; a Conceptual Framework. *Journal of Systems and Information Technology*, 10(1), 39-55.
- Temesgen, Z., Knappe-Langworthy, J., St Marie, M., Smith, B., & Dierkhising, R. A. (2006). Comprehensive Health Enhancement Support System (CHESS) for People with HIV Infection. *AIDS and Behavior*, 10(1), 35-40.
- Toral, S., Martinez-Torres, M. R., Barrero, F., & Cortes, F. (2009). An Empirical Study of the Driving Forces Behind Online Communities. *Internet Research*, 19(4), 378-392.
- Wang, Y., & Fesenmaier, D. R. (2003). Assessing Motivation of Contribution in Online Communities: An Empirical Investigation of an Online Travel Community. *Electronic Markets*, 13(1), 33-45.
- Warren, J. (2006). IT-Empowered Consumers and Advocates for Chronic Disease Management. *Health Care and Informatics Review Online*, September.
- Wasko, M. M., & Faraj, S. (2000). It Is What One Does: Why People Participate and Help Others in Electronic Communities of Practice. *Journal of Strategic Information Systems*, 9(2/3), 155-173.
- Wasko, M. M., & Faraj, S. (2005). Why Should I Share? Examining Social Capital and Knowledge Contribution in Electronic Networks of Practice. *MIS Quarterly*, 29(1), 35-57.
- Wellman, B., & Gulia, M. (1997). Net Surfers Don't Ride Along: Virtual Communities as Communities. In P. Kollock & M. Smith (Eds.), *Communities and Cyberspace* (pp. 167-194). New York: Routledge.
- White, M., & Dorman, S. (2001). Receiving Social Support Online: Implications for Health Education. *Health Education Research*, 16(6), 693-707.
- Winkelman, W. J., & Choo, C. W. (2003). Provider-Sponsored Virtual Communities for Chronic Patients: Improving Health Outcomes through Organizational Patient-Centred Knowledge Management. *Health Expectations*, 6, 352-358.
- Zrebiec, J. F. (2005). Internet Communities. Do They Improve Coping with Diabetes? *The Diabetes Educator*, 31(6), 825-836.