UPDATE

Where’s the patient’s voice in health professional education?

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Summary  The first international conference to address the question Where’s the patients' voice in health professional education? was held in Vancouver, Canada, from 3 to 5 November 2005. The 240 participants came from a variety of patient groups, including marginalized populations, lobby groups and patient-as-teachers programs. In addition there were health professional educators, researchers and students from schools of medicine, nursing, pharmacy, occupational therapy, physiotherapy, chiropractic, social work, psychology, law, and other related professions.

Conference presentations

The conference opened with a panel of students talking about their experience of hearing — or not hearing — the patients' voice in their own education in medicine, pharmacy, midwifery, counseling psychology, and genetic counseling. The students volunteered to participate because they recognized the value of the patients' stories and experiences, yet they had also experienced tension between their educational needs and the provision of patient-centred care. The students used some of their own experiences to develop scenarios that they acted out at the conference to show “bad” interactions (for students and patients) and how situations might be improved. Conference participants were asked to view the scenarios from the perspectives of student, patient, and educator to analyze the situations and generate ideas for improvements. The issues and ideas raised by this exercise became a frequent source of challenging and reflective exchange between participants for the remainder of the conference.

The 134 conference presentations (oral presentations, workshops and posters) described a wide range of innovative educational, research, and

1 Chair of the Conference Task Force. Other members of the Task Force are Lesley Bainbridge, Christine Farrell, Martha Gaines, William Godolphin, Cathy Kline, Beth Lown, Penny Morris, Samantha Van Staaldenun, Wayne Weston.

2 We use patient as the single most widely understood term and is meant to encompass consumers, users, clients, etc.
community initiatives, mostly from the UK, USA, and Canada. These included:

- patients who sit on advisory groups helping to define curricula of professional schools;
- lay people who serve as volunteer, simulated or standardized patients giving expert feedback to help students learn communication and other clinical skills more effectively;
- patients who contribute their experiential knowledge as teachers to help students understand the impact of illness and disability on people’s lives;
- patients who participate as equal partners in research projects;
- patients who work with health professionals in practice to improve services and stimulate in-service learning.

Many of the initiatives that were implemented as specific educational interventions within an educational program originated from the personal experiences and convictions of one or two individuals. The challenge is how to embed these isolated initiatives into the culture of the institution for sustainability and impact. Some of the most complex and potentially systemic models of patient involvement came from the UK where initiatives are being driven by government policy to involve the public in the delivery of health education programs. The challenge of professional educators is to translate directives from the top into meaningful partnerships at a community level.

Issues

The conference raised many interesting issues for debate and further work. Four examples are: use of language; training and support for patients and community members; barriers to patient involvement; and evaluation of outcomes.

In a conference that included “voice” in the title it was hardly surprising that the theme of language ran through everything and participants became sensitized to the words they used and their impact. The words used in patient-professional interactions have a powerful effect on the care experience. In an educational setting the words used by the teacher can create an environment for learning that is comfortable, or uncomfortable, for patient and student. The use of the word “patient” in itself is controversial but “patients” at the conference disagreed about the word they would prefer. The choice of “client”, “survivor”, or “user” for example depends on how individuals view their condition and their relationship to it. There are cultural differences too. Service user in the UK is a normal and accepted term; in North America a “user” is associated with taking drugs. It was noted that despite the power of words, concepts of language are rarely addressed in health professions curricula.

Training and support are required for patients to work effectively at committee levels, in recruitment and selection of students, and in teaching, facilitating, and assessing learning. There were several interesting debates about payment for patient involvement in teaching and research. Experience varied, with some projects giving financial payments to participating patients and others not. Patients themselves had different views. Some felt strongly they did not wish to be paid and that the satisfaction of making a contribution was sufficient reward; others viewed this as exploitation. There was general agreement that training for patient involvement was a good thing.

A variety of barriers to involvement of patients were identified during the conference. These ranged from access (e.g., library cards; physical access to university buildings) to attitudes (the defensive behavior of some health professionals). Volunteer community networks can be fragile and unreliable; individual patients may be unable to participate consistently in curricula because of the nature of their illness. What patients want students to know may not be the same as what educators think is important. Health professionals who are committed to involving patients may themselves be marginalized within their own institutions and lack the support and commitment of senior management or leadership.

Finally, more work is needed to evaluate the outcomes of patient involvement in health professions education. Although some of the conference presentations included evidence of benefit to patients and students, many initiatives have not been rigorously evaluated. Participants identified the need for expertise and funding for strong community-based participatory action research.

Next steps

The conference papers and participants provided a wealth of material. From it we were able to identify a number of issues to inform future work and development. Although it is certain that there are other programs, developments, and initiatives in action, of which we are unaware, the work presented at the conference provided a foundation for the conviction that the patient’s voice should be an integral part of health professional training.
Specific actions that have been taken as a result of the conference include:

- Production of a series of reports, articles, and editorials for publication in journals and newsletters to disseminate information and ideas arising from the conference.
- Establishment of a "Patient’s Voice" website and network to continue to share information and ideas.
- A follow up survey on research and evaluation studies on the topic.
- Development of an "innovations manual" based on case studies of a range of different initiatives.
- Development of a comprehensive bibliography.
- A follow up meeting in the UK in September 2006 and planned second international conference in 2007.

For further information or a copy of the conference summary contact isdm@interchange.ubc.ca or visit the website at http://www.health-disciplines.ubc.ca/DHCC.