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

Warren J. Winkelman MD MBA FRCPC* and Chun Wei Choo PhD†

*Centre for Global eHealth Innovation and †Faculty of Information Studies, University of Toronto, Toronto, Ontario, Canada

Abstract

Correspondence

Warren J. Winkelman MD MBA FRCPC
Department of Health Policy,
Management and Evaluation
Centre for Global eHealth Innovation
Toronto General Hospital – University
Health Network
University of Toronto
Toronto, Ontario
Canada M5G 2C4
E-mail: w.winkelman@utoronto.ca

Accepted for publication

14 May 2003

Keywords: chronic disease, empowerment, information system, knowledge creation, patient-centred care, patient participation, virtual communities

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 treat-

ment 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 disease⁷ 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 structure³⁷ 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 organization⁴¹ 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 in 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.

References

- 1 Shine KI. Health care quality and how to achieve it. *Academic Medicine*, 2002; **77**: 91–99.
- 2 Hope S, Williams AE, Lunn D. Information provision to cancer patients: a practical example of identifying the need for changes in practice from the Dorset Cancer Centre. *European Journal of Cancer Care*, 2000; **9**: 238–242.
- 3 O'Donnell M, Entwistle V, Skea Z. Bridging the gap between evidence-based medicine and patient-centered medicine. *Patient Education & Counseling*, 2001; **42**: 295–296.
- 4 Rycroft-Malone J, Latter S, Yerrell P, Shaw D. Consumerism in health care: the case of medication education. *Journal of Nursing Management*, 2001; **9**: 221–230.
- 5 Bandura A. *Health Functioning. Self-Efficacy – The Exercise of Control*. New York: W.H. Freeman and Company, 1997: 279–313.
- 6 Coulter A. Patient-centered decision making: empowering women to make informed choices. *Womens Health Issues*, 2001; **11**: 325–330.
- 7 Carr AJ, Higginson IJ. Are quality of life measures patient centred? *British Medical Journal*, 2001; **322**: 1357–1360.
- 8 Harrison A, Pablo A, Verhoef M. The consumer's role in co-ordination: making sense of transitions in health care. In: Mark AL, Dopson S (eds) *Organisational Behaviour in Health Care*. London: Macmillan Business, 1999: 47–62.
- 9 Cross R, Parker A, Prusak A, Borgatti SP. Knowing what we know: supporting knowledge creation and sharing in social networks. *Organizational Dynamics*, 2001; **30**: 100–120.
- 10 Anderson G, Knickman JR. Changing the chronic care system to meet people's needs. *Health Affairs*, 2001; **20**: 146–160.
- 11 Laine C, Davidoff F. Patient-centered medicine. A professional evolution. *The Journal of the American Medical Association*, 1996; **275**: 152–156.
- 12 Mort EA. Patient-centered decision making: empowering women to make informed choices—experience in the United States. *Womens Health Issues*, 2001; **11**: 319–325.
- 13 Boisot MH. *Information Space: A Framework for Learning in Organizations, Institutions, and Culture*. London: Routledge, 1995.
- 14 Choo CW. *The Management of Learning—Organizations as Knowledge-Creating Enterprises. The Knowing Organization: How Organizations Use Information to Construct Meaning, Create Knowledge, and Make Decisions*. New York: Oxford University Press, 1998: 105–153.
- 15 Holman H, Lorig K. Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *British Medical Journal*, 2000; **320**: 526–527.
- 16 Lave J, Wenger E. *Legitimate Peripheral Participation in Communities of Practice. Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press, 1991: 89–117.
- 17 Brown JS, Duguid P. Organizational learning and communities-of-practice: toward a unified view of working, learning, and innovation. *Organization Science*, 1991; **2**: 40–57.

- 18 Wenger E, McDermott RA, Snyder W. *Cultivating Communities of Practice*. Boston, MA: Harvard Business School Press, 2001.
- 19 Snyder JR. Managing knowledge workers in clinical systems. *Clinical Leadership Management Review*, 2001; **15**: 120–123.
- 20 Wickramasinghe N, Ginzberg MJ. Integrating knowledge workers and the organization: the role of IT. *International Journal of Health Care Quality Assurance Incorporating Leadership in Health Services*, 2001; **14**: 245–253.
- 21 Sorrells-Jones J, Weaver D. Knowledge workers and knowledge-intensive organizations, Part 3. Implications for preparing healthcare professionals. *Journal of Nursing Administration*, 1999; **29**: 14–21.
- 22 Manville B, Ober J. Beyond empowerment: building a company of citizens. *Harvard Business Review*, 2003; **81**: 48–53.
- 23 Collis B, Winnips K. Two scenarios for productive learning environments in the workplace. *British Journal of Educational Technology*, 2002; **33**: 133–148.
- 24 Mills P, Moberg D. Perspectives on the technology of service operations. *Academy of Management Review*, 1982; **7**: 467–478.
- 25 Malhotra Y. Tools@work: deciphering the knowledge management hype. *Journal for Quality and Participation*, 1998; **21**: 58–60.
- 26 Rothaermel FT, Sugiyama S. Virtual internet communities and commercial success: individual and community-level theory grounded in the atypical case of TimeZone.com. *Journal of Management*, 2001; **27**: 297–312.
- 27 Stanoievska-Slabeva K. Toward a community-oriented design of internet platforms. *International Journal of Electronic Commerce*, 2002; **6**: 71–95.
- 28 Andrews D, Preece J, Turoff M. A conceptual framework for demographic groups resistant to on-line community interaction. *International Journal of Electronic Commerce*, 2002; **6**: 9–24.
- 29 Peris R, Gimeno MA, Pinazo D *et al*. Online chat rooms: virtual spaces of interaction for socially oriented people. *Cyberpsychology & Behavior*, 2002; **5**: 43–51.
- 30 Weiser EB. The functions of Internet use and their social and psychological consequences. *Cyberpsychology & Behavior*, 2001; **4**: 723–743.
- 31 Berendt M, Schaefer B, Heglund MJ, Bardin C. Telehealth for effective disease state management. *Home Care Provider*, 2001; **6**: 67–72.
- 32 Loader BD, Muncer S, Burrows R, Pleace N, Nettleton S. Medicine on the line? Computer-mediated social support and advice for people with diabetes. *International Journal of Social Welfare*, 2002; **11**: 53–65.
- 33 de Clercq PA, Hasman A, Wolffenbuttel BH. Design of a consumer health record for supporting the patient-centered management of chronic diseases. *Medinfo*, 2001; **10** (Pt: 2): 2–9.
- 34 Hejlesen OK, Plougmann S, Ege BM, Larsen OV, Bek T, Cavan D. Using the internet in patient-centred diabetes care for communication, education, and decision support. *Medinfo*, 2001; **10** (Pt: 2): 2–8.
- 35 Bers MU, Gonzalez-Heydrich J, DeMaso DR. Use of a computer-based application in a pediatric hemodialysis unit: a pilot study. *Journal of the American Academy of Child Adolescent Psychiatry*, 2003; **42**: 493–496.
- 36 White M, Dorman SM. Receiving social support online: implications for health education. *Health Education Research*, 2001; **16**: 693–707.
- 37 Butler BS. Membership size, communication activity, and sustainability: a resource-based model of online social structures. *Information Systems Research*, 2001; **12**: 346–362.
- 38 Hampton KN, Wellman B. Examining community in the digital neighborhood: early results from Canada's wired suburb. *Digital Cities*, 2000; **1765**: 194–208.
- 39 Bers MU, Gonzalez-Heydrich J, DeMaso DR. Future of technology to augment patient support in hospitals. *Studies in Health Technology and Information*, 2002; **80**: 231–244.
- 40 Hardey M. 'The story of my illness': personal accounts of illness on the internet. *Health*, 2002; **6**: 31–46.
- 41 Finn J. An exploration of helping processes in an online self-help group focusing on issues of disability. *Health & Social Work*, 1999; **24**: 220–231.
- 42 Hsiung RC. The best of both worlds: an online self-help group hosted by a mental health professional. *Cyberpsychology & Behavior*, 2000; **3**: 935–950.
- 43 Wikstrom S, Normann R. *Knowledge and Value: A New Perspective on Corporate Transformation*. London: Routledge, 1994.
- 44 Leonard-Barton D. *Wellsprings of Knowledge: Building and Sustaining the Sources of Innovation*. Boston, MA: Harvard Business School Press, 1995.
- 45 Heaney CA, Israel BA. Social networks and social support. In: Glanz K, Lewis FM, Rimer BK (eds) *Health Behavior and Health Education*. San Francisco: Jossey-Bass, 1997: 179–205.
- 46 Gustafson DH, Hawkins R, Boberg E *et al*. Impact of a patient-centered, computer-based health information/support system. *American Journal of Preventive Medicine*, 1999; **16**: 1–9.
- 47 Gustafson DH, Hawkins R, Pingree S *et al*. Effect of computer support on younger women with breast cancer. *Journal of General Internal Medicine*, 2001; **16**: 435–445.
- 48 Penson RT, Benson RC, Parles K, Chabner BA, Lynch TJ. Virtual connections: internet health care. *Oncologist*, 2002; **7**: 555–568.
- 49 Eysenbach G, Sa ER, Diepgen TL. Shopping around the internet today and tomorrow: towards the

- millennium of cybermedicine. *British Medical Journal*, 1999; **319**: 1294–1298.
- 50 Rosal MC, Ebbeling CB, Lofgren I, Ockene JK, Ockene IS, Hebert JR. Facilitating dietary change: the patient-centered counseling model. *Journal of the American Dietetic Association*, 2001; **101**: 332–341.
- 51 Glick TH, Moore GT. Time to learn: the outlook for renewal of patient-centred education in the digital age. *Medical Education*, 2001; **35**: 505–509.
- 52 Coyle J, Williams B. Valuing people as individuals: development of an instrument through a survey of person-centredness in secondary care. *Journal of Advanced Nursing*, 2001; **36**: 450–459.
- 53 Noring S, Dubler NN, Birkhead G, Agins B. A new paradigm for HIV care: ethical and clinical considerations. *American Journal of Public Health*, 2001; **91**: 690–694.
- 54 Ozbolt JG. Personalized health care and business success: can informatics bring us to the promised land? *Journal of the American Medical Informatics Association*, 1999; **6**: 368–373.