Where's the Patient's Voice in Health Professional Education?

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A report from the 1st International Conference, organized by the Division of Health Care Communication, College of Health Disciplines, The University of British Columbia

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Published by, and available from:
Division of Health Care Communication, College of Health Disciplines
The University of British Columbia, Vancouver, British Columbia, Canada V6T 1Z3
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The aim of the Division of Health Care Communication is to promote informed and shared decision making and patient/client involvement in health care through collaborative research, curriculum change and program development in the academy and the community.

Acknowledgements
The conference "Where's the Patient's Voice in Health Professional Education?" and production of this report were made possible through financial support from the College of Health Disciplines, the Vancouver Foundation, the Social Sciences and Humanities Research Council and the Primary Health Care Transition Fund, Health Canada. The views herein do not necessarily represent the views of these supporters.

* ***The word 'patient' is used as the single most widely understood term and is meant to encompass client, consumer, user, survivor, etc., as preferred in various contexts and health care disciplines.***

Library and Archives Canada Cataloguing in Publication

Farrell, Christine
Where's the patient's voice in health professional education? / Christine Farrell, Angela Towle, William Godolphin.

A report from the 1st international conference, organized by the Division of Health Care Communication, College of Health Disciplines, University of British Columbia, held Nov. 3, 2005, Vancouver, B.C.
Includes bibliographical references.

ISBN 0-9782028-0-5

1. Medical education--Congresses. 2. Patient participation--Congresses. 3. Medical personnel and patient--Congresses. 4. Medicine--Study and teaching--Congresses. I. Towle, Angela, 1952- II. Godolphin, William, 1941- III. University of British Columbia. Division of Health Care Communication IV. Title.
R737.F37 2006 610.71'1 C2006-906605-1

Where's the Patient's Voice in Health Professional Education?

Sommaire

Ce rapport est le compte rendu du premier congrès international intitulé Where's the Patient's Voice in Health Professional Education? (Où est la voix du patient dans la formation des professionnels de la santé?) qui a eu lieu à Vancouver, au Canada, en novembre 2005.

On y démontre que le rôle autrefois passif que le patient jouait dans l'éducation des professionnels de la santé est en voie de devenir actif. Les nouvelles tendances observées dans le monde universitaire, les bonnes pratiques dans les soins de santé, la modification des programmes d'études et les mouvements populaires des consommateurs constituent la force d'impulsion de ce changement.

Le rapport fait la synthèse de la participation active des patients dans le cadre de la formation du personnel infirmier, des médecins, des travailleurs sociaux, des ergothérapeutes, des physiothérapeutes et d'autres professionnels de la santé en Amérique du Nord, en Europe et en Australie.

Les activités les plus courantes comprennent l'enseignement que les patients dispensent aux étudiants, la participation des patients à la planification et à l'exécution de projets de recherche, de même que les patients qui racontent leur histoire pour le bien des étudiants. La plupart des initiatives sont des séminaires ou des cours magistraux uniques ou encore des modules uniques. Les projets à plus long terme font participer les patients aux comités de programmes d'études, au mentorat et à l'évaluation. Certains projets sont à l'origine de partenariats de travail étroits entre les collectivités locales, les universités, les hôpitaux et les cliniques.

Voici quelques facteurs déterminants du sondage.

- Les étudiants se souviennent de ce que les patients leur disent. Le message authentique et distinct des patients favorise l'apprentissage des soins axés sur le patient.
- Dans ce travail, la collaboration entre les établissements, les professionnels et les collectivités locales est essentielle. Elle aidera en effet le monde universitaire à atteindre ses objectifs relativement à son obligation sociale de rendre des comptes et à adresser les enjeux par rapport à la sécurité des patients.
- Le congrès a servi de tribune pour bon nombre de professionnels, d'étudiants, de soignants et de patients. La confrontation des différents « langages » que nous utilisons a été une cause de surprises et de réflexion. Ce travail sert de tremplin et s'avère particulièrement bien adapté aux intentions de la formation interprofessionnelle.
- La plupart des interventions pourraient être utilisées de façon plus générale, et non de façon particulière à une discipline, ce qui favoriserait la collaboration et le transfert des connaissances.
- La documentation et les connaissances actuelles relativement à ce travail sont largement descriptives. Il devient urgent de concevoir des études des résultats, de les financer et de les publier.
- Même s'il y a suffisamment d'enthousiasme dans la collectivité pour aider, celui-ci doit être cultivé et soutenu. Il est important de préparer les patients à leur rôle de formateur, puis de les reconnaître et de les récompenser.

Le congrès a rapproché de nombreux pionniers qui oeuvraient en vase clos. Nous espérons que d'autres tiendront compte de leurs modèles novateurs et les mettront à l'essai. Les défis à relever sont importants, mais intéressants. Un développement plus systématique s'impose. Ce rapport vise à promouvoir le lancement d'un mouvement international et interdisciplinaire qui fera véritablement entendre la voix des patients dans l'apprentissage des soins axés sur le patient.

Executive Summary

This report arises from the 1st international conference "Where's the Patient's Voice in Health Professional Education?" held in Vancouver, Canada in November 2005.

It documents a change from patient as passive to active participant in the education of health professionals. Drivers for this change are modern trends in academia, good practice care, health care reform, curriculum change and grass roots consumer movements.

It summarizes active patient involvement in the education of nurses, doctors, social workers, occupational and physical therapists, and other health disciplines in North America, Europe and Australasia.

The most common activities are patients teaching students, patients involved in the planning and execution of research and students listening to patients' stories. Most initiatives are one-off seminars or lectures or single modules. Longer-term projects involve patients in curriculum committees, mentoring or assessment. Some projects led to close working partnerships between local communities, universities, hospitals and clinics.

The following are some key points from this survey.

- Students remember what they hear from patients. The authentic and autonomous patient's voice promotes the learning of patient-centred care.
- Collaboration between institutions, professionals and their local communities is essential for this work and will help academia to meet social accountability goals and address patient safety issues.
- The conference was a forum of many professions, students, carers and patients. Confrontation with the different 'languages' we use yielded surprises and insights. This work is a platform well suited to the intents of interprofessional education.
- Most interventions have potential for wider application, not discipline-specific – an opportunity for collaboration and knowledge transfer.
- Current literature and knowledge about this work is largely descriptive; there is a pressing need for outcome studies to be designed, funded and published.
- There is plenty of enthusiasm in the community to assist but it must be developed and nurtured. It is important to prepare patients for teaching roles and to recognize and reward them appropriately.

The conference brought together many isolated pioneers. We hope that others will consider and try their innovative models. The challenges are significant (and interesting) and more systematic development is needed. This report aims to foster an international and interdisciplinary movement that truly brings the patient's voice into the learning of patient-centred care.

Overview

This report is for educational leaders, for heads, deans and directors of health professional training. It looks at practical ways to respond to curriculum imperatives such as professionalism and social responsibility.

It is also for innovative educators who want their students to learn about interprofessional practice and the bio-psychosocial model. It provides new ideas from different health professions and at all levels from undergraduate to in-service training.

And it is for the honourable, sometimes marginalized few (lay and academic) who have moved beyond the patient as audiovisual aid and brought the patient's authentic and autonomous voice into education. It may encourage you and provide ideas to expand your repertoire.

Trends in health care policy emphasize involvement of the community and service users in many aspects of their care. Much of the impetus for reports such as *To Err is Human*[1] and the Bristol Inquiry[2] was the lack of awareness of the patient's voice in determining the course of care. Even more recently the value of actively involving patients and the community in research has arisen,[3] in part, from recognition that endpoints measured by researchers are not necessarily the ones of greatest importance to patients. For example, we now have calls for lay members on advisory panels and review boards of CIHR[4] and guidelines for public involvement that aim to make research "more relevant to people's needs and concerns, more reliable and more likely to be used."[5] How then do professionals, who hold more than the balance of power in health care service delivery and research acquire knowledge, skills and attitudes suited for these trends? When and how do they learn to listen for the patient's voice?

Patients have always been a part of health professional education: the living illustration of an interesting or rare condition, as teaching material and as part of students' experiential learning in the clinical setting. The value of a more active role for patients as teachers has been the subject of some recent reviews in medical education,[6] nurse education,[7] mental health training[8] and social work.[9]

DRIVERS TO CHANGE

There appear to be five inter-related movements driving change from passive to active patient involvement in health professional education. They apply across professions and health care systems. Each has generated statements (some examples follow) from governments, professional bodies and other influential organizations.

1. Academia in the community. The terms "social accountability" and "community engagement" signal recognition by academic institutions of the importance of partnerships with communities they serve. A recent series of papers[10] on academia-community relationships link them to the concept of medical professionalism. Social accountability, as defined by the World Health Organization was adopted by the Association of Faculties of Medicine of Canada in partnership with Health Canada as the focus for its unifying vision for academic medicine. Central to this vision is the Partners Forum with representatives of the key stakeholder groups: policy makers, health managers, health professions, academic institutions and communities.[11]

2. Good practice care of the individual patient. Each health profession espouses a version of patient-centred care in its good practice model: care that responds to patients' preferences and involves them in decision-making with a focus on the specific individual experience of illness. How best to teach and learn it, however, is rarely articulated. There is a prevailing expectation, arising from ethics, the law and some evidence of better outcomes, that health care professionals will actively involve patients in decisions about care. Evidence-based practice requires the combination of best research (usually population studies) and clinical expertise with patient values – but how do professionals learn to enquire about, and understand the individuality of the patient? It seems obviously important to provide opportunities for learners to encounter the individual's voice in circumstances that attenuate the power differential and deference to the professional.

3. Health care reform. Themes that run throughout the rhetoric and objectives of health care reform are patient autonomy, patient partnerships, the expert patient, user involvement, services responsive to needs, etc. The involvement of patients and carers as partners in health care has been identified as an important component of patient safety.[12] Governments have promoted user involvement in health service delivery at a community level, for example in the UK, with a wide range of policies ".. to make services more responsive to individual needs and preferences and to involve citizens in the planning of their local health services."[13] The US Institute of Medicine prescribes new rules,[14] in which "care is customized according to patient needs and values" and "the patient is the source of control." Its formula for implementation puts competency in patient-centred care at the fore in the training of all health professionals.[15]

4. Curriculum changes. Recent influential policy documents from bodies that oversee health professions education, determine accreditation standards or assessment of competency (such as the General Medical Council in the UK, the Association of American Medical Colleges, the Medical Council of Canada) declare the need for students to have a better understanding of the patient's experience of illness, the social determinants of health and disease and the needs of the community. Curricula have been reformed to include humanism, bio-psychosocial integration and early clinical contact. A role for patients in the assessment of clinical competence has been recommended. In the UK the Chief Nursing Officer makes the connection between pre-registration education and the eventual provision of effective and values-based care – by recommending that higher education institutions involve service users and carers in every aspect of education, including recruitment, curriculum planning, teaching and student assessment.[16]

5. Grass roots consumer movements. A broad based movement has emerged over the last decade and is gathering momentum. Service users, consumers, patients and their families seek a partnership in their own care with health care practitioners. Dissatisfied with traditional paternalistic relationships, united by the Internet and fueled by increasing fiscal constraints, patients have organized self-help and political pressure groups to influence patient care. An example that influences care through education is Project DOCC,[17] a parent-directed teaching program begun by three mothers of children with chronic illness and now part of over 20 medical training programs in the USA. In most cases these self-help and pressure groups have been successful when nurtured by individuals within academia but as they gain confidence and expertise their energy and commitment is infectious.

The first international conference "Where's the Patient's Voice in Health Professional Education?" held in Vancouver, Canada in November 2005 brought together patients, carers, educators, researchers, administrators and students from different health professions to share experiences and ideas. The 134 presentations illustrated many ways in which patients or lay people have become involved in health professional education in North America, Europe and Australasia.

The following report presents a fairly comprehensive map of the range, in kind and discipline, of innovations that have been tried. It also includes examples from the literature not directly presented at the conference. These educational projects are interesting and varied, but often isolated interventions and not integrated into whole programs.

CHALLENGES

1. How can the patient's voice be incorporated into the continuum of health professional education? What are the clear and measurable objectives and how can patient experiences be introduced effectively into a coherent and progressive curriculum? The hidden curriculum[18,19] and professionalisation tend to undermine the ability of students to hear the patient's voice – what is the remedy?

2. What changes need to occur in the culture of organizations that provide or govern health professional education to meet the challenge of social responsibility and truly engage the community in their educational mission? This is an institutional challenge requiring support through policies, processes, structures, resources and a philosophy of community partnership.

Tensions inherent in these endeavors are manifold. The prevalent culture of health professionals tends to make them feel 'responsible' for their patients (and reluctant to give up control). Students are usually rewarded for having the 'right' answer (from the book or preceptor) not the one made imprecise or qualified by introduction of patient values. Lay health care activists may have their own 'agenda', stimulated by a misunderstanding or harrowing experience. Professional education programs are complex, arcane and not well understood even by many academics (who often see only their small teaching component). University teachers, guardians of the traditions of academic freedom, may resent being told what and how to teach (especially by 'outsiders').

Most of these difficulties can be overcome if we put the learner at the centre. This enterprise is not primarily about patient-empowerment (though that is an expected and desirable outcome). It should not unduly increase the complexity or burden of a teacher's job (though it may make it more interesting). It is about training for best professional practice and improved health care.

FUTURE

This report concludes with a discussion of emerging issues identified by conference participants and arising from their practical experience and aspirations. We highlight some important questions especially for those with policy, institutional and curricular responsibility. There is a brief sketch of continuing activity begun at the Vancouver conference by the Task Force. It includes reference to publications, networks and conferences. Finally, there is an agenda of questions. We think these are important to answer in the next stage of development and expansion of this work.

Education and training do make a difference. Unfortunately, the evidence indicates that we develop a tin ear for the kind of voice that patients wish we could hear. If we are to be truly patient-centred we must learn it in training; it doesn't come naturally. If we are to really hear patients, we must learn to listen in circumstances where their authentic and autonomous voices are not attenuated by our professional privilege or drowned by the clamour of our care.

The conference opened with a reflection from John HV Gilbert, Principal of the College of Health Disciplines and a pioneering advocate for interprofessional practice education: "I hope that it will be possible for us to better understand the patient as educator and how to bring that understanding to changing our health education curricula. … I hope that we can begin to better understand the importance of the patient's inner voice in our professional interactions and reflect on how we bring our own inner voices to that interaction. … I leave you with a lament that has been documented across many literatures: 'If you hear me – why aren't you listening?'"

It is this lament, usually unspoken by patients at the time of encounter with health care professionals that we should and can do something about.

What is happening where?

One purpose of the Vancouver conference was to ‘map the territory’. One hundred and thirty-four papers, workshops and posters were presented to an international and multidisciplinary audience of about 240 people. The nature and extent of 112 papers (for which abstracts and notes made by rapporteurs who attended the presentations were available) was analyzed and is the basis of this commentary.

There was a wide range of educational and community initiatives in a variety of educational settings. The largest category was patients as teachers (37), followed by involvement of patients in health research (21). Other categories included: patient narratives (hearing the patient’s story) (14), curriculum development (10), improving health services (10) and community-university-institutional partnerships (12). Some (8) did not fall into any one group.

Often there was overlap of these categories. For example, projects listed under curriculum development may also have involved community-university-institutional partnerships. Research projects sometimes contributed to improving services or curriculum development. In the patient narratives category the primary focus was on effective integration of the patient’s voice in the learning process, but the improvement of health care services may have been the intent of the learning. It was clear though, that collectively, they were beginnings of a movement in health professional education.

Of course, patients have always been used as teaching material in clinical training but some recent practice has changed this role so that patients share their expertise in a more active way. In a systematic literature review in medical education Wykurz & Kelly found 23 articles that detailed programs with patients involved as active teachers.[20] They concluded that when patients were supported, trained and paid, they could become colleagues in medical training rather than simply teaching instruments. A more recent literature review identified 38 papers that described the involvement of service users and carers in professional education more generally – not restricted to medical education.[21] Five approaches to patient involvement were distinguished. They were: consulting with existing user groups for advice, teaching resources and personnel; creating a reference group of service users or carers to inform educational curricula and content; surveying the views of service users about what should be taught; service users producing learning materials; and service users as teachers and assessors. All these elements (and more) were present in the papers presented at the Vancouver conference but are categorized differently here:

- patients as teachers, including patients’ narratives,
- patient involvement in research,
- patient involvement in curriculum development,
- community-university partnerships, and
- improving health services.

In the following review, references to presentations at the Vancouver conference illustrate the categories and kind of work being done. They are a sample, often from similar work presented by others that equally deserves to be noted.[22]

PATIENTS AS TEACHERS

Simulated or standardized patients

Actors or ‘real’ patients trained to play a patient role have been used for quite a few years in some health professional training and more recently in licensing examinations. The innovations presented went well beyond this to patients creating the roles[23] and providing assessment – giving both formative and summative feedback to students about their interpersonal, communication and physical examination skills. The importance of patient-clinician collaboration is crucial in these teaching and assessment exercises.[24,25] The fact that students must now demonstrate proficiency in these skills during the US Medical Licensing Examination lends credibility to the involvement of standardized patients as teachers and evaluators of student performance. A medical education unit in Leeds, UK, innovates and evaluates a range of ways of using standardized patient teaching and assessment methods. For example, patients, carers, service users and students are involved to develop and enhance the quality of teaching of both staff and patient contributors.[26]

Mentoring

In Denver, USA, patients and their carers are mentors to first year medical students who visit patients with chronic conditions in their homes. Here they learn skills of listening, empathy, observation and respectful care.[27] In Bethesda, USA, students work with parent and patient-advisors in the classroom and during home visits to learn about advocacy, bioethics, pediatric development and communication. Patients and families serve as advisors and major resources to students during a research elective.[28]

At Queen’s University, Canada, a volunteer program involves patients with a variety of conditions to tell their stories and experiences to undergraduate nursing, physiotherapy, occupational therapy and medical students.[29] This program benefited the volunteer patients as well; they gained feelings of being valued and increased confidence in themselves and feelings of being valued. Student nurses in New Zealand worked in a disability unit where hearing patient stories provided the connection and understanding that illuminated classroom theory with clinical experience.[30]

Individual patient stories

In many other teaching situations, the patient experience was integrated into student learning but in a less structured way; individual patient voices were often introduced for single sessions. One example was in a course in chiropractic; the teacher was concerned that students did not fully understand the nature of the diagnostic interview. She invited a patient to talk to the students, who subsequently said they had gained a better understanding of the psychological dimensions of the patient's condition.[31] One radiotherapist videotaped a seminar in which a woman undergoing treatment had talked to students about the realities of radiotherapy side effects and importance of humour during treatment.[32] She had subsequently died but her story continued to have an impact on student learning.

Students' learning from these educational 'experiments' seemed to be so enriched when they heard directly from patients that the teachers were often led to develop broader programs of patient involvement.

Patient narratives

Some evaluation of patient involvement in teaching and learning has looked at the experience from the patient's point of view. Much of this work was with mental health clients for whom involvement in teaching is said to have positive benefits.[33] Small-scale studies looked at user and carer views of involvement in nurse education.[34,35] The evidence, although limited, suggests that being involved in teaching has benefits for patients and carers. Patient delegates at the Vancouver conference asserted these positive experiences. Some described the impact on students of their personal stories. A man living with AIDS presented his narrative through a slideshow presentation of artistic photographs to illustrate his journey through the illness experience. He believed these photographs had helped him to come to terms with his condition and would be useful to students, practitioners and caregivers in their learning and practice.[36]

A different technique was used by two presenters who demonstrated the impact of using 'life event' charts to help women come to terms with their heart attacks and help health care providers to have a better understanding of the needs of women in this situation.[37]

A study, called the Patient Voice Project, demonstrated how to help chronically ill patients to write their stories.[38] These exercises benefited the patients and the university. Other teaching departments used the written narratives to inform learning and enhance practice experiences. The experiences of patients with Alzheimer's Disease and their caregivers provided insight into the implications of this condition for students involved in a narrative writing project at Drexel University in Philadelphia.[39]

Students remember patient narrative and patient teachers; this is well documented. What is less clear is the effect on subsequent clinical practice by these students.

INVOLVING PATIENTS IN HEALTH RESEARCH

Innovations in teaching and curriculum development should be evaluated but this equation often works the other way round: research ideas and findings feed into, or are responsible for innovation and curriculum development. The importance of involving patients in health research has been widely recognized over the past decade.[40,41] The international Cochrane Collaboration set up a Cochrane Consumer Network in 1995 specifically to encourage patient participation in all aspects of health and social care research. In England in 1996, a government-funded organization, now called INVOLVE, was established to encourage patient involvement in the design and execution of health services research.[42]

There are inextricable links between innovation and research. Many projects in this category were evaluative studies of involving patients in teaching and learning. However, some studies explored more complex aspects of involving patients in teaching. One sustained research program in the UK regularly involves patients in health research projects.[43] The aim of the program is to "… create a research culture that is meaningfully influenced by service users, patients and carers." A network of patients, carers, service users, academics and health professionals was established to work collaboratively on research projects. Patients are actively involved in the activities of project design, methods, questions and outcomes.

Quantitative research methods were used to evaluate community health care professional perspectives on the assessment of carers' needs in Belfast, Northern Ireland. The study is part of a review of the nurse training curriculum to facilitate collaboration between clients, carers and educators for curriculum development.[44]

A small exploratory study in Wales, designed to evaluate the teaching and learning of patient-centred interpersonal skills to student nurses, used the results of conversation analysis, observation and questionnaire findings as teaching aids. Students assessed the value of this material on their learning as positive.[45]

Survey data from patient satisfaction studies in the USA was explored to illustrate how such data can provide teaching material for continuing professional development courses.[46]

CURRICULUM DEVELOPMENT

Curriculum development requires more sustained input from patients. Most patient involvement initiatives are one-off courses or modules but there are examples of longer-term initiatives.

The incorporation of patient values into an occupational therapy curriculum was the purpose of teachers at the University of Western Ontario, Canada, beginning 11 years ago.[47] The curriculum committee appointed a consumer representative with full voting rights to inform their developments. Other methods of involvement included clients as guest educators in classes and client interviews as course assignments. Of particular significance was the evolution of teaching the importance of client confidentiality that culminated in students signing confidentiality forms annually.

In Bristol, UK, the Social Work department is developing a model to involve service users and carers as equal colleagues in the social work degree program.[48] Four key principles underlie this initiative:

- support for the users and carers involved
- space for dialogue between tutors, practice partners and service users
- training for the involved users, carers and resources to support them
- a framework for linking users and carers to decision making groups in the Faculty.

In Leeds, UK a panel of expert patients was established to contribute to curriculum development. They are trained and supported and work collaboratively with teachers and researchers to develop and evaluate.[49]

Papers under this heading (patients directly involved in curriculum design and development) had much in common with the next category, which, however, were primarily about partnership development.

COMMUNITY-UNIVERSITY-INSTITUTIONAL PARTNERSHIPS

Most of the initiatives in this category set out to create partnerships to provide educational opportunities for students and services to a community. The partnership between the Faculty of Medicine in the University of British Columbia and under-served communities across the province began three years ago with a focus on community medicine teaching. The program introduced and evaluated initiatives in advocacy, research and teaching.[50]

Through the Center for Patient Partnerships at the University of Wisconsin, USA, students provide advocacy services to patients with life-threatening and chronic diseases.[51] A learning laboratory provides a multidisciplinary setting for a range of health and other professional students to learn from patients. Students supervised by expert Center staff provide patient advocacy services on treatment choices, communication skills, financial and legal problems.

Project DOCC is a grass roots program for physicians-in-training in which the curriculum and teaching is devised and delivered by parents of children with chronic diseases.[52] Its aim is to help residents see, hear, and feel what their patients' lives are like outside of the clinical setting.

The DUCIE network (Developers of Users and Carers in Education) consists of workers employed specifically to develop service user and carer involvement in health care education and is part of the Mental Health in Higher Education project.[53] The Comensus Project at the University of Central Lancashire, UK aims to provide for systematic participation of health and social care service users in all aspects of their Faculty of Health. They developed a 'Community Involvement Team' of service users who provide a forum for information exchange, consultation, negotiation and influence within the university.[54] Some of the most productive and continuing activities to involve clients and carers in mental health education occur in the UK.[55]

IMPROVING HEALTH SERVICES

Some of the literature suggests that one motive patients have for involvement in professional education is to improve services.[56,57,58] One of the difficulties with this category is that there is little assessment of whether or not the initiatives actually improved those services. What evidence that does exist is limited. One project began by asking a question about ways to improve perinatal care. Nurses, educators and parents from two institutions in London, Canada, sought ways to plan appropriate care for a culturally diverse community.[59] Their methods included listening to a panel of women from different cultural backgrounds. Outcomes were the development of perinatal cultural awareness questions and increased use of translation services.

Nursing staff at the Centre for Addiction and Mental Health in Toronto, Canada, working with patients with schizophrenia aimed to improve their practice by incorporating the patient's voice into their daily routines.[60] The underlying philosophy for change was task-oriented and centred on the concept of therapeutic relationship as the essence of psychiatric nursing. Staff had some difficulty designing care plans, making decisions and taking initiative but they made progress. The strategies for change included: weekly case conferences, clinical supervision feedback and faculty members signing up to a care plan. Evaluation showed that staff had difficulty with clients with learning disability and patients were unaware of their care plans.

Two self-help initiatives are included in this category. Both aimed to train patients with chronic conditions to help themselves in collaboration with their health professionals. A 'lay-led' patient education and training program in Victoria, Canada, aims to help patients and their families manage their conditions more effectively.[61] The training is also being implemented in Chinese and Aboriginal communities. Six training sessions with small groups of patients last for two and a half hours, offering information and establishing 'contractual' arrangements for behaviour modification within the groups.

Interviews with patients with chronic conditions, before and after 'expert patient' training,[62] were part of an evaluation of the Expert Patient[63] program in the UK. Self-management skills of some improved while others stayed the same; confidence improved in some cases and social networks and contacts improved. Patients' use of health services decreased on some occasions. Where change happened, patients themselves often brought it about. One problem identified was a lack of mechanisms for providing feedback to the services.

Emerging Issues

Models for patient involvement in health professional education

Initiatives in teaching and research that aim to understand and promote the role of the patient's voice in health professional education are geographically widespread and varied in kind and discipline. Some of the educational programs have been in operation for over ten years although most are more recent. Now there is a need for systematic and sustained program development.

The need for program evaluation

Research to support initiatives and to create others is thriving. What seems to be missing is any systematic attempt to identify which models of involvement are most effective for learning. As Repper & Breeze point out: "Further research is needed to explore the impact of consumer involvement in education and training on students' attitudes, behaviour and practice, and to compare different ways of involving consumers (in different aspects of education and training and at different levels of the organization) to identify those having the most extensive and enduring impact."[64]

Mutual engagement

Some academics and some academic institutions are moving from the ivory towers to reach out to their communities, demonstrating an awareness of the need to work collaboratively with community organizations. Patients and their organizations are eager to contribute to the learning process, and when they do, students say they learn more effectively. Many of the patients involved in teaching and research identified the personal benefits of involvement. These included personal growth, increased confidence, new interests and learning to value themselves and their experiences.

The use of language

Participants stressed the importance of language. Words used in patient-professional interactions have a powerful impact on their experience of care. Students need to know about the power of language and learn how to express themselves both verbally and non-verbally in a caring and considerate manner. One of the suggestions made for addressing these issues is to develop curricular elements that focus on the concepts and cultural aspects of language, and ways in which forms of non-verbal communication can be used by patients and professionals (e.g., film, photography, movement and touch).

Training and payment for patient involvement

Participants generally agreed that patients should have training and preparatory sessions. Many of the established programs do provide training sessions from which teachers, patients and curricula benefit. Financial reimbursement for participating patients is more controversial. Sometimes they are paid expenses and a fee. Sometimes they are not paid at all. Patients themselves have different opinions about payments. Some felt strongly that they did not wish to be paid and that the satisfaction of making a contribution to learning was sufficient reward. Others feel that this is exploitative and that people should be paid for the time they give to teaching and research, a *quid pro quo*.

Interprofessional, collaborative practice

Enlightened course developers have recognized that interprofessional and interdisciplinary working is an essential ingredient of successful training. Given that most health care episodes will involve more than one practitioner, often from different disciplines, collaborative working should be an integral part of practice. The philosophy of 'putting the patient at the centre of health care' means that students need to understand what is involved when they work together with others, including the patient. It is not simply a matter of telling the patient what treatment is appropriate from the nursing point of view (for example). It is also knowing and understanding different professional perspectives and the impact of treatments being delivered by other carers. It is also being able to procreate the treatment plan with the patient and other professionals. There are so many different elements to team working that learning together clearly offers an important grounding for working together.

Future Directions

Since November 2005, the Task Force has continued to promote this movement with activities that include:

- a survey of participants' research activities on the topic and assembly of an updated bibliography;
- a website with links to the conference proceedings and a forum to facilitate networking:
  http://www.health-disciplines.ubc.ca/DHCC/
- publication, on the website, of papers that describe educational innovations, written by conference presenters and others working in the field;
- publications that describe the conference in these journals: *Canadian Family Physician,*[65] *Nurse Education in Practice,*[66] *Medical Encounter,*[67] *Nursing Philosophy,*[68] *Journal of Health Services Research and Policy,*[69] *Patient Education and Counseling;*[70]
- a network of UK teachers and researchers with an email forum PEPIN@JISCMail.ac.uk (Professional Education and Public Involvement Network);
- a conference in September 2006 in Cambridge, UK: *Patient and Community Voices in Professional Learning: Building a Platform for Change;*
  http://www.leeds.ac.uk/medicine/meu/
- planning for future regional and international conferences.

We see the next work (following a development model) as a consolidation stage – to build on achievements of the conference. The first stage was to explore what was happening where, to record the extent and types of initiatives and to find out what kinds of support, if any, the conference participants wanted.

The enthusiasm and commitment of the patients, students and teachers who offered their work in Vancouver was palpable. The suggestions for ongoing work listed above came from them. Almost all who attended said how much they had learned and how much they valued the opportunity to talk to others working in this arena.

The Task Force identified issues and questions to address during a second developmental phase. These are based on discussions and material from the conference:

1. Interprofessional work entails difficulties. How can teachers be helped to negotiate their way through extended partnerships, funding agencies, rules and regulations at the same time as teaching students?
2. Students, patients and teachers have different perspectives and complex relationships. What are the most effective ways of dealing with these demands?
3. Local communities and academic institutions have different needs and cultures ('town and gown'). Do we need 'community brokers' to act as intermediaries? What approaches to these tensions might achieve the objectives of all the partners?
4. Few rigorous evaluation studies have been done. What are the objectives? What are the measurable values to patients and students of active patient involvement? What are the practice outcomes?

The Task Force aims to develop an organization that can provide leadership that responds to these questions. Obviously, this will also require the commitment of energy and resources from others.

There is a convincing case for involvement of patients in health professional education. Students, patients, teachers and communities all appear to benefit. However, the development of these activities and placement in curricula should be more systematic to be most effective.

Ultimately, it is leadership from the guardians of curriculum (deans and directors of professional schools) and the guardians of professional training standards (accrediting bodies and professional guilds) that will ensure the full benefit of this enterprise.

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They can be viewed online at: http://www.health-disciplines.ubc.ca/DHCC/
Follow the link to the conference site and sign in as guest.

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23 **Where is the patient in the standardized patient?** Presenter: Nancy McNaughton, Wilson Centre for Research in Education, University of Toronto, Toronto, ON Canada

24 **What makes a good doctor? Who knows? Who decides?** Presenter: Kathryn Robertson, The Joint Universities Centre For Education and Training in General Practice, Department Of General Practice, University Of Melbourne, Victoria, Australia

25 **Patients and families assessing medical students' communication.** Presenters: Kathy Zoppi, Indiana University School of Medicine, Indianapolis, IN and Beth Lown, Harvard Medical School, Mt Auburn Hospital, Department of Medicine, Cambridge, MA USA

26 **Whose voice is it anyway? Embedding the patient voice in the simulated and standardized patient.** Presenters: Penny Morris, Andrea Armitage and Julie Symons, Medical Education Unit, University of Leeds, Leeds UK

27 **Difficult discussions in the neonatal intensive care.** Presenters: Dorotha Graham Cicchinelli, Colorado Pregnancy & Newborn Loss, Parker, CO and Mary Cohn, Denver, CO USA

28 **Teaching with parents and patients in medical school.** Presenters: Janice Hanson, Departments of Pediatrics and Family Medicine, Uniformed Services, University of the Health Sciences, Bethesda and Carolyn Jordan-Alexander, Clarkesville, MD USA

29 **Every voice counts: a model for meeting educational needs through matching patients and health professional students.** Presenters: Cheryl Descent and Deborah Docherty, Queen's University Faculty of Health Sciences Volunteer Patient Glaxo Wellcome Clinical Education Centre, Kingston, ON Canada

30 **Enhancing undergraduate nursing education: The patient and the family.** Presenter: Judy Seccombe, Universal College of Learning, Palmerston North, New Zealand

31 **Students experience of a patient as the teacher.** Presenter: Annabel Kier, Welsh Institute of Chiropractic, University of Glamorgan, Wales UK

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36 **The question was: Could I find a way to live with AIDS?** Presenter: Jacob Peters, Toronto, ON Canada

37 **Stories from the heart: using life review to elicit narratives of illness and recovery in women following myocardial infarction.** Presenters: Michele Bowers, University of British Columbia and Sally Halliday, Sally Halliday Counselling and Consulting Services, Vancouver, BC Canada

38 **The Patient Voice Project: teaching creative writing to the chronically-ill.** Presenter: Austin Bunn, Arts Share, University of Iowa, Iowa City, IA USA

39 **Alzheimer's narratives: voicing the experience of patients and caregivers.** Presenters: David Flood and Rhonda Soricelli, Drexel University, Philidelphia, PA USA

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43 **Learning Lessons From Involving Patients In Research – The Folk.us Experience.** Presenter: Rachel Purtell, University of Exeter & Peninsula Medical School, Exeter UK

44 **Introducing the voice of the older person into health professional education.** Presenter: Catherine Monaghan, Queen's University, Belfast, Northern Ireland UK

45 **Patient participation and the use of multiple methods to research and teach student nurses: results from an exploratory study.** Presented by: Aled Jones, School of Health Science, Swansea University, Wales UK

46 **Patients are teachers (with a little help from their friends).** Presenter: Laura Vercler, Press Ganey Associates, Inc, South Bend, IN USA

47 **Clients as partners in curriculum planning and delivery.** Presenter: Sandra Hobson, School of Occupational Therapy, University of Western Ontario, London, ON Canada

48 **Local realities of national requirements: involving service users in UK social work education.** Presenter: Pat Taylor, Faculty of Health and Social Care, University of the West of England, Bristol UK

49 **Working together: patient, community and university. Reflections on personal and professional development.** Presenters: Andrea Armitage, Chris Essen, Julie Symons, Shelley Fielden, Sam Samiciuk, Fiona O'Neill, Rob Lane and Penny Morris, University of Leeds, Leeds UK

50 **Building a foundation for community engagement in the Faculty of Medicine at the University of British Columbia.** Presenters: Vince Verlaan, Peter Granger, Patricia Boston, Evan Adams, Betty Calam, Andrew Morgan, Faculty of Medicine, University of British Columbia, Vancouver, BC Canada

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60 **Building in patient's voice in daily practice: Springboard to improving practice outcomes and accountability in nursing staff.** Presenter: Rosanna DiNunzio, Centre for Addiction and Mental Health, University of Toronto, Toronto, ON Canada

61 **The chronic disease self-management program.** Presenter: Patrick McGowan, Centre on Aging, University of Victoria, Victoria, BC Canada

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