Talking Together: Consumer Communities and Health Care

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ABSTRACT

Consumer involvement in computer mediated communities (CMCs) is increasing particularly in high involvement services such as healthcare. This paper examines the role of CMCs as providers of patient information and support and the subsequent effect on the relationship between ‘informed’ consumers and health care providers. The evolving dialogue between consumers in virtual communities provides one key axis along which professional service consumption will evolve. The challenge for service consumers is to develop frameworks that facilitate robust dialogue and exchange of information and emotional support to complement their rising authority. The parallel challenge is for the established medical profession to recognise the consequences of this evolving dialogue and develop approaches to service delivery that effectively engage with consumers on the basis of this increasing authority.

INTRODUCTION

Consumer communities are not a new concept, indeed as Muinz and O’Guinn (2001) point out, the concept of community is a core construct in social thought, possessing a long intellectual history. What is new is the potential for modern communications technology, specifically the internet, to facilitate communities that lie outside of traditional social or geographical boundaries, enabling consumers to communicate with like minded individuals with whom they would not normally have contact. Evidence suggests that this type of virtual community is increasingly common: Horrigan & Rainie, (2002) suggest that 84% of U.S. internet users have, for example, visited one or more online consumer groups and 79% of them could identify at least one virtual community with which they stay in regular contact. There is evidence that participation in online forums such as chat rooms, bulletin boards, listservs and newsgroups can significantly impact on consumer knowledge and behavior, such that virtual communities act as important reference groups for their participants (Jolink, 2000; Kozinets, 1997). Clearly, the value of the internet as an information resource is potentially immense, it is in the nature and veracity of information available that problems arise. Although this might not be of particular concern in most situations, the use of virtual communities as a source of information in respect of professional services such as health care, has important implications for consumers. Specifically, if the information which consumers gather from the internet is inaccurate or biased, significant health problems may ensue. While significant research is emerging which focuses on health care professionals’ perception of internet based information (see for example Impicciatore 1997; Neuberger 2000; Eysenbach 2002; Kunst 2002; Purcell 2002) there is little research to date addressing consumers’ use of internet communities in health care situations. In this paper we examine the dynamics and use of virtual consumer communities as sources of medical information. Based on interviews with consumers and site managers, the research specifically examines the role of virtual communities as providers of patient support, consumer’s view of the information they receive in this way and the subsequent effect on the relationship between consumers and health care systems at both service delivery and policy levels.

LITERATURE REVIEW

The role of the internet in the consumption of professional services has potentially important implications for both the conceptualisation of consumer behaviour and the delivery of professional services. The internet offers consumers access to a level of specialist technical information that was formerly the preserve of service professionals. Equally, it facilitates close interaction between diverse groups of consumers across national boundaries through the emergence of service specific computer mediated communities (CMCs). Such CMCs may be viewed as analogous to the emergent online brand communities (Muniz and O’Guinn, 2001) in which the customer rather than the company is the central source of communication (Hoffman and Novak, 1996). This empowerment of consumers through enhanced access to technical information has the potential to redress the informational asymmetries characteristic of professional services and challenge the established legitimacy and power of professionals within the service delivery process (Hogg et al, 2003). Professional services have traditionally been characterised by an in-built power imbalance where the consumer engages with the professional from a position of dependency, and the professional determines what is in the consumer’s best interest on the basis of his or her professional judgement (Parsons, 1975). Mills and Moshavi (1999) describe such services as knowledge based services which “use intellectual capital—a body of ideas—to diagnose or determine client priorities and justify a recommended course of action” (p.49). Health care has been described as an arch-typical professional service (Wilson, 1994): core to the health care exchange is the fact that the consumer is inexpert, lacking both diagnostic skills and knowledge of treatment options, while the professional is presented as the specialist, possessing the relevant technical skills and knowledge. The analogy has been that of supplicant and priest:

“The consumer’s only right is to have access to the health care system, to the secular church: once that has been achieved, it is for the professional providers to determine what treatment is appropriate” (Klein, 1995 p.307)

The consumer is viewed as passive, a patient by displaying patience, deferring to the expert judgement of the professional and limiting his or her involvement to consenting to the professional’s preferred option (Ham and Alberti, 2002). Thus in the twentieth century modernist settlement, a clear boundary was apparent between healthcare professionals and the broader population of consumers.

This deferential patient-professional relationship is increasingly challenged by the ongoing socio-economic changes occurring across post-industrial societies. These have created the environmental conditions where a growing proportion of consumers are increasingly willing and able to utilise the emerging information resources to challenge this conventional professional supremacy. Driven by government policy initiatives, increased levels of education, particularly tertiary education, and high profile cases of professional negligence indicative of a ‘failure’ in health care services, the relationship between health service professionals and patients is increasingly redefined. Although the professional remains a source of professional knowledge, the patient is increasingly challenged to actively engage with the medical consultation process.

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consumers is changing. Consumers are no longer inclined to accept
the uncorroborated advice of the professional and are increasingly
turning to other sources of information to educate themselves about
their health. The internet is an important source of such information,
offering consumers a range of information sources and facilities for
discussion. No longer is technical and comparative health care
information the preserve of the professional, rather it is now
accessible to consumers (Hogg et al 2003). A key source of such
information is the virtual communities of consumers focusing on
specific conditions.

It is possible to discriminate between four types of consumer
communities active on the internet. These communities encompass
firstly, the type of brand communities discussed by, for example
Muinz and O’Guinn (2001), which are focussed on particular brands or products; secondly, communities of interest which are based
around hobbies such as gardening or cookery and members share
information about these interests; thirdly, fantasy communities
which are focused on particular computer games and share
information such as ‘cheats’; and finally communities of relationship
which are based around personal problems and illness and provide
support and information to members based on shared experience.
It is this latter group that is the focus of this research. Under the classification developed by Kozinets (2000) this type of community is
constructed around chat rooms and email lists. Following Muinz and O’Guinn (2001), we define the internet based communities examined in this study as specialised, non-geographically
bounded groups, marked by a shared consciousness, rituals and
traditions and a common sense of moral responsibility. In this context the rituals and traditions are based on an understanding of
medical care and its social practices and rituals that “serve to
contain the drift of meanings” (Douglas and Isherwood 1979, p65),
i.e. to create a common understanding of the social and cultural
experience of healthcare. To this extent we concur with Muinz and
O’Guinn (2001)’s contention that contemporary communities are
imagined, based on the sense of unmet fellow members, liberated
from geography by relatively inexpensive and accessible commu-
nication (see also Anderson 1983; Wellman 1979). The essential
difference between virtual and traditional communities is the vol-
untarily nature of membership, whereas in traditional communities
membership may be imposed by chance of birth, proximity of
residence, etc (Bagozzi & Dholakia, 2002). Membership of these
groups is highly fluid and levels of interaction with the community vary and behavioural change as a result of membership is likely to
be a result of the perceived value of the information obtained
(Okleshen and Grossbart 1998). The internet provides the vehicle
for motivated individuals to communicate, to exchange informa-
tion and to provide what Gusfield (1978) referred to as ‘conscious-
ness of kind’ provided by communities; thus by their very nature
contributing participants in these virtual communities of relationship
are high involvement consumers, having deliberately deter-
ned to engage with other consumers confronting similar situa-
tions (Mathwick, 2002).

One of the challenges faced by consumers in interacting within
such a virtual community is the legitimacy, and indeed identity of
the participants. Very little background information needs to be
supplied by participants and there is no obvious way to verify the
accuracy and quality of information available (Impicciatore et al,
1997; Wyatt, 1997). Recent developments linked to the problems of
children being contacted by paedophiles over the internet has high-
lighted that on the internet you can be whoever you want, may
make untrue claims and give inaccurate information with impunity.
This anonymity strips individuals of their ‘status trappings’ such as
race, age, gender, looks, timidity, handicaps and encourages frank-
ness (Garrison 1994) allowing the development of what Tambiah
this implies the democratic and relational nature of the internet, it
also exposes the anarchic nature of the medium: freedom from
control can also mean freedom from accuracy. Meyrowitz (1985
p.39) suggests that in any given situation we unconsciously ask
“who can see me, who can hear me? and who can I see, who can I
hear?” The answers to these questions allow the choice of appropri-
ate behaviour and the role that will be acted out. The internet alters
the possibilities by providing an alternative social situation where
the roles are negotiated beyond the normal boundaries and social
markers that determine interpersonal behaviour. Given that in most
social situations 90% of communication takes place non verbally
and that non verbal cues are the most powerful indication of
detecting deceptive communication between individuals (Argyll
1994), the absence of these cues leaves consumers exposed and
vulnerable. A fundamental requirement of such communities is
therefore trust: members trust that the participants are acting in the
best interests of the community and that they are providing
the benefit of their experiences in an open and altruistic way. This has
important consequences in health care situations where inaccurate
or misleading advice regarding, for example, drug treatments may
cause physical harm.

It is, however, important to recognise that with regard to the
actual health care information available via the internet at one level
this may in fact not be substantially dissimilar to the word of mouth
information and misinformation passed between individuals, albeit
within a broader network encompassing greater shared experience
and potentially expertise. There are frequently divergent views on
the validity of treatments, even amongst professionals (Flanigan
and Metzger, 2000) and patient support groups have been a feature
of healthcare for many years. However, it is in the range and reach
of these groups in terms of participation that the internet has had an
effect. These groups have lower barriers to participation than
traditional patient support groups in terms of factors such as time
and commitment. Importantly, because the participants can remain
anonymous and therefore protect their privacy, they are more
inclined to be open and to express views or feelings that they would
be reluctant to share in a face to face encounter. A central theme in
this regard is the scope for participants to adopt alternative identities
as part of the process of ‘anonymousisation’ facilitated by the internet.
Reflecting such characteristics on line communities offer consum-
ers the opportunity to compare healthcare systems across national
boundaries, diagnosis and treatment as well as offer mutual support
and ‘counselling’. In addition, because of the evolving expertise of
the ‘members’ of such communities, they have the potential to
provide a mechanism for consumer education, thereby addressing
the cognitive shortcomings of consumers in utilising specialist
technical information. Equally the social inter-connectedness, or
communitas that develops within net communities has been shown to
lead to the development of bonds that are as powerful as
traditional communities (Tambiyah 1996). It is against this complex
expertise and relational context that the dynamics of virtual com-
nunities require to be considered in respect of their impact on
patterns of professional service consumption.

RESEARCH FOCUS

This paper is based on exploratory research undertaken in the
United Kingdom and the United States into a small number of
consumers’ and professionals’ perceptions of health based con-
sumer communities and the impact of participation in this type of
forum on their health care experiences. In understanding and
researching such communities two types of community membership
have been identified, namely ‘posters’ and ‘lurkers’. Posters
actively contribute to the discussions and provide continuity to the
group while lurkers observe without participating (Rheingold 1993). Each may feel a sense of belonging to the community but until lurkers make a contribution to the discussion their presence is unknown to the rest of the group. As a result, in this research we only address the community of posters, i.e. individuals who are willing to participate in the discussion. The data collection involved in-depth interviews with 20 consumers who participated in such interactions (10 in the UK and 10 in the US) selected by posting a message on a range of health based web sites chosen at random from a search engine. The interviews were conducted either face-to-face or online. It is important to recognise that the consumers represented in the interview sample are ‘high involvement’ consumers, that is consumers who have experience with both the internet as an information source and participation in relationship communities. As such they are not necessarily typical of current patterns of consumption. However, they give an indication of how ‘early adopters’ are using the internet and may provide indicative evidence of evolving patterns of consumption behaviour. The interviews were supported by observation of health related discussion forums. Such participation enabled both the content and dynamic of these forums as sources of consumer information to be analysed. Whilst there are clear limitations of this research in both the size of the study and the generalisability of the findings, it provides a valuable insight in an emerging issue and as such we believe is of value to both professionals and patients.

RESULTS

Three core themes emerge from the interviews with consumers participating in internet based virtual communities. The first theme concerns the dynamics of such virtual communities, and particularly the nature of interaction within such communities. Associated with this is the issue of the quality and credibility of information and advice available through such communities as well as the implications for consumers. The second core theme relates specifically to the nature of the information available to consumers through such communities. Two key sub-themes emerge in respect of the nature of information, namely the comparative nature of the information available due to such communities bridging multiple health care systems, and the generation of participant awareness of the service options available in respect of a particular condition. Implicit within these sub-themes is the challenging of existing service provision, both at the health care system, that is policy, level and at the operational, that is consultation or service encounter level. The third core theme relates to the support function of these virtual communities both in terms of providing immediate personal support to individual consumers and in terms of campaigning for changes in service provision at the collective level.

Dynamics of Virtual Communities

The most common mechanism through which virtual community interaction occurs through the internet takes the form of so called ‘chat rooms’ (Pew Research Centre, 2001). Structurally within such a forum a host generally monitors the postings, i.e. the contributions made by participants and helps to stimulate the conversations. By effectively controlling what is posted and who is allowed into the chat rooms, hosts mediate and ‘manage’ the community. While the range and power of the host varies, they play a critical role in shaping the nature of the information exchange undertaken, in the same way as a traditional editor. This raises questions over the perceived democratic nature of the internet and the associated implication for patterns of behaviour. What is striking about the information exchanged through such forums is the level of sophistication. For example a consumer in a chat room calling herself “young women with heart disease” had a question about the risk of heart disease due to menopause. The response given by the host was:

Here is what I have learned! At menopause a woman’s risk of cardiovascular disease increases. This includes diseases of the heart and blood vessels such as heart attack, angina, stroke, and hardening of the arteries. The pro’s of hormone replacement therapy? Estrogen replacement reduces the rate of bone loss after menopause, which would affect osteoporosis. Research indicates the estrogen replacement in post-menopausal women reduces the incidence of heart disease. It may be due to the change in cholesterol and triglycerides produced by estrogen...

Although the host did not present herself as medically qualified the information provided is detailed, and explained medical treatment options in considerable depth and from a position of someone who is in the same situation. This sharing of personal experiences is a particularly powerful source of information, creating an emotional tie which generates strong source credibility and empathy. This tie may even take precedence over the traditional consumer-professional relationships, which tend to be less personal and frequently criticised for their non-empathic nature (John 1996).

Not all reported experiences of such chat rooms were positive. For example, this US consumer felt sufficiently knowledgeable to challenge the information and advice provided by the host. This highlights the ongoing importance of ‘intellectual capital’ in determining the relative power of participants in professional service ‘encounters’:

I have mainly used two Websites and one is very good, the host is objective, but the other one is very bad. The host bullies people that do not agree with his opinions and he tries to sell them treatments that he agrees with. He is selling 16 grams of hydrocortisone, which is very dangerous. I told him, so he struck me off the page. (Female– US)

Such experiences not only highlight the power dynamics inherent in virtual communities but also that in effectively utilising internet based information there is, for some consumers, evidence of a steep ‘learning curve’. Managing to get information from the internet that the consumer views as adequate can prove a challenge. Novice chat room users are inherently vulnerability to the influence of both hosts and apparently knowledgeable community members. For example a female community participant from the UK indicated:

When I first started using the internet I would like go off on all these tangents, and waste all this time, lots of junk which just confused me, some really technical stuff to which was more for scientist instead of patients. It took me a long time to learn how to use the internet chat rooms to answer my questions.

A number of key issues regarding the role of the internet as a source of health care information are evident from such representative experiences. First, the objectivity of the information provider must be questioned given the prevalence of site ownership by providers of health care products and services. This is particularly insidious in the context of a chat room, which is perceived by consumers to be an open and neutral information forum and rarely is site ownership or the affiliation of members declared. Second, the power of the host to control the conversations and to monitor participation thereby shaping the information provision has the potential for abuse, as evidenced in the experience quoted above. This is an issue of particular significance given the characteristic vulnerability of...
health care consumers arising from the circumstances under which the consumption of such ‘distress’ services occurs (Strasser et al., 1995).

Informational Function: Comparative Information

A central theme arising from this research is the comparative nature of the information accessible to consumers. This can range from advice on second opinions within a particular healthcare system to comparing treatments between countries. For example, certain treatments are not permitted under the UK NHS, where the scarcity of public resources has resulted in, and in turn been further highlighted by, decisions not to allow the prescribing of certain drugs. This leads some patients to believe that they would be better treated in other countries, for example:

The government won’t let you have that ‘flu drug, they say it hasn’t been proved to work yet, but I was on the web and they can get it in Australia—if its safe there, why not here? Its just political because they think too many people will want it, but why not? (Female UK)

These communities offer patients a network of information gathered around the world. For example a UK consumer stated:

I receive about 20 e-mails a day, using the list box system. This is how I found the current medication that I am taking, which is working. First I contacted a person in the US who put me in touch with someone in Canada, who knew a doctor in Australia, who had a colleague in London who provided me with information and treatment (Male, UK).

An important aspect of this patient-to–patient communication is the comparison of healthcare systems. One particular list box group consists of about 200 people from twenty countries and highlight deficiencies in each country’s medical system. For example an UK patient using the ‘list box’ e-mail system stated:

The list box system makes you aware of healthcare in other countries. Everybody in the US has lists of tests for the same condition that I have. They included neurological, tilt table and live blood test (TV screen). The UK government is not big in testing, they look down a government chart for a pill that fits the condition. It is silly because testing helps prevent illness. (Male, UK)

This level of dissatisfaction with their own health care system was apparent on both sides of the Atlantic with US patients perceiving the European system was better based on evidence from chat rooms:

Well I think one of problems here [USA] is that we pay too much for healthcare. In Europe they all get it free or at really low costs. I also think the pharmaceutical companies are making out like bandits, because they get a higher price in the USA for their drugs (Female, USA)

These communities emphasise and reinforce the differences in health care systems between countries and break down the traditional geographical restriction on comparison. Whilst a limited number of international travellers had previously had the experience to make these comparisons they are now regularly discussed in chat rooms with potentially significant political consequences. As these quotes indicate, this erosion of boundaries between health care systems raises fundamental questions regarding consumer choice within publicly funded health care systems and costs in privately funded systems. In the face of increasing consumer ‘knowledge’ the system of healthcare is politicised and its sustainability is brought into question.

Informational Function: Service Options

Information exchanged is not confined to health care systems or drug and other product related information. Equally several consumers indicated that they had received suggestions about tests to establish the nature of their illness, usually undiagnosed by current health care providers, for example:

For ten years I had a condition that would destroy my throat and tongue. I kept going to the hospital but they could never find the problem. I was in a chat room and someone suggested it could be an allergy so finally I told them [hospital staff] that I would not move from the chair unless they gave me an allergy test. It turned out to be an allergy to the mercury in my fillings. As soon as my fillings were changed the condition went away. It was a simple test. Why didn’t they try it first! Why did they make me suffer for ten years! (Male UK)

A central theme in this regard is the perception that professionals do not offer patients the full range of service options they expect as informed consumers. Many patients who are utilising chat rooms are often looking for alternatives to the therapies recommended by their conventional health care professional, particularly in respect of drug treatments. There was a commonly held view that the medical profession turn to drugs without considering alternative therapies and that by speaking to other patients, advice on alternative therapies could be shared, for example:

I took control over my own destiny by setting down a recovery protocol based on homeopathic medicine. I got information about alternatives to prescription medication from the chat room and brought it into my physician, he did not seem interested and I had the feeling that I was wasting his time. (Female, USA)

This indicates another common theme, namely the reluctance of health care professionals to accept the information which patients gather from such sites and their scepticism of the validity of the information. In this respect a UK respondent commented:

I did not agree with the traditional science based attitude towards illness. They seem to try to fit illnesses into a codebook and just look up the prescription. That’s why I started to look at the internet and found other people who agreed with me. (Male UK)

This is reinforced by anecdotal accounts in the letters pages of journals such as the British Medical Journal and New England Journal of Medicine from health care professionals describing consumers arriving for a consultation armed with reams of internet printouts (see Coiera, 1996; Eysenbach and Diepgen, 1998). More fundamentally such attitudes and behaviours can be seen as part of a broader questioning not just of professional power and authority but also of established scientific paradigms and the nature of knowledge in post-modern societies (Laing and Hogg 2003).

Support Function: Individual and Collective

It is clear that members find support and comfort from communicating with other people with similar conditions over the internet,
regardless of the information exchange. For example, a female participant from the USA stated that she used the internet as:

A source of hope and something to keep me busy, it also lets me interact with other patients’ which makes me feel that I am not alone.

In a similar vein a male participant from the UK described the support he gained from these chat rooms

When I was first diagnosed I knew no one else with my particular illness. I was scared and finding people on the internet to talk to helped me cope, just to know it is possible to live a normal life (male UK).

These support groups have common emotional ties through illness and strong personal bonds are formed. Many of these patients have been through the same emotional process of dealing with illness which allows them to offer support on a more personal level than professionals. The patients discuss medication and compare treatment but also support each other using terms like “hugs”, “positive things come out of negative”, “hang in there”.

Traditionally a patient’s medical history has been regarded as confidential due the personal nature of illness. This research found evidence of a cultural change associated with a more open environment of health care information through the net. Patients were willing to post entire medical histories, either describing positive success stories or negative stories of medical mistakes or drug side effects. This arguably reflects the anonymity afforded to consumers by the internet and the reduction of the parochialism associated with geographically defined communities.

An example of a success story would be “Alexandra’s heart page”, which is dedicated to a parent’s (Trent & Diane) successful struggle with their newborn baby’s congenital heart defect (http://www.geocities.com/Heartland/Prairie/1187/). This Web site included the complete patient history from diagnosis to the surgical operation that provided the cure, the child’s heart diagram, complete with initial diagnoses and a diagram of heart after the operation. When interviewed these parents commented:

Sharing our child’s treatment helped to ease the pain and also helped us to connect with other parents who had similar experiences. It was just such a traumatic experience and using the net helped to cope.

The emotional trauma associated with the treatment of their illness helped to elevate some of the negative aspects of being a primary caregiver for their child. Clearly, contributing to the web site was in itself a help to the family, in addition to support from the net public who visited the site, sent letters of support and also shared their experiences with the family. These Web sites are frequently linked through ‘webring’ technology which links Web based communities that are organised by related interest into “easy-to-travel” networks. For example, the ‘webring’ for one particular illness, namely childhood heart disease, had at the time of the research, 128 linked web-sites which received 10,682 hits in an eight-week period (http://stat/webring.com) providing a robust indication of the reach and popularity of such interconnected communities of interest.

Similarly, in addressing negative consumer experience patients who have had damaging side effects from prescription medicine are able to meet and organise against the manufacturers of pharmaceutical drugs and the established healthcare system. One example is a patient group called the National Lupron Victims Network (NLVN) (http://www.voicenet.com/~nlvn). This is an independent grass roots organization comprised of men and women who had taken the prescription drug Lupron and were experiencing medical problems after stopping the medication. The information provided by the NLVN is supplied in a factual, scientific manner indicating a high level of education of the authors and the NLVN homepage includes detailed articles attacking the clinical and medical data associated with the marketing of this drug.

Patient groups who challenge the effects of medication are not new to the healthcare environment, what is new is the speed and ease of organization with which they can develop as a result of computer based communication technologies. Such developments have important implications for pharmaceutical companies in terms of managing both the product development process and organisational reputations. It also has implications for drug regulatory bodies. If they are perceived to make a mistake and approve a drug with weak clinical data, patients through their ability to assimilate and analyse data have the ability to rapidly create an anti-drug movement. Obvious examples of such behaviour can be identified in the public rejection of the MMR vaccine campaigns in the UK against mercury based DWTP vaccines for children. Once again a key theme in this regard is the ability of such communities to mobilise data across national health care system boundaries. Inevitably this power may also be used as a ‘political’ tool to influence the drug regulatory approval process.

Of particular interest in understanding the dynamic and role of such virtual communities, is the emerging evidence that these communities are starting to develop as entities outside the net environment through the formation of geographically based chapters. For example on the “little-hearts” home page (http://nav.webring.com/cgi-in/navig.cgi?ring=littlehearts;list) there is a picture of the Connecticut group meeting for a picnic, followed by the California group expressing an interest in forming a similar social meeting. This is significant because it suggests that whilst the internet provides the impetus for these people to connect with each other it does not necessarily replace social interaction on an interpersonal level. Such developments in turn have significant implications for the role of established support and information communities centred on particular medical conditions as well as the relationship between such traditional communities and the emerging virtual communities of interest.

CONCLUSION

The emergence of virtual communities of interest in health care has profound implications for future patterns of health care consumption and delivery. By creating forums where consumers can address complex health care problems relatively free from the script and role constraints imposed by health care professionals, the resultant inter-consumer dialogue empowers health care consumers to challenge conventional patterns of behaviour and interaction. Specifically by offering consumers access to technical and comparative information, as well as by facilitating consumer understanding of such information, the dialogue in such communities creates the scope for consumers to re-balance the health care encounter from one of elitist professional domination to a more egalitarian format. In its most acute condition, the conventional boundary between the informed consumer and the established medical profession dissolves. If they are perceived to make a mistake and approve a drug movement. Obvious examples of such behaviour can be identified in the public rejection of the MMR vaccine campaigns in the UK against mercury based DWTP vaccines for children. Once again a key theme in this regard is the ability of such communities to mobilise data across national health care system boundaries. Inevitably this power may also be used as a ‘political’ tool to influence the drug regulatory approval process.

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native healthcare discourse to establish a plurality of ‘products’ and service options.

Alongside this informational role such virtual communities also serve a relational function in terms of the provision of emotional support. Drawing together consumers with shared experiences of a condition, yet varied experiences of treatments and outcomes, virtual communities offer an empathic environment that provides consumers with the emotional support frequently perceived to be lacking in traditional consumer-professional relationships. By facilitating consumers’ cross boundary comparisons it also significantly adds to the politicisation of healthcare provision.

The potential anonymity offered by such virtual communities allows a degree of intimacy in sharing experiences and emotions that is unlikely to occur in IRL communities where participants may be identifiable and familiar through membership of other overlapping communities. Additional to the relational dimensions occurring at the level of the individual service encounter, such virtual communities also provide a collective support function through enabling the emergence of campaigning communities operating across geographical and political borders capable of mobilising the expertise to challenge the professional and political health care establishments. It is as a consequence of such factors that virtual communities can be viewed as enabling a fundamental change in the format of professional service consumption. One aspect of such communities that has yet to be examined is the motivation for participation and the extent to which consumers are motivated by learning goals, i.e., the gathering of information, or performance goals or the desire to parade knowledge without the desire to improve it. Further research in this area is required to address the motivation for participation and to compare this with traditional geographic communities.

Yet it would be erroneous to suggest that these virtual communities of interest are uniformly advantageous for consumers and do not pose significant challenges for participants. At the core of such problems are themes of identity, credibility, power, control and democracy. As with real life communities, central to the workings of virtual communities are the characteristics of the participants, their background and experience together with the environment within which such communal dialogue occurs. However, within virtual communities these issues are exacerbated by scope for participants, as a result of the inherent anonymity associated with the internet, to adopt net identities unconstrained by their ‘real’ identity measured in terms of status, education and expertise. Even for highly socialised consumers such virtual environments may disable their ability to form adequate judgements regarding the credibility of community participants, the role and affiliation of participants, and the veracity of the information being exchanged. Consequent to this is the heightened dependence on trust in the ethical behaviour and community ethos motivating participants to share information and provide advice. Given that health care is a high involvement service and highly personal in its impact, it is striking that consumers evident trust in dialogue with other consumers as a source of health care information is matched by striking that consumers evident trust in dialogue with other consumers as a source of health care information is matched by declining levels of consumer trust in health care professionals. Arising in part from high profile cases of professional negligence, declining levels of consumer trust in health care professionals.

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The challenge for service consumers is to develop attitudinal, behavioural and social frameworks that facilitate robust dialogue and exchange of information and emotional support to complement their rising authority. The parallel challenge is for the established medical profession to recognise the consequences of this evolving dialogue and develop approaches to service delivery which effectively engage with consumers on the basis of this increasing authority.

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