

Cultural issues in health services for immigrant women in Australia

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In this presentation, I draw upon research conducted with immigrants from Sahel Africa and the Middle East particularly, but also on both earlier and more recent research I have undertaken with various populations, primarily from Asia and Europe, and on our collaborations with state departments of health (in Queensland and Victoria), hospitals and NGOs.

In 1977, Devva Kasnitz, then a doctoral student in anthropology from the USA, and a small group of immigrant factory workers and advocates, started an NGO, which they called Action for Family Planning, which aimed to provide reproductive health education to women in their own languages at their workplaces. At the time, women had complained that they had no way of getting information about contraception; the general assumption by doctors was that, because of their poor English, women would not understand the information provided to them. Action for Family Planning initially provide outreach in five languages – Italian, Greek, Turkish, Yugoslav and Arabic – with peer-to-peer education conducted on the factory floor. It was to evolve into Women in Industry, Contraception and Health, then Women in Industry and Community Health, then Working Women's Health. Now a large agency called the Multicultural Centre for Women's Health (MCWH; <http://www.mcwh.com.au/>), it covers more than 24 languages and dialects including Arabic, Cantonese, Croatian, Dari, Farsi, Greek, Hindi, Italian, Khmer, Macedonian, Mandarin, Somali, Spanish, Tagalog, Thai, Tigre, Tigrigna, Turkish, and Vietnamese. It still provides peer-to-peer education, using especially trained Bilingual Health Educators to deliver health education on almost all topics. Annually, these educators provide services to an estimated 4,000 women per year at their workplaces and community centres, undertaking advocacy, training and research in sexual, reproductive, occupational, and mental health.

The point of introducing my talk with a brief history of MCWH is because it has not only simply continued to operate for 30 years, but has continued to grow. In 2003-2004 (most recent data), it conducted 571 sessions in various languages, making

approximately 6,840 contacts. The Cross-Cultural Training Program was similarly active, with 915 trainees, including 163 people from other agencies receiving training in order to enhance their effectiveness in working with immigrant women. During the 30 years in which MCWH has operated, there have been major changes in terms of Australian immigration policy, health policy and service development. Clearly not all of these have resulted in improvements in access to services or the quality of care for immigrant women, or MCWH would have been out of a job.

Mid 2005, an estimated 24% of the Australian population indicated that they were born overseas, 18% of the Australian-born population had at least one parent born overseas (ABS 2001). This population – 2 out of 5 of all Australians - is from diverse and culturally distinct backgrounds. Half of overseas-born residents are from Europe (31% and 17% respectively). Around 10% of Australian population is from Asia: China and Viet Nam (4% each). Increasingly migration is extending to other countries: from Sudan (an average increase of 28% per year), Afghanistan (12%) and Iraq (10%) especially, and 70% of migrants to Australia for the year 2004-5 were aged 15-34 years. Migrants are much younger than the population as a whole, fewer are < 15 yo but very few are > 65. Newer immigrants have more children than Australian-born or others from European immigrant background, and children born to immigrant Australians are an important and increasing proportion of all births in Australia, highlighting the importance of addressing the needs of children as well as women in terms of reproductive and sexual health. These require intelligent and timely adjustments in the provision of health services and clinical care. How health care is delivered influences not only the immediate needs for care (eg at time of pregnancy), but the willingness of women to seek health advice.

Stereotypical interactions reduce access and quality of care. Our research with women from Sahel Africa and the Middle East provides numerous examples of the extent to which women felt vulnerable in clinical encounters, both in private practice and in hospital outpatient departments. This partly relates to the focus of inquiry regardless of why they present for care. Because of the publicity being given to FGM at the time of our study, women felt that they walked into surgeries to see doctors with “(their) vulva status on their face” – that doctors were more interested in whether or not they had been circumcised and/or de-infibulated than the condition for which they had presented. The result was that women were discouraged from seeing doctors and especially discouraged from health preventive measures that might

involve examination, including therefore antenatal care as well as sexual and reproductive health care. The consequence of this, compounded with sporadic anti-Islamic sentiment especially after 9/11, and public harassment related to this and clothing style, has led many women to feel deeply suspicious of health services as well as other aspects of Australian society. The use of Heparin for women as an anticoagulant, to prevent thromboembolism after Caesarean section, is an example. As one example, rumours began to circulate among women that hospital staff were intentionally polluting women. The basis of the rumour was that women had been advised that they would receive Heparin as “a matter of routine” for a Caesarean section. The husband of one of the women, unconvinced of the need to perform a Caesarean section first place, had inquired about the drug and discovered that it was suspended in porcine gut mucosa. Women interpreted this as an intentional act of pollution, and the husband began discussions with his *imam* regarding necessary purification rituals. Meanwhile one of women with whom we were working declared that she would rather die than be unclean, spurned by her community because of what was now being referred to as a “pork injection.” We intervened, raising questions with the hospital about the religious and cultural implications of this (with a hint of the possible involvement of the Jewish Board of Deputies as well as the Islamic Council), and the original resistance for replacement (of porcine with a bovine suspension) on the basis of cost was subsequently overturned. The point was the difficulty in shifting attitudes, and the fact that no one had anticipated such difficulties in the first place.

A second example relating to women's reproductive health further emphasises the need to be mindful of interpretations and the context in which particular actions and practices are understood. One of the women with whom we were working was recommended to have amniocentesis after an indication of abnormality as a result of alpha fetoprotein screening test, leading to concern by the hospital obstetrician about congenital abnormality (due to cross-cultural marriage). What she was told by an interpreter was that she needed to have the stomach injection for “the good of the baby”. When the results came back, she was advised to have a termination. She sought the advice of other women in the community, and was told that the Australian government was conducting terminations because it didn't want African or “black” babies. While she was trying to make a decision, she began to have cramps, was admitted to hospital and subsequently miscarried. She had been given two tablets in

this course (probably analgesic), but the story went that if women went to hospital while pregnant, they would be given tablets to kill the foetus.

Reproductive health is one component but not the totality of women's health. However, sexuality and sexual health needs are often poorly addressed and misunderstood. Many of the broad issues associated with sexual health are “undiscussable.” Women with whom we have worked are often reluctant to seek medical advice about problems that they do not understand, and are especially reluctant to seek help if they feel that there is a risk of loss of confidentiality. There is an ongoing need to provide safe and secure services for women affected by domestic violence, sexual violence and abuse. One cannot assume that on migration women leave behind risks that threaten their personal security. Women at risk - usually accepted with children and so heads of households - are not necessarily out of risk on migration, but are often subject to continuing sexual harassment because of their perceived availability without a man.

Lay beliefs about sexual health may also impede women's access to health care services (Dawson and Gifford 2003), contributing substantially to the burden of primary and secondary health problems in Australia, resulting in personal suffering and heavy demands on the health system. We need to continue to work with community lead agencies to ensure appropriate and acceptable services, and to acknowledge that people will not necessarily hold concordant values with dominant community groups. In Australia, the health of immigrants deteriorates, irrespective of ageing, the longer their residence in the country. *Health and social needs are inter-related..* Social inequalities are risk factors for ill health and disability, and these factors are often compounded where, for example, skilled migrant arrivals are unable to find commensurate work because of the non-acceptance of the qualifications. Disadvantaged individuals often lack the information, personal resources and support systems to prevent poor health and disability. These barriers make patient-provider communication difficult (Newbolda and Danforth 2003; Stewart and Do 2003).

Let me illustrate this with an example from research we conducted with women diagnosed with gynaecological cancer. Asma had been diagnosed with endometrial cancer and was scheduled for an operation, but her family members decided against surgery. Several oncologists had tried to convince Asma, her husband and her daughter, who interpreted for her, that radiotherapy would be inferior to surgery. However, the family had a strong preference for radiotherapy because of a

positive outcome for another family member who had had cancer; people who they knew who had had surgery had subsequently died and they were worried about the risks associated with surgery as advised to them by the surgeon (in order to get informed consent). The way in which this was resolved was for the radiologist to sit down with Asma, her husband and daughter, and to discuss with them the limitations of radiotherapy, including possible intestinal damage, and the relatively low risk of complications as a result of endometrial surgery. The intent of the consultation was to ally their fears and reverse their decision, but in the process, we were more impressed by the comments from family members. The daughter commented to her father (in English), 'This is the first time we received information about radiotherapy'. Here, the patient's participation in decision-making was determined by the type of specialist providing information about treatments. The patient and the family learned from gynaecologic oncologists about the risks of surgery that informed their decision against it, but they had not been advised of the risks associated with alternative therapies. In general, many patients receive limited information, because of the lack of time taken to talk through information that others, with greater facility in reading English, might acquire from brochures and other printed sources. Interpreting services are expensive, family and friends are not always familiar with medical terminology, may not understand the procedure even if they are able to translate the exact words, and are reluctant to translate "bad news." *Clinical interactions that are time bound reduce the possibility of understanding.* Most health providers in Australia are English speaking, many clients are not. We need therefore to ensure flexibility in relation to interpreting, while ensuring too that doctors are cognisant of the dynamics that influence the flow of information from doctor, to interpreter, to patient.

Australians from European origins are aging, with significant declines in immigrants born in Poland, Italy and Hungary (2% per year each). *Health needs vary over the life cycle.* Health conditions are complex and co-morbidity is common, especially with age. Our recent research illustrates how immigrant women (older women, and young women married to older Australian-born men) take on caregiving roles of ageing parents and partners, in addition to other domestic, labour force and caregiving responsibilities (including caring for grandchildren), often without taking advantage of government provisions because of their understanding of gender roles and their notion of entitlement as immigrants. They are, in consequence, often

profoundly isolated. As the example below also illustrates, inequalities compound: gender, education and location, and household structure, all shape health outcomes

For example, Lena, in order to stay in Australia with her aging, dependent and sick mother, married a man, not from her own background. She was grateful to him for marrying her. Shortly after they married, he asked her to stop taking care of her mother, who was living with them. Lena saw no choice but to obey, as she had no other place to live and had limited finances. She therefore only took care of her mother when her husband was not at home, sneaking her into the house to bathe and eat, making sure that she stopped caring for her before his return home. As she tells it:

I found a partner, rich, he had a large two-storey house and a car, a rich person, a good housekeeper. What did I do? I married him. As soon as we were at the doorstep, “I am not taking your mother”. “Where would I leave her?” “Let her live with Vasia [Lena’s uncle]. “She is coming with me, where I am, she will be too”. “No. No”. [He] did not [want to] take us. She [Lena’s mother] was living on the veranda of his house. She was sitting in a cold room. Simply sitting. She needed a walker at the time.... I asked just for a heater [to put in her room]. I bought [it], I showed [it to him], and he [said]: “No”. How can I not turn it on? You are sitting in a warm room and she should freeze there. So when he was away I secretly [put the heater on]... when I heard him return, I disconnected it [the heater]. It is impossible to describe how we lived there. .. [Sometimes] the potty [commode] remained for three days [in my mother’s room] because he was at home, and I was unable to deal with all of this. I was unable to overcome all this. I did not know if and where there was any support

Lena was worried about her mother when she was not at home, when attending English lessons, and cried a lot. A classmate provided information on special support services for domestic violence survivors in Australia: “One day, we were taken to a refuge. We were in a refuge for about three months.” *Mental health needs attention, with increasing attention to community literacy in relation to mental health outcomes.*

In the 1990s, a number of handbooks were developed as guides to providing appropriate quality health care for immigrants, the majority written on the grounds that the primary reason for poor health care provided to immigrants was the absence of “cultural” understanding. Many of these, including one that I developed for Queensland Health, listed specific communities which were often seen by health

providers as “problematic.” My favourite manual, produced in the USA, includes an entry on Australians, advising US health providers that “Australians have big teeth.” Our resistance to this approach is because of the presumption that health problems faced by immigrant women - and immigrant men - can be resolved by a recipe approach to culture -- a quick summary that warns against misreading “Mongolian spots” as proof of abuse, or of ensuring that women have “heaty” food after delivery, while at the same time dramatising other aspects of culture as risk factors requiring surveillance (for example, of young girls returning to home countries who are perceived to be at risk of circumcision). As we now know in relation to FGM, the most sensitive aspects of discordance between traditional and host country culture are best resolved through the communities themselves. Other aspects of culture vary by individual and education. This is particularly significant that most immigrants to Australia are from skilled and urban backgrounds, and as respectful and variable with regard to the adherence to “tradition” as other Australians. Our general response to this then was to argue the case for increased communication: to continue to return to the fact that most appropriate person to advise on cultural aspects of care was the patient herself.

The health workforce itself has changed, too, with immigration, although it is notable that immigrant doctors are primarily in rural areas, where Australian-born doctors are least interested in working. Their presence does not necessarily improve the care provided to women, and certainly does not ensure choice by cultural background across the community given that, with some exceptions, new immigrant Australians and others from culture linguistically diverse backgrounds are largely concentrated in urban areas. Moreover, immigrant doctors do not always come from the same backgrounds as their patients -- indeed they rarely do -- and their values are not always concordant with majority or local values, e.g. with regard to women’s roles. We need to invest more in providing ongoing education to support new doctors. It remains true, too, that few other health and related services are available in languages other than English, partly driven by the economics of meeting the needs of people from a vast number of community languages, but partly also because of the patterns of recruitment into different allied health professions.

When accounts of incompetence and misunderstanding are presented in public fora, as occurred when we organise seminars involving immigrant women, bicultural workers and medical professionals, there is considerable resistance: individuals

contradict statements or seek to corroborate as one side argues the poor preparedness of health services and medical institutions, while the other argues in terms of unrealistic expectations on the one hand and lack of support for appropriate services, through the inadequate distribution of funds higher up, on the other. Many stories, including the case studies that I have provided today, draw attention to the negative interactions between immigrant women and health providers: they are cautionary tales of misunderstanding in the context of a wider climate of racism, suspicion and fear. They are stories that travel through the community, illustrating to others how to deal with an unfamiliar health system, in which information specific to a particular medical condition and more generally, in terms of entitlement and access to a wider range of services, are provided. People share with each other stories of "worst-case scenarios," building up a picture of an unfamiliar system that others may have to negotiate as well. We learnt, however, that good stories always followed their bad stories, and that most people thought that hospitals and other services, while "not perfect," were doing "their best." People have good insight into the ways in which constraints on resources impact upon quality of care: after all, most immigrants come from systems much worse than they experience in Australia. While people often felt that particular services were poorly placed to respond appropriately to community needs, perfect sensitivity to specific cultural groups, understandings and needs, multiple demands and fixed resources shaped the ability to respond of any service, and in the end, most people simply required that they be respected and heard. This has been the recommendation from much of our work: that the ability to listen to women's accounts, and to acknowledge the validity of embodied experience, makes up for much lost in communication when language is inadequate to the task.