Viewpoint

# Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management

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## Abstract

Patients with long-term chronic disease experience numerous illness patterns and disease trends over time, resulting in different sets of knowledge needs than patients who intermittently seek medical care for acute or short-term problems. Health-care organizations can promote knowledge creation and utilization by chronic patients through the introduction of a virtual, private, disease-specific patient community. This virtual socialization alters the role of chronic disease patients from external consumers of health-care services to a 'community of practice' of internal customers so that, with the tacit support of their health-care organization, they have a forum supporting the integration of knowledge gained from the experiences of living with chronic disease in their self-management. Patient-centred health-care organizations can employ the virtual community to direct and support the empowerment of chronic patients in their care.

## Introduction

Forty per cent of Americans have at least one chronic illness, accounting for two-thirds of all medical expenditures, with nearly 80% of these expenditures related to 20 specific chronic diseases.[1] A chronic patient's knowledge-related needs include information on their disease, treatment side-effects, treatment plans, professional contacts, as well as supportive information for family and friends.[2] In addition, access to the highest quality evidence is important when patients participate in decisions about their care choices,[3] and patients with diseases in which medication therapy is the primary treatment option may have greater and more in-depth informational needs.[4]

If supported by a program or tool that promotes self-management, a chronic patient's sense of self-efficacy increases over time, and this has positive effects on many health outcomes, including disability and pain reduction, immunological functioning, and social functioning.[5]

## What do patients know?

Patients with long-term chronic disease become experts in the experiential aspects of living with disease.[6] They acquire tacit knowledge over extensive periods of time, not only about the

symptoms and sequela of disease and the effects of medications, but also pragmatic insights into the realities of adaptation to chronic disease[7] and problems in care delivery processes.[8] Patients form social networks with their care providers, clinicians, therapists and other patients in their health-care organization, and knowledge is acquired through interaction with this network to fulfil their needs.[9]

Greater involvement in their care develops as a matter of necessity, as it is often the patient who has to synthesize contradictory opinions from diverse specialists into the development of a co-ordinated treatment plan.[10] Many of the required decisions are not necessarily clear cut even for experienced specialists,[11] and patients frequently utilize medical literature, the World Wide Web, family members, other patients, disease organizations and other resources for assistance and clarification. Thus, already experts in issues related to living with their disease,[6] patients also acquire a significant body of knowledge about the disease itself and the choices for management.[12]

## How can health-care organizations manage patient knowledge?

The patient's body of knowledge is 'uncodified, difficult to diffuse, personal knowledge based on personal experience'.[13] It is closely equivalent to a worker's tacit knowledge in that, as defined by Choo, it is 'used by organizational members…to make sense of their worlds' (p. 111).[14] However, unlike work-related tacit knowledge, it is not purely 'expressed through action-based skills'.[14] In other words, a chronic disease patient's tacit knowledge is not 'action centred' in the sense that it is acquired through the performance of a series of manual tasks; rather it is acquired experientially through the activities of daily living with a chronic disease.[15]

The individuals possessing this tacit knowledge must be given a forum, tool or medium through which it can be shared or socialized.[14] This can be achieved through a reconceptualization of the role of chronic disease patients from external consumers of health-care services into a 'community of practice' of internal customers so that, with the tacit support of their health-care organization, patients can share experiences, the perspective gained from these experiences, and how they have each integrated these new factors in their own lives.[16]

Among organizations that have pursued knowledge management, 'communities of practice' are emerging as one of the most promising structures for building and sharing knowledge. Communities of practice are self-organizing informal groups, whose members regularly share knowledge and learn from each other.[17,18] Communities of practice are defined by three features. First, members face common work activities or share common interests. Secondly, they can view the collective benefit of sharing knowledge, with each member recognizing the need to have access to the expertise of other members. Thirdly, members have developed norms of trust, reciprocity and co-operation that support knowledge sharing.

## Can patients be considered organizational knowledge workers?

Knowledge workers are members of knowledge-based organizations (such as employees and internal professionals) who gather, distribute and add value to information.[19] Information and knowledge are principal products of knowledge-based organizations,[19] and modern developments in information technology have facilitated the appreciation of information and knowledge as important organizational assets.[20]

Health-care is a knowledge-based service industry, and the primary knowledge workers in health-care organizations are considered to be providers (e.g. physicians and nurses) and senior administrators.[21] Health-care organizations have not traditionally considered patients as knowledge workers. They are viewed largely as external customers, driving the priorities of service delivery and retrospectively influencing the quality of services, but they are not considered an internal, usable source of knowledge for developing service delivery innovations.[22]

However, in light of ever shrinking economic resources for health-care, this appears to be a potential opportunity.[23] In a patient-centred health-care organization, the patient is already viewed as an active partner in clinical decision-making, and by default, an active member of the organization.[24] It seems a natural progression for such an organization to combine the data and information-processing capacity of their existing information technology infrastructure with their patients' desires for community and support, their capacities for creativity and innovation, and their interests in communication, collaboration and knowledge sharing with health-care providers.[25]

## The virtual chronic patient community

There are four requisite elements for effectiveness in promoting a positive change in health practices, including encouraging self-management of chronic disease. These include adequate information (knowledge), self-regulatory skills development, building a sense of self-efficacy and construction of a social support system.[5] The virtual patient community, integrated within the functioning health-care organization, embodies all four of these elements.

A virtual community functions similarly to a traditional community, combining content and communication to bring people together, facilitating the exchange of information and the creation of knowledge, and satisfying perceived needs.[26] On-line communities consist of two parts, community members and a platform, the latter providing the infrastructure upon which community members can virtually meet and interact.[27] These communities can become effective tools of communication if members have common interests, needs, goals, as well as an aspiration for mutual communication and the furthering of relationships,[28] and as such can supplement already existing face-to-face communication opportunities.[29] In addition, if a motivating factor of on-line use is also the acquisition of information, then the psychological well-being and social integration of participants increases.[30]

Chronic diseases lend themselves to electronically mediated, comprehensive, structured self-monitoring and self-management alternatives, because of their longer time frame perspective and high attendant costs over time.[31] On-line disease-related discussion groups have been observed to offer well-informed chronic disease-affected patients a secure space for discussion of information, the conversion of information into integrated personal treatment knowledge, and its implementation into personal lifestyle choices.[32] Prototypes of web-based, patient-centred health information systems designed for patients, nurses and physicians, with capacity for discussion between patients and some interrogation of providers have been demonstrated to support management of disease and enhance understanding of the development of complications of poorly controlled disease,[33,34] although these are not structured as virtual communities *per se*.

One well-documented example of a health-care organization-sponsored virtual patient community is Zora, an animated virtual community for paediatric haemodialysis patients that has been found in limited clinical trials to help children and families cope with their disease. However, Zora has not been specifically designed to promote the value of patient-centred knowledge on the improvement of organizational health outcomes. Although patients and nurses have found Zora to be an effective tool to help children cope with their disease, they have also found its educational value to be minimal.[35]

Many patients already construct narratives of their illnesses on personal home pages and proprietary virtual patient communities such as WebMD (http://www.webmd.com). However, the comparative advantages of a provider-sponsored on-line community over publicly available equivalents regarding knowledge creation and sharing have not been extensively studied. Both types have reported increased empowerment, improved health outcomes, less social isolation, a sense of solidarity and some economic support.[36] The smaller, more controlled size of the private community may render it more sustainable as a social structure[37] and its

integration within an already existing patient support organization may render it more effective as a social structure.[38]

Furthermore, while the sharing of experiences helps others to cope with chronic illnesses and provides support and interaction,[39] many anonymous on-line authors may unintentionally (or intentionally) become producers of dubious quality of health information and unregulated dispensers of care.[40] A virtual community sponsored by a health-care organization and mediated by an 'on-line group worker' from that organization[41] can maintain an air of greater legitimacy as a continuously supportive workspace for patients.[42] Thus, new high-quality knowledge is generated within the health-care organization's own on-line context and can be efficiently operationalized and embraced throughout the organization.[43]

Participants in organizationally sponsored virtual communities can also import high quality information of pertinence to other patients,[26] to be assessed by and shared with their actual health-care providers. Patients with internet access import new explicit knowledge into the virtual community from external sources, potentially enhancing and expanding a health-care organization's core capabilities over time while challenging core rigidities that can impede organizational innovation.[44] Through synchronous and asynchronous communication tools integrated in the virtual community's infrastructure, they learn from their entire on-line social network, other patients and health-care providers acting as community mediators, about the information's meaning and significance.[45] This new external knowledge becomes internalized explicit knowledge for potentially all organizational knowledge workers to use in their work activities.[44]

## Effects of virtual patient community-based knowledge on outcomes

There may be added therapeutic and economic value for a virtual community administered by a central health-care organization. The Comprehensive Health Enhancement Support System

(CHESS) of the University of Wisconsin, an on-line health information system, was one of the most studied chronic disease virtual communities in the literature.[46] CHESS provided access for HIV-positive individuals to information sponsored by the organization, limited access to personal medical data, and social support in the form of on-line discussion groups between patient participants. Quality of life significantly improved and health service utilization significantly dropped during the study period.[46] Similar findings were noted for breast cancer patients.[47]

Socially contextualized knowledge is an important factor is the apparent success of CHESS.[47] Explicit knowledge, when provided in tandem with a vibrant social support system from the virtual community, can reduce patients' uncertainty and fears about the implications of their own diagnoses.[48,49] Patients can review their data within the context of high-quality, organizationally relevant health information at their own speed, and at times when they are most receptive and with the support of people whom they trust.[50]

Validation of patient participation is another important factor in the success of CHESS.[47] A patient's data are contextualized within their health-care organization's actual clinical care processes, making patients feel more in partnership with their clinicians, knowledgeably sharing in the responsibility for any improvement in personal and organizational health outcomes.[6] By providing virtual interaction not only between patients, but also with clinicians, the organization is implicitly confirming the value of patients as knowledgeable participants. The formal construct of the virtual community provides physical evidence to patients that the organization intends to disseminate their knowledge among other knowledge workers, physicians, nurses and administrators,[51] to promote greater understanding of the impact of illness on patients' daily lives.[52]

The virtual community can also facilitate development of an innovative patient-focused integration of medical, social and supportive services by the health-care organization.[53]

Administrators can design more personalized care trajectories that are directed towards the patients that the organization is actually serving.[54] Health-care providers can more efficiently devote their energies and time to a collaborative, cost-effective, patient-centred role as direct consultants to the specific health-care needs of an individual chronic patient that arise at a point in time. Nurses and physicians in the organization can access the explicit knowledge contained within the organizational memory, employ it in their daily work, and convert it to their own tacit knowledge that can be used to manage new patients entering the organization in the future.

## Conclusions

Patients provide a heretofore untapped resource of knowledge that can be employed by health-care organizations to inform advancements in service delivery and improve health outcomes. Formally introducing a virtual, private, disease-specific patient community operationalizes the principles of patient-centred care by validating the needs, preferences, contributions and experiences of chronic patients as high quality sources of knowledge.

The virtual community is a dynamic, patient-centred organizational memory potentially accessible to all of the organization's knowledge workers. This innovation can spur directed improvements in patient care outcomes for chronic patients, establishing the organization as a hub of patient-centred expertise about a chronic disease, adding significant long-term value to the organization as a whole.

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