Health Communities as Permissible Space: Supporting Negotiation to Balance Asymmetries

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Abstract

Online communities provide promising opportunities to support patient-

professional negotiations that address the asymmetries characterizing health services.

This study addresses the lack of in-depth understanding of these negotiations, what constitutes successful negotiation outcomes, and the potential impact of negotiation on offline health behaviors. Adopting a netnographic approach, two threads were observed from each of four online health communities focusing on breast cancer, prostate cancer, depression, and diabetes, respectively. This analysis was supplemented with 45 in-depth interviews. The evidence suggests that online health communities can be constructed as permissible spaces. Such virtual spaces facilitate the type of patient-professional negotiations that can redress asymmetries. The critical elements of the negotiation process are identified as occupation, validation, advocacy, and recording. These support patients and professionals as they debate and resolve conflicts in how they experience health. Direct tangible offline negotiation outcomes are reported (e.g., changes in treatment plans). Implications for professional-patient partnerships are also explored.

*Keywords***:** online communities, health services, patients, professionals, negotiation, asymmetries, power, knowledge, information

Introduction

"In general you [a medical professional] probably have a big advantage and a big disadvantage. The big disadvantage is that you are probably surrounded by the professional "truths" about diabetes treatment. The big advantage is that you're probably well aware of how such "truths" become so generalised for the population (and often outdated) that they don't meet the full needs of the individual, and can critically assess your own best approach" (Patient member of a diabetes community).

"I know what you mean about being medical having advantages and disadvantages but I'm trying to overcome any prejudices from my training!" (Doctor member of a diabetes community).

This exchange is emblematic of complex healthcare services that are traditionally characterized by the exercise of professional authority. Foucault (1980) referred to this as a regime of truth. Typically, patient-professional consultations are based in part on informational asymmetries and exclusive possession of and access to specialist skills and treatments. Time-pressured consultations often lack emphatic understanding and under-appreciate patients' contributions to their own well-being. This is not to say that all professionals are paternalistic in their approach or that all patients wish to take more control. Rather, this has been a dominant approach within health services despite the individual preferences of patients and professionals (Ozanne & Anderson, 2010). In response, dyadic encounters are increasingly complemented by online healthcare communities as a parallel environment in which patients exchange information, experiences, and support (Laing, Keeling, &

Newholm, 2011). Less well acknowledged is that these online spaces offer the scope to equalize the asymmetries that have characterized the traditional healthcare service encounters (Nambisan & Nambisan, 2009).

Acknowledging healthcare as a collaborative effort between professionals and patients is important. Accumulating evidence suggests that the patient's role in managing his or her health is an essential element of treatment plans (von Roenn, 2013). More informed and balanced decisions result in situations where patients are offered scope to assert their *truths*, take responsibility, and pose questions about their role. For doctors, this has the potential to offer treatments that are a better fit with the personal circumstances of the patient and that overcome the rigidity of their medical training. The aforementioned exchange is illustrative of how members of online healthcare communities are raising the issue of bridging the gap that has traditionally existed between professionals and patients. Researchers have argued that the accommodation and legitimation of different viewpoints is crucial for the continuity of online communities (Thomas, Price, & Schau, 2013).

Based on the rising prevalence of online community discourse on this topic, it is increasingly clear that patients and professionals can potentially benefit from framing the community as, what this paper terms, a permissive space. That is, the online community is a space not based on power asymmetries but instead on the premise that both sides have valid perspectives on how to manage health and define the best outcome for the individual. This is consistent with recent research suggesting that it is important to focus on pivotal community practices (McColl-Kennedy, Vargo, Dagger, Sweeney, & van Kasteren, 2012). Permissible means that communities support practices through which professionals and patients draw together evidence-based medical perspectives and the personal, affective experience of treating or living

with a condition. Through balancing power positions, the doctor's professional understanding must be negotiated with the patient's in-depth understanding of his or her life conditions. In offline practice, this is essential for achieving mutual understanding, better treatment decisions, and successful outcomes (Cosgrove et al., 2013; Novelli, Halvorson, & Santa, 2012). In line with contemporary practice (Cosgrove et al., 2013; Purtilo, Hadad, & Doherty, 2012), this paper adopts a patient-centered approach to health services delivery focusing on the underlying negotiation process that requires a delicate balancing act between patient and professional perspectives. Hence, the focus of the paper is on information exchange regarding treatment-related aspects of patient health and, thus, cure-related value creation.

This study makes two substantive contributions. First, knowledge of how professionals and patients negotiate is developed. Despite innovations in patient-professional consultations (e.g., shared decision-making models, concordance agreements), negotiation is still often stifled in consultations (Sandman & Munthe, 2010). The literature has been characterized by a strong medico-dominant perspective on the quality or value of content and the potential for risk in the provision of incorrect information (Laing et al., 2011). Only more recently has the focus turned to the structural (e.g., role adoption), cultural (e.g., language use), and diversity in activities that support online discussions, contributing to cure-related value creation (e.g., McColl-Kennedy et al., 2012; Thomas et al., 2013). Addressing this gap in the extant literature, this study observes how patients negotiate with health professionals and/or other patients to understand and manage their condition within the context of naturally occurring patient-patient and professional-patient multi-way interactions in online health communities. The paper adopts the position that online communities offer a permissible space in contrast to the more (necessarily) restricted space of the

consulting room. Thus the negotiation processes adopted to manage this permissible space are explored and defined within this framing.

As the second contribution, this paper addresses the nascent research stream on what constitutes success outcomes of treatment or consultations (Cosgrove et al., 2013; Novelli et al., 2012). From a patient-centered perspective, descriptions and evaluations from within online communities are offered of the self-reported impact of community negotiations on offline health-related behaviors. Insights are presented into how the novel nature of negotiations and information exchange within the context of a permissible space can redefine the scope of health outcomes. This paper builds on the contention that health should be viewed more broadly in terms of well-being, rather than an absence of disease (Ozanne & Anderson, 2010). Within the study framework, therefore, an expanded understanding of outcomes nested within negotiation processes is also offered.

Linking Negotiation, Permissible Space, and Outcomes

Negotiation in Healthcare

In the context of health services, negotiation has been defined as a means to *"foster a relationship of mutual influence between patient and clinician"* (Lazare, Eisenthal, & Wasserman, 1975, p. 553), to *"resolve conflicts of interest"* (Sandman & Munthe, 2010, p. 26), and to *"increase the patient's influence"* (Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007, p. 633). Negotiation, thus, embraces differences of opinion and conflicts within a patient-professional relationship based on equality of roles, input, and influence. Thus, the resolution of conflict is a distinguishing characteristic of negotiation. That is, it is a settlement of differences between equal partners who represent their own views. It is inherently relational and focuses on achieving *"mutually rewarding ... ventures"* (Sandman & Munthe, 2010, p. 28) based

on mutuality of input and output (Sahlsten et al., 2007). Negotiation incorporates being informed; both parties participate in developing a mutual understanding of the meaning of information, especially for the life of the patient. The goal is that the patient learns how to assert influence over his or her health management. Negotiation is, thus, an inherently permissible concept, which as a process permits knowledge building and equality of input.

Commonly, negotiation is thought of as consisting of two elements. The *negotiation process* is the interaction between actors that includes communication between bargainers and the behavioral enactment of bargaining. The *negotiation outcome* results from this process and may be a joint or individual outcome. The negotiation process opens many possible avenues for negotiation outcomes, some of which are outside the narrow boundaries of agreed-upon prescriptions. Thus, it contrasts with contemporary approaches to patient-professional interactions. First, advocacy, which is an ill-defined concept, ranges from the healthcare professional as an advocate of the patient's rights to actually representing the patient in decision-making. There is an assumption of inequality in this advocacy with a presumed insight into the patient perspective (Schwartz, 2002). Second, advocacy is distinct from education that informs patients of what they need to do to fulfill their role; however, their role may be determined by the health professional. The goal of negotiation is not to educate the patient to comply with or adhere to a professionally prescribed pathway (Horne, Weinman, Barber, Elliott, & Morgan, 2005). Compliance and adherence are not always the most positive paths, especially when side effects seriously affect quality of life. Without the mutual understanding reached through negotiation, patients may not voice reservations or disclose non-compliance with prescribed treatment (Cushing & Metcalfe, 2007).

Furthermore, negotiation enables, but does not necessarily lead to, shared decision-making (Sandman & Munthe, 2010) and is a precursor to, but does not imply, concordance in agreement with a treatment choice (Cushing & Metcalfe, 2007). For patients, negotiation need not always be focused on decision-making or self-management, but patients may benefit from negotiating the meaning of health, illness, and treatments in their own lives from an emotional perspective (Cushing & Metcalfe, 2007). Others may feel empowered to choose to do nothing (Novelli et al., 2012). What is important is that negotiation permits mutual benefits associated with a better understanding of each other's perspectives; it is not synonymous with making a treatment decision. The importance of negotiation is as a route to facilitate patient empowerment and engagement by addressing the power asymmetries in patient-professional relationships. However, negotiation is often lacking within the physical space of and time-constrained professional consultations (Henderson, 2011; Novelli et al., 2012). This paper argues that negotiation as a permissible concept requires a matching permissible space to facilitate it appropriately, this is explored next section.

The Case for Permissible Space to Support Negotiation

In attempts to achieve patient-professional partnerships, the most fundamental step of negotiation is often neglected (Rogers, Kennedy, Nelson, & Robinson, 2005). In regular consultations, the option to negotiate is typically not presented, although it is desired by patients (Novelli et al., 2012). Some have argued that this is because of the persistence of the paternalistic biomedical model; that is, negotiation is simply not compatible with health consultations (Sandman & Munthe, 2010). Others have blamed lack of professional understanding and training, as well as deficiencies in the supporting infrastructure (Rogers et al., 2005). Underpinning these arguments is an agreement that negotiation is hindered by the formal context within which it takes

place, which implicitly preserves power symmetries. Within formal contexts (e.g., a consulting room), healthcare professionals are in their own territory, have access to and are the gatekeepers of resources, and hold the badge of competency (Sandman & Munthe, 2010). The patient is often in a position of anxiety and uncertainty with little to use to bargain. In contrast, within this paper it is argued that the permissible space of the online community context enables negotiation by equalizing input and facilitating professionals and patients to collaborate directly.

The concept of online communities as permissible spaces has not been explicitly explored in the extant literature. Nambisan and Nambisan (2009) developed a coherent taxonomy identifying four types of value co-creation in online healthcare communities: the partnership model, the open-source model, the support-group model, and the diffusion model. These models differ on the dimensions of community leadership (consumers vs. healthcare organization) and knowledge activity (creation vs. sharing). However, the practice of healthcare communities does not necessarily adhere to strict taxonomic criteria. This paper argues that they are often eclectic and simultaneous manifestations of all co-creation elements. Hence, this study focuses on negotiations as an underlying process, a mechanism to help understand how stakeholders employ different knowledge strategies to achieve desirable outcomes. Recent work has extended Nambisan and Nambisan's (2009) framework beyond the customer-organization dyad to focus on the activities healthcare customers undertake when co-creating value (McColl-Kennedy et al., 2012). This paper focuses on negotiations, a healthcare community phenomenon that is a specific, multi-stakeholder process that has received virtually no conceptual or empirical attention in the literature.

In identifying the nature of the permissible space, an obvious starting point is the anonymity inherent in online communities, which strips individuals of inhibitors such as race, age, gender, looks, timidity, and disability and encourages candor. However, this anonymity is the cause of much debate. On one hand, it is the well-heralded cornerstone of equalization in online communications; on the other, there are fears that there is no obvious way to verify the legitimacy of inputs. In the context of this study, communications within online health communities are often not totally anonymous and it may not be necessary for community members to verify the legitimacy of input (Laing et al., 2011). In this way, declaration of professional background could serve to legitimize input by healthcare specialists. The debate on anonymity poses important questions on the nature of membership, perspective diversity and conversation in understanding the dynamics of equalization within the notion of permissible space.

First, online community membership is fluid and dynamic; that is, access to and input to the conversation are openly permitted to a diversity of people. Equalization of input can be facilitated as it is not limited by the functional roles of professional versus patient (Oldenburg & Brissett, 1982). This paper argues that the advantage of fluidity is in the presentation of diverse perspectives, such that one perspective is not dominant in a conversation. It may not be necessary for a conversation to be fully developed within a community; rather, the importance lies in having an issue raised. The exchange of ideas can be across communities as well as within communities because people can belong to many networks (Murray, 2012). This cross-fertilization opens up communities to a wider collection of viewpoints and, thus, is likely to be more permissible in contrast to closed professional-patient consultations. However, one must be cautious with regard to the potentially chaotic

space that multiple viewpoints might produce. In this respect, it essential to learn how negotiations within the online space help to manage this dilemma.

Second, communities can be characterized by generating a democratic conversational style, which permits topics to be directed by common experience and emotions to be more freely expressed (Oldenburg & Brissett, 1982; Muniz & O'Guinn, 2001). This paper accepts that not all online communities are truly democratic. They are not free from conflict, self-interest, or commercial influence. Some effort or form of moderation may be needed to maintain a democratic conversational style (Murray, 2012). However, dismissing communities on the grounds of lack of regulation, as has been the case within the health arena, overlooks how community can facilitate equalization of input to engender empowerment and responsibility. This capacity within online communities paves the way for lively debates based on more equal grounding and a variety of viewpoints.

Third, patient health is part of an ongoing conversation; it is not a single event, e.g., one consultation (Novelli et al., 2012). A patient's life is a web of activity of which health is but one element (Purtilo et al., 2012). The reality for most patients is that they may see a multitude of health professionals, but with no coordination of the conversations. Online communities are persistent threads of discussion and, thus, it is argued that they are a natural framework to host linked, enduring conversations about health. Setting the negotiation process within this permissible space could release the potential for diverse development opportunities or negotiation outcomes.

Negotiation Outcomes

It is stressed above that negotiation is not synonymous with the process of shared decision-making; nor is it intrinsically linked with outcomes such as compliance, adherence, concordance, or better treatment outcomes, although these

may result. These medically defined goals are traditionally used as measures of success and incorporate the professional focus on improving the quality of prescribing to increase compliance, a practice that fails to appreciate that the patient decides whether to follow the prescription. There is increasing recognition that what is a valid outcome and how that is judged a success are defined differently by patients and professionals. For example, a clinically successful reduction in pain may not be meaningful to a patient. A distinction is often made between the medically defined objective cure and the patient-defined subjective cure. Value in healthcare should be measured around the patient; outcomes are only meaningful when measured longitudinally in relation to the patient's life (Porter, 2010).

It is a premise of this study that underpinning these arguments is a persistent focus on treatment outcomes, whether health status, process of recovery, or recovery sustainability. Rather than final treatment decisions, what patients want to negotiate may focus on adjustment in terms of understanding and knowledge building, roles and responsibilities, and self-service activities (Novelli et al., 2012). Within this paper it is argued that the permissible context of communities accommodates and permits these different levels of negotiation and that these levels are themselves associated with a wider range of successful outcomes and cure-related value.

Professionals should not fear a loss of influence or a relinquishing of professional and ethical standards (Sandman & Munthe, 2010). This paper argues that drawing on the collective wisdom of the community enables individuals to develop a more balanced perspective on health. In particular, it helps them to come to terms with difficult emotional issues (e.g., taboo subjects such as death; von Roenn, 2013) and learn how to let go of lost aspects of the self (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). Rather than being antagonistic to formal health service provision,

these concerns are more likely to lead to a mutually acceptable agreement. The persistent nature of the conversation allows for longitudinal observations of the diversity in the range of outcomes, from the highly practical to the highly emotional.

It is against this complex expertise and relational context that the dynamics of online communities in healthcare settings require consideration with respect to their impact on patterns of patient engagement with healthcare professionals and service provision. Following the methodology, the results of a qualitative study are presented that was designed to examine negotiation in online health communities.

Methodology

A netnographic methodology is adopted (Kozinets, 2009), that is, an online ethnographic approach that facilitates an in-depth understanding of the online health communities studied. This research is one part of a three-year program of research into patient utilization of online health resources in the United Kingdom (UK) and, thus, necessitated a focus on UK healthcare. Health policy in the UK places increased responsibility for health on patients. Policy-led initiatives aim to increase patient choice and access to information; they are also intended to give patients a more active role in decision-making and generate an array of pilot initiatives, including information prescriptions. The experiences of the study community members are therefore located within the healthcare framework. Four online communities were studied focusing on four conditions (breast cancer, prostate cancer, depression, and diabetes), which reflected national clinical priorities at the time of study. All four conditions are severe; breast and prostate cancers are clinically defined as acute conditions, while depression and diabetes are clinically defined as chronic conditions.

Selection of Communities

Communities were identified through Google. Selection of communities was based on the following criteria: hosted and moderated in the UK, a high volume of traffic with active posting, and a range of discussion threads focused on clinical issues. High volume was based on total number of posts; a baseline level was established in the initial screening of forums. The average number of posts for the top 10 most prominent forums for each of the four conditions was 288,199 posts (ranging from 8,506 to 773,534 posts). The selected forums were placed relative to this benchmark. In practice, all of the forums were selected from the top three most prominent results in the searches. The lowest number of posts was in the diabetes forum at 69,066 posts and the highest was in the breast cancer forum at 773,534. Administrators of the top three most popular UK-based communities for each of the four conditions studied were approached initially.

Selection of Discussion Threads

Threads within these four communities were reviewed against a set of relevant criteria derived from preceding studies of online communities, as follows: recent postings (occurring from 2009), UK-based content established by searching on indicative terms (GP [general practitioner] vs. physician; chemist vs. pharmacy; NHS [National Health Service]), content discussing the professional/patient engagement (searching for terms: GP, doc, onc), condition and treatment focus (rather than parallel issues such as friendships and families), and richness and volume of threads (sequences where participants interacted with each other rather than posting notices). In the depression forum, "Zoloft help!" (351 posts) and "Effexor XR and memory loss" (171 posts) were selected. In the diabetes forum, "Metformin dose regime and grumpiness-help?!" (37 posts) and "Statin drug side effect" (56 posts) were selected. In the prostate cancer forum, "Laparascopic RP – Big success so far" (81 posts) and

"VIT D3" (104 posts) were selected. In the breast cancer forum, "Anyone starting chemo around end of May?" (140 posts) and "What helps you with Arimidex side effects?" (27 posts) were selected.

This paper categorizes contributors' position within a community as insider, devotee, mingler, or lurker (Kozinets, 2009). In this specific case, both insiders and devotees suffered from the condition (or were related to those who do) and posted in the community. Insiders, however, were essential to and well-connected within the community. Minglers had no great interest in the central condition but had strong ties with the group and or a parallel interest that brought them to the community. Lurkers suffered from the condition (or were related to those who do) but did not (usually) post in the community. The paper further identifies contributions from healthcare professionals who self-declared their professional status within their postings. Community moderators through their strict registration processes and without disclosing identities were able to verify that registered members were healthcare professionals as claimed.

Analysis of Threads

Discussions within identified threads were tracked for six months. The nature of exchange was observed (e.g., how members conversed, information versus experiential exchanges) alongside the content of these threads in terms of what was discussed. These observations of the text discourse were combined with the reflective field notes concerning initial insights and perspectives on the first readings of the threads (Kozinets, 2009). Self-disclosure of the impact on offline behaviors was relied on. Qualitative content analysis of the selected threads was combined with simple discourse analysis of the interactions between members to offer ethnographic insight (Belk, Wallendorf, & Sherry, 1989; Coffey & Atkinson, 1996; Langer & Beckman,

2005). Through qualitative content analysis, themes and subthemes were developed progressively from the data. Following a two-level scheme, specific *emic* consumer understandings were nested in general *etic* conceptual interests. The resultant thematic structure presented in Table 1 documents development of the first- and second-order concepts within the aggregate dimensions (Corley & Gioia, 2004). Simple discourse analysis was utilized based on the notion that online contributors strive to build successful accounts of events (Potter, 1996). This was an appropriate approach as the contributors often used narrative as a chronicle of their experiences (Coffey & Atkinson, 1996). Understanding *"how constructions of the 'real' are made persuasive"* (Simons, cited in Potter, 1996, p. 106) and socially negotiated provides insights into how these as contributions can be valued as meaning making in health.

Member Check Interviews

Following this observational research, online interviews (N=45) were conducted to serve as a form of member checking of the main interpretations. Self-selection recruitment resulted in 5 prostate cancer, 30 breast cancer, 8 diabetes, and 2 depression patients being interviewed (female:male=35:10, mean community membership=24 months (s.d.=14 months), median visit rate was 'at least once a day', median posting rate was 'at least once a day'). Following a phenomenological approach, an unstructured interview format was adopted where respondents were asked about their experience in an opening question and follow-up remarks were geared toward more elaboration and explication. An online chat room was specifically designed for this study. Interviews lasted on average one hour. The average number of pages per transcript was 5.96 (s.d.=2.99) and the average word count per transcript was 2883.68 (s.d.=1122.95).

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Table 1: About here

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Results

To aid in communicating the findings, the results are structured around three areas: community context as permissible space, the naturalistic negotiation process, and negotiation outcomes. In practice, the identification and understanding of these three areas emerged as the researchers progressed through the thread narratives, as revealed in the explication of the findings and subsequently in the discussion.

Community Context as Permissible Space

In the prostate cancer thread 2, VIT D3, Susier reported a professional skepticism to her partner taking supplements: *"He is on HT and asked his doctor about vit D supplements and he (the doctor) was very cynical about it."* In contrast, Martini replied, *"I mentioned [to a consultant at St Bartholomew Hospital] I was taking vit D3, and he reacted very positively to the news. He said he believed that vitamin D deficiency is one of the main triggers for PCa."* Edward H***** posted that *"my information contradicts the "official" medical information which by default has to stay within the current consensus and NEW research findings are inevitably outside that consensus."* This exchange presents to forum members a picture, which might be the case, of a divided medical profession on the subject of supplements. Indeed, Edward H***** is broadly dismissive of the UK/NHS medical profession, which he sees as out of date. Regardless of the validity of this perspective, this thread highlights the breaking of international health system boundaries by such communities. The insiders are predominantly UK-based but contributions are also received from what appear to be citizens living in New Zealand and Spain. The lack of geographic constraints was observed as facilitating international contributions and comparison of treatments and also, perhaps more meaningful, contrasting critiques.

Communities, thus, connect members to the wider medical and lay debates. Critiques are supported by lay references to and discussion of peer-reviewed research of a wide breadth and depth. The content of the advice given on the diabetes community thread "Statin drug side effect?" comes from a variety of sources, not only international (e.g., UK and US) but also professional and independent. For example, this thread references *The Lancet* and the *Bandolier*, an independent journal about evidence-based healthcare, The Internet Health Library, an alternative medicine resource, Cholesterol and Health, which appears to be an independent website, and the *Telegraph* newspaper. The emergence of *lay experts* becomes evident and enquirers are referred on through the knowledge network and connections to lay and professional publications.

Remaining with "Statin drug side effect?," the originating request is from G*****Bear seeking advice about a prescribed drug, which she had previously associated with adverse symptoms, as she was unsure of the medical advice she had been given. She received postings from two insiders in a conversation of eight posts within the first day. The first reply expressed confidence in the community by reassuring her: *"OK, Kathy we'll look into it."* One might think of this as a holding post (later confirmed by the interviewees). Subsequently, T****Lily, an insider, referring to another thread, said, *"A*** has a treatment plan that he follows, and he won't take a statin med, either hope he catches this thread! and replies here."* In just a little more than 10 hours, A*** posted and an exchange began. This interaction provides some sense of the networking possibilities in and out of communities and threads. The extent of this was indicated by one of the interviewees saying *that "there are a network of people that I know online, not just in my own forum but in chat rooms in newsgroups and in other forums. We all criss-cross each other in different*

places" (Susan, Diabetes). Similarly, another interviewee observed, *"I have studied alternative nutrition. During studies I came across a doctor's website. Can't recall her name. But I was exceptionally impressed by her analysis of the ADbA & DiabetesUK research papers. Her site pointed me at the forum"* (David, Diabetes). Professionals thus contribute to cross-community/thread networking. In that sense, the various communities act as information resources for knowledge distribution among the members. There is also evidence that networking extends to offline meetings.

In the forums studied, sufferers with the topic condition predominated. Clearly, this is not the case with all contributors (e.g., professionals as contributors were observed). Another category of contributor in evidence is relations and care-givers. In some cases, the researchers interpreted these positions as occupying highly respected positions within the community. The prostate cancer forum that was studied, as one might expect, primarily comprised a close-knit group of males experiencing prostate cancer and engaging closely with the medical profession. Perhaps surprisingly, 10 females, who seemed to be spouses/partners and daughters, contributed to these forums. Such contributions were sometimes under a joint pseudonym with the contributor's partner and suggested the influential role of care-giver, as when a spouse said: *"I'll tell Hugh to increase the dose [of vitamin D3]."* This role of a group as patient is termed by this paper as the *compound patient*. The composition of communities is complex with cross-functional (or role) interactions. One contributor stated, *"It's a sad reflection on the medical profession that people always seem to be surprised when Doctors are human."* Thus, the distinction between patient and professional becomes an anathema. Seemingly more important is the networking of people according to their experiential backgrounds and concerns.

The Naturalistic Negotiation Process

Within the threads interactions were observed as they naturally occurred: how ideas are introduced, who reads and occupies the spaces, on whose authority are contributions permitted, welcomed, or discouraged, and how experiences are shared and (in)validated. That is, the researchers observed what could be termed negotiation. Communities were generally presented as valuable sources of help but mostly ignored by health professionals. However, interviews with key insiders confirmed that health professionals not only look at communities, but also register and post:

"I am cheered by the fact that a very eminent Endocrinologist reads our forum and from time to time he will contact me and say "the person who's having difficulty with.... tell them that x will help" so I paraphrase it and try to get the message across" (Susan, Diabetes).

"We have a member who actually told us she was a GP and now she has another identity as the forum GP. So there is some medical input. We also have an incredible number of nurses and at least a couple more docs" (Abigail, Breast cancer).

Contributors with medical training and/or relationships to those who have such training were, thus, not uncommon.

The thread entitled "Metformin dose regime and grumpiness- help?!" on the diabetes forum originated from a relatively new member with medical training. This thread concerns the request for advice from a participant (Histrionic) who, in subsequent posts, credibly presented himself as a qualified doctor specializing in psychiatry. To the date of this study, the thread comprised 28 replies to postings (total of 37 posts). In his opening post, he related his prescribed diabetes control drug for mood swings and sought advice on possibly altering the dose regime. Here, as elsewhere, the community is introduced as a resource, in this case by T****G:

"As well as experiences shared with you here, you may be interested in the

D-solve "how to" series by Katharine, one of our members. Plenty there to

inspire thoughts on how you may want to manage your own diabetes to

achieve what you want in terms of medication, appetite and

temperament."

Additionally, T****G expressed that the professional's contribution from experience

will then be seen as valuable: *"I'd be keen to hear what choices you do make along*

the way about what works best for you", suggesting recognition of the distinctive

evaluation and decision-making skills of trained medical professionals in their role as

patient. An early respondent expressed a similar welcome response to a medical

professional seeking advice from an online community: *"Welcome to the forum.*

Great to have you aboard. … if you stick around you might learn a thing or two, I

hope!" However, this latter comment echoed skepticism of the professional

perspective that was observed earlier.

Histrionic received responses and attention from forum insiders that included

practical advice. One post perhaps expressed the insiders' overall perspective best:

"In general you [as a medical professional in this community] probably

have a big advantage and a big disadvantage. The big disadvantage is

that you are probably surrounded by the professional "truths" about

diabetes treatment. The big advantage is that you're probably well aware

of how such "truths" become so generalised for the population (and often

outdated) that they don't meet the full needs of the individual, and can

critically assess your own best approach."

Following five such replies on the same day, Histrionic's first response read:

> *"Wow, Thanks everyone!!! So many helpful replies and so rapidly! All your comments were really useful. I especially liked the idea of the split lunch, VBH, and thanks for the links. Libra... […] T****G - I know what you mean about being medical having advantages and disadvantages but I'm trying to overcome any prejudices from my training! I'm a psychiatrist, P****, so I'm not as up to date with medicine as I used to be. Thanks so much for your warm welcome, everyone. I don't feel nearly so grumpy now!"*

One can gain some sense of the swiftness of the forum response from both the poster's language *"wow"* and the response being posted in less than two hours after the original request for advice. Members are addressed individually, potential criticisms are treated with respect, and Histrionic acknowledges a warm welcome. Subsequently, he posted that:

> *"Currently trying to follow official advice, sort of, but I'm rapidly becoming aware that it's all a lot more complicated than I had hoped. [….] It is very reassuring that lots of you seem to have got the hang of it, so hopefully I'll be able to benefit from your experiences."*

The community space is thus permissible in that it facilitates communication between expert patients and professionals, reflecting a reversal of functional roles outside the highly structured service encounter. Histrionic's pathway can be described as moving from asking what seemed simple questions to becoming a condition novice within this experienced group. However, later his role developed as he contributed to other threads by drawing on his medical experience to say that *"[there] is a link, unfortunately, as many commonly prescribed antipsychotic drugs predispose to weight gain and (?hence) to diabetes"* and reflecting on his position as a practitioner: *"Yeah - it's a dilemma [the confounding effects of alcohol on tests] but it's taken my*

own diagnosis to make me more fully aware of the implications for my patients of

making the wrong choice."

The opening sequence to the 'Effexor XR and memory loss' thread reads:

"I have never posted anything on the web before, but its my last resort. I need

to know if anyone has suffered from memory loss, and attention problems

while on or after starting Effexor XR. My Pharmacist (who is a close freind of

mine) tells me there is no way the two can be related as far as he knows, and

my doctor tells me the same. I don't believe it. In the last four years of being

on this med. […] my memory has been going down hill, and I'm not over the

hill yet I'm only 33! I'm also wondering if this memory loss is going be perm.

or is it going to come back. I hope some one will reply."

This was followed by some of the more regular posters who debated whether memory

loss might or might not be attributed to anti-depressant drugs. While the general

opinion was that it is attributable, Meope suggested stress and depression as the cause.

Some others agreed. Chickie44 offered an alternative explanation: *"I was on Effexor*

for 3 years and never experienced the memory loss. There were a lot of things during

my depression I suppressed, but didn't forget." One contributor went on to note:

"Only you truely know how the medication affects you, Gp's and chemists can only

tell you how it's "supposed" to work. What works for one person may not always work

the same way for some-one else." Similar debates are echoed in other threads that

were observed. Typical relief at finding a receptive space was expressed by a

newcomer to the thread 'Zoloft help!' in the depression forum, which discusses

weight gain: *"I have never tried a website like this one before, and it is a huge help.*

So many other people to do not understand. Even my psychiatrist's only words of

wisdom are "eat right and exercise more." Can you believe that?" Whether or not

weight gain is a side effect of the drug, those posters on the forum generally wanted their experience validated by the professional. Another contributor said: *"Success at the doc [...]. She acknowledged that my weight gain could indeed be from Zoloft."*

Hence, a prominent characteristic of topics raised is that they relate to an experience that conflicts with the accepted medical view. Patients sought resolution to this conflict through negotiation in the form of sense making. The convictions of some contributors did not always agree with medical opinion. Online, however, individual experiences were invariably unchallenged, what this paper termed validation, because, one might argue, of the size of the potential audience and audience members' common health condition. Validation is used to mean that each individual experience is recognized as important and accepted as a truth for that individual; at the same time, the experiences of other individuals are equally important and constitute their truth. This allows for multiple truths to exist within the same space, regardless of contradictions. Despite this, the researchers observed that it is the explanations for conflicting experiences that become the subject of negotiation among contributors. With regard to perceived memory loss on the thread observed above, "Effexor XR and memory loss," while the initial post received replies of sympathy and shared experiences, more importantly, it stimulated a discussion where some argued that there is a causal relation between memory loss and the drug while others offered alternative explanations. For example, the possibility that memory loss might be better understood as memory suppression challenges the prevailing explanation of an experience. It seems that validation of experiences enables opposing or alternate views to be negotiated in a non-confrontational environment.

Returning to the "VIT D3" thread, a group of insiders was dominated, at least in terms of content, by a participant who might be seen as a devotee. Edward H*****

did not have prostate cancer and said, *"I popped in out of curiosity as jimnic posted a link to here from the BBC message board."* Later he said, *"I probably won't be a frequent visitor here."* Despite his position, he contributed 72% of the text in this thread and was thanked by name for his contribution by eight of the members. It is evident from his postings that, while not having a specific agenda regarding prostate cancer, he did have a broader agenda relating to the medical profession. Jimnic's introduction is illustrative of this posted content: *"Sometimes he sounds like a vit D salesman but anyway here are some of the many arguments."* When Edward H***** said of himself *"I've had a lot of trouble on other forums"* because of his unconventional views, it might be presumed that his strident advocacy was sometimes not appreciated. It is perhaps significant that two members requested that Edward H***** fill in his forum profile. Edward H***** might be seen as an itinerant poster who avidly researches and posts on a given enthusiasm providing a considerable resource of information. During the two-year pathway, Edward H***** consistently advocated that prostate cancer sufferers take higher levels of vitamin D3 supplementation than most members report taking. He also maintained a strident critique of what he saw as an *"ignorant,"* *"incompetent,"* and *"neglectful"* UK medical profession. The behavior of Edward H***** provides a clear illustration of the impact a contributor with a particular agenda has, albeit substantiated by evidence, and the challenge facing other contributors to place the views of such an active participant within the context of the conventional medical discourse and broader evidence base. The four insiders, who originally established the thread, were nevertheless convinced in various ways as to the benefits of this supplement. During the two-year period of data reviewed, some others became convinced. For example, M***** said:

> *"I have read and re-read all your posts on Vitamin D and find the*
>
> *argument utterly convincing. As a result both I and my husbands are now*
>
> *taking 4000iu/ day and are waiting to have some blood tests done. So*
>
> *thank you for bringing some clarity to the topic."*

Similarly, Martini said, *"The whole topic has been an eye-opener for me."* However, despite Edward H*****'s efforts to convince them otherwise, the perceived optimum level of intake remained the subject of debate. The researchers observed a limited number of such cases of advocacy of treatments and causalities not sanctioned by the medical profession orthodoxy. Advocacy is used here to indicate that options are permitted in the sense that they are offered, discussed, and, not infrequently, contested. That is, there is space for options to be identified and championed, but the options are open to debate. In that sense, these communities open space for the advocacy of orthodox, emerging, and unorthodox views.

In most of the threads that were examined, ideas were introduced through similar interactive opening sequences as observed above: an initial post recounting an experience and/or asking advice, resulting in a fairly swift response from insiders (within days or sometimes hours) followed by a discussion. In the thread "Effexor XR and memory loss" on the depression forum, an opening post posing a problem with memory loss associated with use of the Effexor XR drug was followed by rapid responses from six of the more regular posters and a debate ensued. However, over the six-year period covered by the thread, single posts predominated (54%) and after the initial discussion, neither the instigator nor the insiders who dominated the early sequence posted contributions. Despite this seeming abandonment, the researchers observed two further periods in this thread during which live debates occurred. The prime example lasted for a year during which time four contributors discussed exit

strategies from the drug Effexor XR. This was not a strongly interactive discussion;

for example, one contributor provided only two bulletins of developments on this

thread. The concern of this study is to note that the threads that apparently do not

exhibit continuous interactions seem to offer space for colonization over an extended

period of time (measured in years). Occupation is used to label this phenomenon; that

is, points of view and issues can be raised by contributors other than the original

instigator(s). What is important about occupation is that the space is not owned by any

one person. What results is a recording of experiences that combined tells the story of

using Effexor XR that would otherwise have remained as unlinked comments. Thus,

patients may build on an existing thematic space, which an existing right of

discussion, and historical content provides validation of experience and confidence in

the context of patient vulnerability.

Negotiation Outcomes – Success Factors

Community narratives illuminate the perceived value of community

negotiations to the everyday lives of contributors. Earlier the "Effexor XR and

memory loss" thread (depression community) was encountered, characterized by a

pharmacist, doctor, and/or psychiatrist arguing that memory loss is connected with the

condition rather than the anti-depressant drug (13 instances). One insider explained:

> *"Regarding your question on Effexor medication, i was prescribed the same*
>
> *thing last year… after a few weeks I refused to take it any longer. I felt I was*
>
> *turning into a "cabbage". […] I went back to my GP and explained how I was*
>
> *feeling while on this medication and she changed it with out hesitation."*

Seven people within this thread were encouraged by what they read to negotiate either

withdrawal or a replacement drug with their professional. One insider stated, *"HI. I*

actually used your message to talk to my doctor. He agreed to put me on remeron." A

discussion between two insiders, both from the UK, illustrates how personal frustration with side effects led these two individuals to report actively voicing their concern over the drug to their GP, leading to a direct change in their treatment regime. Actively voice is used here to mean that individuals raise a concern or preference with their healthcare professional without being prompted. They take the responsibility to make their concern or preference known. In prostate cancer thread 2, "VIT D3," George_H reported a *"battle to even get a 25-Hydroxy VitD test done. For some reason my GP refused, my urologist didn't see the point, and I had to twist my oncologist's arm for weeks to get him to reluctantly agree to let me have one done."* This post indicates that direct action**,** that is, going beyond an expression of concern or preference and behaving in such a way as to bring about a change (e.g., in treatment) is not always easy. In this case, there is no information regarding the oncologist's seeming reluctance to change treatments.

Returning to the "Effexor XR and memory loss" thread, one contributor cautioned, *"I believe it is very wrong to give medical advise to anyone, other than to just share your own experiences."* Another contributor agreed, saying, *"don't do anything as far as changing your meds UNTIL you consult your doctor!! [....] If you don't want to take Effexor anymore, please call your doc and get help with tapering off it gradually."* Similarly, typical of insiders on the diabetes forum, one contributor suggested options but encouraged consultation with the GP:

> *"if your present dose schedule isn't working to control your bg levels thru the day, please see your GP as he can change you to 3 X 850mg/day on the metformin........... OR he can add Actos to your treatment plan, ... i'm just mentioning that there are lots of treatment options, but you are going to have to see what your Dr wants you to do."*

Members of the prostate cancer forum generally expressed positive comments about their healthcare professionals, with the GP presented, approvingly, as a gatekeeper. Thus, it was observed that encouragement for others to withdraw from medication or treatment was not universally advocated. These contributions could be interpreted instead as a shared desire to develop more satisfying relationships with professionals, that is, to engage in interactions with healthcare professionals that are fulfilling as defined by the individual, which can be achieved through diverse means.

In "Statin drug side effect?," A***, lozzark, sedge, and VBH in their engagements with professionals expected to have to be informed and to argue their case. Their critique was of the doctor as generalist. Part of this can be attributed to the notion that professionals will not refer to the latest knowledge and part to the scope of evidence-based medicine being too narrow and, for example, giving insufficient prominence to diet. VBH exemplified the notion that doctors might be insufficiently familiar with specialist literature when he mused: *"I wonder if your doc has been reading some odd figures such as Bernstein's assertion that 4.2 to 4.6 is a non-diabetic A1c?"* sedge made a similar assertion: *"I was going to say exactly the same as Nick without the scientific bit LOL - it's just the lab doing their job, without knowing you are diabetic. 'Computer says High' so they flag it for the Doc."* At his or her most strident, lozzark said, *"I'd discovered quite early on that the quacks had no idea about the disease so I enrolled on a nutritional therapy course, more to find out about the effects of food on health."* From their perspective, it was therefore necessary, and possible, for the patient to become informed as a specialist. An example of this approach is A***'s help for G*****Bear: *"Looking at your sig, this is quite a list: Type 2, Omnipod using Humalog, Meteprolol, Norvasc, Micardis/HCTZ, Levothyroxin, Alprazolam, Clonazepam, Metformin, Symlin, Crestor*

(now dropped?). I'll run that through an interaction checker after I send this." As for the patient's knowledge influencing professionals, in the "VIT D3" thread, M***** said, *"I have also indoctrinated our GP so that not only does she now test other patient, she also takes extra vit. D herself!"* In a diabetes thread, "Metformin dose regime and grumpiness- help?!," one insider cautioned:

> *"We are all aware of the wide knowledge a doctor needs to acquire*
>
> *during education and experience. Unfortunately as patients we have also*
>
> *become aware of how small a part of that education is related to diabetes.*
>
> *Despite diabetics being about 15% of the population."*

Thus, along with the role of an informed specialist comes acceptance of responsibility or perhaps recognition of the necessary limitations of the professional. That is, patients become more cognizant of the expectations that are placed on professionals and whether these expectations are realistic or in fact go beyond the abilities of the professional concerned (later confirmed by the interviewees).

Despite this critique, the predominant expectation of members was that they would negotiate understandings and treatment regimens with the professional, confirmed by the interviewees. A*** typified this when he reported:

> *"I based much of my argument with the doctor on this paper, but there are*
>
> *several supporting references: Ratio of Triglycerides to HDL Cholesterol*
>
> *Is an Indicator of LDL Particle Size in Patients With Type 2 Diabetes and*
>
> *Normal HDL Cholesterol Levels. I also knew which tests to request from*
>
> *reading Dr Davis' Heart Scan Blog, [discussing] lipid particle sizes."*

Similarly, sedge clarified his relationship with his doctor by saying:

> *"Well that's not true, she doesn't give me argy bargy. She knows I'm*
>
> *intelligent enough to evaluate what she says. She makes her point, that's*

all, which is fine by me. It is, after all - her job! She will request full lipids

on my next blood test in a couple of months, which I would have requested

anyway if not, cos I want to know too in any case LOL."

Nevertheless, others were frequently advised to engage with their professional, in this

case by A***: *"Possibly something to discuss with your doc."*

For probably less knowledgeable and perhaps less assertive patients, their

concern was more that they felt no-one had listened to their story. G*****Bear said,

"I guess what distresses me the most at present is the fact that my doctor did not

listen to me when I told him of all the prior times other doctors have tried statin drugs

with me and they have all produced the same muscle pain." When G*****Bear

related her protracted difficulties in getting satisfactory service in the US, P****E in

the UK responded, *"What a performance K****! At least we only have to ring the*

surgery and at my surgery you usually get an appointment the same day. Sometimes

the Dr will ring you back and you don't even need to go in." Thus, of importance for

the informants within this study was to develop a voice within the consultation. That

is, patients want to feel that they can raise their concerns or preferences in such a way

that they are acknowledged by the healthcare professional.

In a telling sequence in the prostate cancer thread, "Laparoscopic RP - Big

success so far," an insider considered the efficacy of doing nothing:

> *"Even after nearly 8 years of testing where each result has probably been*
>
> *predictable, it still causes me concern. The thought that the cancer was*
>
> *still there. And what to do if it was? And all along, what if I had never*
>
> *tested, would I have been OK – no worries, no surgery, no erectile*
>
> *dysfunction?"*

While there is no criticism of the professionals here, there is perhaps an implied caution about the proactive medical discourse. More typical, however, was that contributors contemplated choosing to stop treatments, but entreated the support of the community to keep going. This was illustrated in "What helps you with Arimidex side effects?," on the breast cancer forum. Within this thread patients were negotiating between a potentially fatal condition and a drug that caused distress. In the first one, the contributor confided:

> *"This morning I'm feeling like giving up Aromasin - my hands and feet are SO achy, stiff and sore and over the last few days the pains are spreading to my knees. [.…] I'm sure there are others on here feeling the same - can we keep each other going and try not to give up just yet???"*

In the other, the same contributor speculated: *"Do you ever worry that the aches may be "it" coming back in the bones - how would we know if it's a recognized side effect or something more sinister.[…] I wonder what percentage of women don't carry on with tamoxifen or arimidex?"* Thus, the researchers observed the phenomenon of considering no treatment or at least stopping current treatments. In terms of exercising choice in relation to treatment, contributors made their selection with regard to treatment or care according to their own preferences regardless of whether this was consistent with professional advice. The thread continued with a contributor stating:

> *"Likewise I am always interested in your comments. We have a similar diagnosis and treatment path and it has been interesting to compare our progress although as we tell everyone, we are all different. However there are some similarities which I believe are useful to report in order to encourage others who are a bit down as we all are from time to time."*

Thus, there is certainly evidence that the long-term relationships that members develop bring about a sense of shared experience that can be invaluable in supporting decisions to keep on a treatment path. That is, patients experience a sense that their experiences are not totally unique or even odd and that, while it is important to preserve a sense of individuality, recognizing the similarities in experiences is valuable in terms of bringing more understanding to one's own experiences, which may inform future choices.

This also points to the importance of online communities accumulating substantial archives of experiential data and making the archives available to current users. The interviewees confirmed that this archive is viewed as a precious resource. The archive is actively disseminated, such as in posts that redirect enquiries. It was also noted above how a posting in the "Statin drug side effect?" thread calls for a member to respond and in just more than 10 hours that named member posted. Thus, one can interpret this archive as being used as a resource to facilitate decision-making for both active members and lurkers, as this post from a prostate cancer forum shows: *"I do understand that there are a lot of readers who don't contribute to this site, but they benefit from it. […] All these documented cases on this site are a help to those silent readers in their decision making."* Some additional support that the archive benefits wider society was given by a post saying, *"I have posted rarely but read all these posts with great interest. [….] to all of you I would like to say thank you even though you didn't realise you were supporting me!"* These archives have only previously been available to relatively localized lay interpretive communities. This paper argues that such an archive has previously not been available to the medical, research, and pharmaceutical professions.

Reflections on Acute versus Chronic Conditions

The interviewees reflected on their use of the internet and their engagement with communities with regard to the nature of their condition. In engaging with the internet as a health resource, those with acute conditions described, at least in the early post-diagnosis stages, being suddenly forced to deal with issues with which they had no prior experience at a time of emotional vulnerability. As one patient stated: *"As soon as I found out I did have the early stage prostate cancer it was probably about a week before I kicked into gear"* (Harry, Prostate Cancer). In such circumstances, interviewees reported a strong dependence on the professional to filter information and to enable them to focus on information relevant to their particular circumstances. Donald (Prostate Cancer) reported: *"I think you're flooded with information at the start of it."* Penelope (Breast Cancer) observed:

> *"well, I can remember that when I heard, I just couldn't stop picking up information on the internet … the more I got, the less I knew really. I kept firing questions at the doctors, he got increasingly annoyed and ended up saying 'this does not apply to you'. I felt even more confused, he told me to trust him and stay away from the internet."*

The situation is different in chronic conditions where patients can, given time and inclination, develop a depth of knowledge to enable effective sifting and filtering. Those with chronic conditions reported gaining an understanding of the technical language as well. This reflects an important difference in initial negotiation of asymmetries within the condition groups. The informants in the acute conditions described an initial need to *"learn about"* their condition, whereas those in the chronic conditions described a need to *"learn to live with"* their condition.

As observed in the sections above, over time this initial impetus may change with prolonged community engagement, with those in both conditions forming

attachments to their fellow members. Furthermore, informants with both acute and chronic conditions reported that they perceived their handling of information as progressively more sophisticated. Although informants acknowledged that they lack the underlying disciplinary knowledge base of professionals, those who have lived with a condition for an extended period of time reported a willingness to acquire, evaluate, and engage with information relating to both lived experiences of other patients and specialist technical information:

> *"if things start going wrong with any of my conditions, then I'll begin searching again, […] I'd be on that Internet finding out, you know, the best place to go and who's going to kill me first"* (Ryan, Diabetes).

This generates a capability for patients to integrate the acquisition of information with the contribution of lived experiences on relevant forums.

Conclusions

Implications for Theory

Contributing to understanding of the impact of space on negotiation (Henderson, 2011), the conceptualization of permissible space developed here defines the key features that facilitate the patient-professional negotiation process. That is, a permissible space is a symmetrical space where both patients and professionals have valid perspectives on how to manage health and defining the best outcome for the individual. Critically, communities are distinguished as permissible spaces through challenging multiple boundaries. These crossings of borders are categorized as *international* (e.g., health service critique), *networking* (e.g., inter-community postings), *wider debates* (e.g., references to professional and independent research), and *functional* (e.g., inputs based on experience not role). This core capacity to simultaneously break down borders at multiple levels creates the permissible space.

That is, the environment encourages (1) genuine many-to-many feedback from contributors with diverse perspectives and experience, (2) equalization, characterized by mutual input and influence, (3) diversity and breadth of input, reducing the dominance of one specific perspective, and (4) recognition of the individual, regardless of role, in experiencing health/illness and the uniqueness of each person's experiences. This space contrasts sharply with the formal consultation where these borders are generally preserved (Sandman & Munthe, 2010), and explains how negotiation can be constrained within the formal service space context. The paper views such crossings of borders as fundamental to the empowerment process; their cumulative force shapes a space that can facilitate challenging power asymmetries within healthcare. This may be achieved as the space, through connections to wider and more varied perspectives, supports (or prompts) a higher level focus on broader motives, interests, and roles/responsibilities; that is, people are better able to see how they and others fit into a wider framework (cf., Henderson, 2011).

The negotiation process with regard to health is poorly understood. The observations of the naturally occurring negotiation process between community members provide much needed insight within the context of severe acute/chronic conditions (Novelli et al., 2012; Rogers et al., 2005). In this paper's conceptualization, the negotiation process is embedded within and supported by the permissible space. Four components define the negotiation process: occupation, validation, advocacy, and recording. *Occupation* refers to the process of new groups of patients creating new or colonizing dormant or semi-dormant spaces with discussion topics. These thematic spaces often have an existing right of discussion and instill confidence in vulnerable contributors. Closely linked to this is the process of *recording* these linked experiences in a substantial archive. The combined result is

that the longitudinal nature of health experiences is naturally supported; points are not raised in isolation, but are integrated with others' experiences. The community's evolving nature is a reflection of patients' ongoing experience with health (Porter, 2010; Purtilo et al., 2012) and it adds to understanding of the changing value of health for individuals within this context.

Validation refers to the process of accepting an individual's experience or perspective of that experience as a truth for that individual, in the light of conflicting truths and accepting that multiple truths can co-exist. Importantly, this validation of experience opens the pathway for debate around why individuals have different experiences, for example, even when taking the same drug, thereby enabling deeper sense making and a resolution of conflict. The researchers also observed that members account for differing motivations as an integral part of their assessment of contributions (e.g., offering suppression as an alternative explanation for memory loss, acknowledging that while appearing as a salesman the points raised by a contributor are still valid). *Advocacy* of options refers to the process of accepting that options exist. These were not necessarily professionally unsanctioned (i.e., unconventional) options, but rather options that were not discussed in consultations because of system-related factors (e.g., budget considerations) or values and beliefs of the individual professional. Again, it was noted that it is the acceptance of options that increases readiness for debate and conflict resolution regarding the value of those options. In denying the validation of experience for the individual or advocating the existence of other options, health professionals can, thus, inadvertently reduce patient receptiveness to discussing problems further. Cushing and Metcalfe (2007) noted that in such situations health professionals lose the opportunity for important learning about the patient that is crucial to decision-making. Ultimately, these elements of the

negotiation process mean that health is discussed in a more democratic, or what the researchers consider to be a more balanced, way. This is a means of ensuring that different patient voices are heard (von Roenn, 2013); indeed, within this paper the voices of expert patients, professionals, and the compound patient were observed.

As Porter (2010) suggested, the outcomes of the community negotiation process are complex. Answering calls for deeper understanding of the patient perspective of outcomes, this paper offers a more nuanced insight that is not limited by medically defined boundaries and draws on a longitudinal perspective. What emerges from the observations is that the patient-defined subjective cure is somewhat distinct from the medically defined objective cure for those with severe chronic/acute conditions. For the patient, outcomes are diverse, exceeding narrow definitions of a measurable impact of treatments and ranging from the highly practical to the highly emotive. Direct action is reported, such as requesting treatment changes or self-service activities in seeking out education or alternative courses of action. For many, however, the focus is on developing their voice. This aspect of community involvement has met with the most criticism and resistance from the healthcare profession. However, it was observed that the development of voice was not for the purpose of confronting professionals but rather as a means of seeking consultation on an informed basis born out of patients' reworking of their understanding of the relational dynamics between patient and professional. For example, members achieved an understanding of the necessary limits of professional services and of their own responsibilities in healthcare. Underpinning these outcomes is meaning, that is, individuals come to terms with the health benefits of treatments versus the resultant life costs, thereby accepting controllable and uncontrollable elements. This includes contemplating the option of doing nothing, an element often neglected in

consultations, but crucial to enabling patients to develop a more complete meaning of their health. This paper proposes that in this way the negotiation process can address broken identities experienced by patients (Aujoulat et al., 2008). The researchers also observed the phenomenon of the shared experience. A by-product of negotiation was a sense of actually going through the same experience as others beyond a sense of support, almost to the point of co-creating experiences. Finally, members reflected on their impact on the wider society; they acknowledged the importance of providing an experiential archive to lurkers. There is evidence that the forums' combined experiences and knowledge aid the decision-making of those who access this archive but are not active members.

Implications for Practice

This paper set out to learn from the insights of naturally occurring negotiations to inform the development of patient-doctor partnerships (Cosgrove et al., 2013; Novelli et al., 2012; von Roenn, 2013). Pertinent to informing patient-professional negotiations in the consulting room is how the patient voice can be heard through integrating a more equal power balance. Patients often struggle in validating their own experience against professional knowledge. It was observed that from the patient perspective it is helpful to gain acceptance and construction of the necessary boundaries of professional knowledge and assistance and to actively keep informed, which leads to informed consultations. Sometimes it is sufficient to discuss options such as stopping treatments; more important is the need to be confident enough to reflect on this within consultations. For the professional, patient non-disclosure is a problem (Cushing & Metcalfe, 2007). Community discussions enhance the understanding of patient priorities, misunderstandings, and challenges to current health systems/thinking, thus highlighting sources of resistance to health policies and

treatments. These discussions are a valuable resource for use in professional training. Professionals' acceptance of both the validity of individual experience as a legitimate perspective even in the face of contradictory medical evidence and the existence of choice will pave the way for more open patient-professional discussions.

However, limits to what can happen in consultations will always exist; they cannot mimic the enduring space available in the online environment. There is no doubt that prolonged contact with a community stimulates development of a sense of empowerment for some; others draw strength from the motivational links. This would be difficult to replicate in a series of consultations. In practice, patients often see many consultants. Patient-professional partnerships are perhaps best supported within a community-style space; it is this permissible context that lays the foundations for negotiation. The permissible space has the capacity to host diverse perspectives; one can see inputs from those who wish to comply with their doctor's prescriptions through to those who wish to take full responsibility for their health. With exposure to different views, patients and professionals learn to reach a balance. This requires professionals to acknowledge communities and understand the way in which they operate, that is, recognize communities as part of the broader health ecosystem. Communities enable patients and professionals to understand both the clinical and ecological validity of illness and treatments. This directly challenges professional-patient power asymmetries and, crucially, the nature of what constitutes valid knowledge. The evolving expertise of community members provides a mechanism for patient education, a peer-to-peer service that can address misunderstandings or miscomprehensions of health services. More controversial is enabling the option to do nothing (Novelli et al., 2012), which seems incompatible with the mission of a healthcare professional to treat the patient (Sandman & Munthe, 2010). However,

within the community, one can see careful negotiation of this, often resulting in more conviction on behalf of the patient to continue with a treatment regime that he or she finds distressing or to seek an alternative. One can harness the natural way in which people negotiate through the processes of occupation, validation, advocacy, and recording to design communities that facilitate knowledge transfer, aid in conflict resolution, and offer mutual benefits. This can be achieved by establishing partnerships between professionals and community moderators or managers. However, one must be careful not to replicate the mistakes of the past in this respect, that is, establish explicitly organization-led communities. Rather, such partnerships should look to establish communities based on a flat hierarchy.

Future Research

One of the most important directions for future research is one advocated by the interviewees within the study. In patient-professional negotiations, it is critical for the patient to receive some validation of the legitimacy of his or her experience and potentially advocacy of options. This is likely to increase patient receptivity to a discussion around health management. Future research can determine the efficacy of this approach. With the increasing demand for more patient-centered care (Cosgrove et al., 2013), this provides a promising pathway to engage patients more fully in their care. An experimental methodology could compare how the approach to negotiation presented in this paper affects medical (e.g., concordance over treatments) versus patient-defined (e.g., exercising their voice) outcomes in the short term. An ethnographic approach could explore the longitudinal impacts on factors such as empowerment and engagement and the ecological validity of implementing this negotiation approach. Such research can draw on this paper's model of negotiation outcomes as a means of assessing efficacy from a patient perspective. It is suggested

that the mechanism through which permissible space may affect empowerment is stimulation of a higher level focus. By seeing the bigger picture, patients are able to see how their and others' actions fit into a wider health framework.

This study explored communities focused on severe diseases, which are an important segment within health. The nature of such disease is that patients self-manage often intrusive impacts on their everyday life over the long term (for chronic conditions) or over intensive shorter periods of time (for acute conditions), while experiencing the prolonged stress and anxiety associated with their illness. There was a corresponding long-term involvement in the communities that were studied. In contrast, non-severe conditions are short-lived and, while immediately impactful, do not require long-term (or intensive short-term) adjustments. There is a need for in-depth understanding of the differences between patient-professional interactions depending on condition severity as this can inform care delivery. Future research could determine the relative levels of negotiation that are appropriate for severe versus non-severe condition patients. For example, given the need for immediate treatment choices in the acute-severe conditions observed here, perhaps advocacy of options for the acute-non-severe is relatively more important than validation of experience.

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Table 1. *Thematic structure emerging from observation of threads.*

First-order concepts	Second-order concepts	Aggregate dimensions	Illustrative quotation
• International contributions, comparisons, & critique • Wider medical & lay debates • Cross-role functions • (Cross) networking	• Multi-way feedback • Diversity & breadth • Equalization • Recognition of the individual	• Permissible space	*"The medics don't tell us in the UK [fasting cholesterol test], but they do in the USA."* *"I dieted […] and never managed to control my bg's, […], i did the 'atkins' my bg's stabilised. i mentioned this to my gp and practise nurse and was […] told 'you cant stay on it !' […] i found a new consultant and this forum and […] follow[ed] the advice given here. my bg's have now stabilised […]. a plumber (me) and a psychiatrist (you) came to the same conclusion YET a gp and a nurse disregarded this information!"* *"there are a network of people that I know online, not just in my own forum […]. We all criss-cross each other in different places"*
• Validation • Advocacy • Occupation • Recording	• Debate • Integration • Conflict resolution • Balance	• Negotiation	*"I have never tried a website like this one before, and it is a huge help. So many other people to do not understand. Even my psychiatrist's only words of wisdom are "eat right and exercise more." Can you believe that?"* *"Only you truely know how the medication affects you, Gp's and chemists can only tell you how it's "supposed" to work. What works for one person may not always work the same way for some-one else."*
• Professional limitations • Informed as a specialist • Archives and dissemination • Shared experience	• Develop voice • Active voice • Exercising choice • Direct action • Satisfying relationships with professionals • Benefits to wider society	• Negotiation outcomes	*"I based […] my argument with the doctor on this paper, but there are several supporting references [list of references]. I also knew which tests to request from reading Dr Davis' Heart Scan Blog."* *"after nearly 8 years of testing […]. The thought that the cancer was still there. And what to do if it was? […], what if I had never tested, would I have been OK – no worries, no surgery, no erectile dysfunction?"* *"I have posted rarely but read all these posts with great interest. [….] to all of you I […] say thank you even though you didn't realise you were supporting me!"*