



Editorial

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CMAJ 1998;159:336-8

The challenge of diversity in the delivery of women's health care

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To understand the perspectives of the many diverse groups in our population and to respond effectively to their particular health care needs is a monumental challenge. Diversity encompasses many things — ethnicity, culture, geography, sexuality, disability, race, age and socioeconomic status, among other descriptors — any of which can present a barrier to our delivery of high-quality health care. Moreover, diversity is a matrix in which every facet intersects with all the others. It is impossible to anticipate every nuance of diversity as we plan and deliver health care, but there are fundamental principles that we should apply as we try to make those services truly accessible.

To be genuinely accessible, health care services must be responsive and intelligible; from the patient's point of view, accessibility also implies safety, respect, comfort and empowerment. If all of our health care services met these criteria, most women would find their interactions with health care professionals positive and productive.

Active listening

Over the last 8 years at BC Women's Hospital and Health Centre (now part of the Children's & Women's Health Centre of BC) we have had the opportunity to develop holistic programming in a number of challenging areas to respond to the diversity of the community we serve. We have come to appreciate that when working with groups that have been underserved or marginalized by the health care system, an essential first step is to establish a trusting relationship based on mutual respect. This can take longer to achieve than one might expect. It involves creating an environment in which the community involved feels safe examining its vulnerability with respect to health care issues. Humility on the part of the professionals involved, together with a willingness to learn about different perspectives on health, sickness and wellness are key ingredients. In our experience, it has been very important to include not only physicians and nurses but also professionals in other disciplines.

As health care professionals, many of us feel that we have a good sense of sociocultural barriers to health care delivery and how to address them. However, to proceed on the basis of this assumption may be to miss the target. BC Women's Breast Implant Centre provides a good example. Although the link between silicone breast implants and recognized systemic diseases is still unclear, a significant number of women in Canada have both local and systemic signs and symptoms that may be related to their breast implants. In BC a strong community voice has emerged advocating services for women with health issues related to breast implants. BC Women's was asked by the provincial Ministry of Health to establish a program for affected women. We thought we had a fairly clear idea of what these women would want: a multidisciplinary clinic providing medical consultation to complement the role of the family physician, a pain management program and a peer-support program. We were proven wrong.

Through our "listening and learning" activities we received a clear message that these services were not of primary importance to our clients. They wanted a



centre that would legitimize this health issue and provide a safe place to share concerns and experiences. They wanted a centre where women would be treated with respect and receive support from staff as well as their peers, where scientific information could be demystified and shared with women and health care providers, and where physicians and other professionals could come together to exchange information. Finally, they wanted research to be done. As a result, the emphasis and format of the program that evolved was radically different from what we would have developed on the basis of our own intuition.

Setting priorities

Large national, provincial and institutional health databases in this country provide a rich source of information on the health status of Canadians. The welcome move toward evidence-based decision-making has encouraged the use of such information in establishing population health goals and program initiatives. However, the priorities of health care planners and providers and those of the population they serve are often far from congruent with one another. This is particularly true in the field of women's health, where there appears to be a significant gap between health status data on the one hand and, on the other, women's perceptions of their own health and their priorities with regard to health care. In practice, it is difficult to engage a community in addressing a given health issue if they do not perceive it as a priority.

The BC Women's Aboriginal Health Program was funded by the provincial Ministry of Health to address the inordinately high rates of invasive cervical cancer among aboriginal women in BC. Research and a demonstration project undertaken by the BC Cancer Agency provided a clear description of the most likely reasons for this: low uptake of cervical screening because of lack of awareness of its importance, difficulty of access, feelings of vulnerability with regard to pelvic exams and other sociocultural barriers. We were given a mandate to work with communities on Vancouver Island, where the data pointed to particularly high incidence rates of advanced cervical cancer. Our program coordinator has strong community connections, and expectations were high. My colleagues in the government who were responsible for funding the project reminded me that outcomes could be readily monitored. We anticipated that by helping to establish community-based women's wellness clinics or even mobile clinics for cervical screening we would achieve a dramatic increase in the number of women living on reserves who would undergo screening for cervical cancer by the end of 2 years.

However, it quickly became apparent as we began to work with women in a number of communities that, in

spite of compelling data on the high rate of cervical cancer, this health issue was either absent from or very low on their list of priorities. With respect to concern with women's health issues in general, each community was somewhere along a continuum. At one end were communities in which women had never had the opportunity to articulate their thoughts about health issues affecting them. At the other end were communities that had, through their own health planning process, paved the way for the establishment of women's wellness services and were therefore very receptive to having us train their community nurses to provide screening. In the middle were communities where other concerns such as violence and teen suicide were more pressing. Needless to say, at the 2-year mark, if our funding model had been based on the number of Papanicolaou smears taken, we would have been in serious difficulty.

However, we have been fortunate that our government colleagues have supported a responsive approach that encourages communities to set their own health care agendas. Over time, opportunities have arisen to put cervical cancer on the table for discussion. After nearly 4 years, we have co-sponsored women's health workshops and conferences in various communities, framing the issues from an aboriginal perspective. For many communities, this was the first occasion when priorities in women's health had been examined and discussed. As a result of this partnering, BC Women's has developed training programs to address the specific needs of nurses and community educators from aboriginal communities with respect to women's health issues. Five communities are now providing their own women's wellness services, staffed by aboriginal nurses who received training through our program. Along the way, a number of resources have been developed that look at women's health issues from an aboriginal perspective, and strong partnerships have been developed with other agencies and organizations who are also working to better meet the needs of aboriginal communities.

Expectations and outcomes

As we learned in the Aboriginal Health Program, working in collaboration with a community to establish a service requires more time than conventional approaches. Moreover, output and outcome are more difficult to measure, a fact that speaks to the need to develop indicators that more adequately measure our progress in addressing the concerns of difficult-to-serve populations. Measuring patient visits or looking for shifts in incidence rates or other health status indicators are of little use, especially in the early years of programs such as this. As Dr. Lorna Sent and colleagues describe in this issue (page 350), the



Asian Women's Health Clinic in Vancouver will not by itself make a significant impact on the number of cases of invasive cervical cancer in immigrant Chinese women even after 4 years of activity. However, in both of these programs we are attempting to track such variables as changes in practice patterns, level of community interest in women's wellness as a whole, and awareness of the importance of screening programs. At the beginning of such initiatives, it is important to establish indicators of success that are innovative and will help us understand how programs such as these affect health-promoting behaviours and health service delivery as well as health status.

Advocacy

Achieving the best possible outcome in our health care services for diverse communities often requires a cross-sectoral approach. The Sexual Assault Service at BC Women's provides urgent medical care, counselling and forensic evidence collection for survivors of sexual assault — who often become isolated after such an event and among whom street women and teens at risk are overrepresented. The program relies on close partnerships with the police, crown counsel, community rape crisis services, victims' services, physicians, nurses, counselors and social workers.

Women who have survived a sexual assault present many challenges to physicians. We have learned that within 48 hours of the assault most survivors cannot be contacted and want to have no further interaction with the health care system. Furthermore, many want to avoid interaction with the legal system because of their perception that they will be revictimized in the process. The goal of our program is to provide women with excellent supportive health care, legal issues being secondary. To return to our fundamental criteria of safety, respect, comfort and empowerment, women who have been assaulted have a right to health care that allows them choice and informed consent. Therefore we do not collect forensic evidence under any circumstance without a woman's consent, nor do we requisition drug testing unless the woman herself requests it. Our health-based framework is sometimes at odds with the legal framework, which has as its goal the arraignment of the perpetrator. Thus, tension sometimes arises in our relationships with our colleagues in the police force and the crown counsel's office with respect to issues such as the collection of evidence from an

unconscious woman or the routine ordering of drug screening for survivors.

To ensure that our health services remain safe, respectful, supportive and responsive, we have spent a significant amount of time in challenging discussions with our law-enforcement and legal colleagues. We have come to a better understanding of one another's paradigms and goals, but the Sexual Assault Service has stood firm on its basic premise that each woman has the right to choose how her case is handled. Our community partners working in rape crisis centres are giving us a clear message that we are on the right track.

Hidden dynamics

Over the last few years our understanding of the barriers to access to health care has improved considerably. Language, culture, geography, family responsibilities, inflexibility in the workplace and poverty are frequently cited as factors that can impede access. But there are other, more subtle, dynamics that are important to understand. Some of these issues may come to light through focus groups or other informal exchanges with groups of women in the community; others are stumbled upon by accident.

In our Aboriginal Health Program we found that a number of women resisted the idea of a women's wellness clinic. On further investigation, it appeared that their male partners perceived the cervical screening program as equivalent to the STD clinic. Because contact tracing is mandatory in the province for STDs, the men were reluctant to allow their partners to access the program. Although the solutions to this problem are complex, understanding the dynamics at work has been an important first step.

The broad diversity of our population presents many challenges to physicians who strive to provide inclusive, respectful and effective health care services. At BC Women's we have learned many powerful lessons over the last few years that will inform our future endeavours. Our hope is that the outcome will be health care that is truly accessible to the diverse groups of women that we serve.

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