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# Negotiating candidacy: ethnic minority seniors' access to care

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#### **Abstract**

The 'Barriers to Access to Care for Ethnic Minority Seniors' (BACEMS) study in Vancouver, British Columbia, found that immigrant families torn between changing values and the economic realities that accompany immigration cannot always provide optimal care for their elders. Ethnic minority seniors further identified language barriers, immigration status, and limited awareness of the roles of the health authority and of specific service providers as barriers to health care. The configuration and delivery of health services, and health-care providers' limited knowledge of the seniors' needs and confounded these problems. To explore the barriers to access, the BACEMS study relied primarily on focus group data collected from ethnic minority seniors and their families and from health and multicultural service providers. The applicability of the recently developed model of 'candidacy', which emphasises the dynamic, multi-dimensional and contingent character of health-care access to ethnic minority seniors, was assessed. The candidacy framework increased sensitivity to ethnic minority seniors' issues and enabled organisation of the data into manageable conceptual units, which facilitated translation into recommendations for action, and revealed gaps that pose questions for future research. It has the potential to make Canadian research on the topic more co-ordinated.

#### **Keywords**

seniors; immigrants; access to services; continuing care; British Columbia; candidacy model

#### Introduction

Recent immigrants into Canada aged 65 or more years have poorer health than either long-domiciled immigrants or the Canadian-born population; and this is especially true of refugees and *family class* immigrants (*i.e.* parents and grandparents sponsored by children/grandchildren) (Gee, Kobayashi and Prus 2004; Newbold 2005; Statistics Canada 2005). These differences highlight the need to determine if and how older immigrants experience access barriers to health care (DesMeules *et al.* 2004). Research on minority elders' health (other than African-Americans or Hispanics in the United States) is only now emerging in Canada and countries with comparable immigrant populations and health-care delivery systems (*e.g.* National Advisory Council on Aging (NACA) 2005; Ajrouch 2005; Aroian, Wu and Tran 2005; Gupta 2002; Ip, Lui and Chui 2007). Ahmad and Walker (1997)

suggested that minority seniors are neglected in both research and social and health policy because their numbers are thought to be too few to constitute a 'problem', and because service providers believe that they are cared for by their families. In fact, Canada is experiencing both an increase in the older population and its rapid ethnic diversification (NACA 2005; Statistics Canada 2001).

The idealised notion that ethnic minority communities 'take care of their own' has also been countered by several studies of elders in different cultural communities (Bowes and Dar 2000; Gupta 2002; Katbamna *et al.* 2004; Keefe 2000; Kobayashi 2000; Manthorpe and Hettiaratchy 1993; Pereira, Lazarowich and Wister 1996; Wong, Yoo and Stewart 2006). Structural factors relating to the availability of family members and to elders' needs and financial circumstances, to the patterning of helping behaviour by gender, and to levels of acculturation are in aggregate more important than ethnicity or filial piety in determining whether or not elders receive care from family members. Explaining ethnic minority seniors' (EMS) lack of access to services by reference to the power of filial piety 'perpetuates the lack of services available to ethnocultural groups' (Canadian Association of Community Care and Canadian Ethnocultural Council 1998), and can lead service providers to shift the burden of care to family members with deleterious consequences for both care-givers and elderly care recipients (Brotman 2002; Neysmith 1999).

This recognition of a change in elders' 'circumstances' and needs by both seniors themselves and service providers in the Punjabi community inspired the 'Barriers to Access to Care for Ethnic Minority Seniors' (BACEMS) research project. It focused on the barriers that Vietnamese, Hispanic and Punjabi seniors experience in accessing Home and Community Care in Vancouver, British Columbia (BC).<sup>2</sup> As well as reporting the major findings of the BACEMS project, this paper also explores the heuristic value of the 'candidacy' theoretical framework that has recently been developed from a critical interpretive synthesis of the literature on access to health-care by vulnerable populations (aDixon-Woods et al. 2006a). Following a discussion of the theoretical context, the paper describes the project's methodology and then moves on to interpret the findings in relation to the seven dimensions of candidacy through which people negotiate access to health care.

<sup>&</sup>lt;sup>1</sup> African-American and Hispanic seniors comprise an extremely small proportion of Canada's immigrant population, the majority of whom originated from Asia (Statistics Canada 2001). Moreover, in Canada, unlike the United States, the majority of services fall under the Medical Service Plans in place for each of the provinces and territories. Evans (2002) showed that private insurance is disproportionately disadvantageous to those of low socio-economic status, including recent immigrants. In Canada and the US, research on Aboriginal peoples is treated separately from that on ethno-cultural minorities, immigrants or refugees. Most importantly, Aboriginal peoples uphold an identity as founding peoples with inalienable rights to land and its usage. Their long-standing and complex relationships with national and provincial governments, as well as other institutions such as churches, have been characterised by mistreatment and distrust (e.g. land appropriation, abuse in residential schools), with unique consequences for their health and wellbeing. Many Aboriginal peoples also live in distinctive rural and remote environments, which also reduces the availability of services. Finally, the separate health authorities and rules specific to Aboriginal peoples preclude the transferability of many of the solutions devised to address the access barriers that they experience (Bennett 2005; Browne and Fiske 2001; Wister and Moore 1998)

Moore 1998).

<sup>2</sup> Vancouver Community Home and Community Care Services are offered so that seniors, and adults with significant health problems, can live independently in their own homes as a first option, with supported housing available as required, and a residential care facility being considered only when other alternatives are unavailable. These services promote self-care in a client's home and prevent unnecessary hospitalization. Services are available through your local Community Health Centre and include: Home Care, Home Support, Assisted Living, Residential Care, Adult Day Centres, Home Hospice Program, Meal Programs, Short Term Assessment and Treatment Centre, [and] Transitional Care' (http://www.vch.ca/community/home\_and\_community\_care.htm unpaginated; see also http://www.healthservices.gov.bc.ca/hcc/index.html Accessed 29 August 2006).

## Framing candidacy: theoretical perspectives in ethnogerontology

Johnson et al. (2004: 267) demonstrated that even when health-care providers share the same ethno-cultural background as their patients, 'middle class values and professional socialisation can preclude practitioners from critically considering how race, gender and class play out in the provision of health care'. 'Othering' practices, typically invisible to those who perpetrate them, take the form of ahistorical and abstracted over-generalisations that are applied to specific individuals to explain their behaviour. Typically, these explanations invoke culture, the socially constructed notion of 'race' or gender as a means of creating distinctions between 'us' and 'them'. People in need of care, and at times their carers, experience 'othering' as discriminatory service provision and even abuse (Brotman 2003; Forbat 2004; Johnson et al. 2004). This form of inadvertent discrimination often originates in policies and institutional structures intended to be equitable but designed in accordance with anglocentric, middle-class values. Brotman (2003), for example, criticised the Canadian model of multiculturalism for rendering institutional racism invisible by problematising it at the level of individual interaction. Culture is nonetheless a vital component of social identity that provides immigrants with the resources they need to adapt to new environments (Torres 2001). Building on Cancian's (1975) social identity theory, Cambridge maintained that human agency is propelled by situational and historically encumbered identities. The value of exploring the forms and structures of cultures lies in the understanding of what they can do for people 'both as individuals and as collective inventors of [their] communities' (Cambridge 1996: 175).

The benefits of drawing on both critical and interpretivist approaches have been recognised by several writers, including Mary Dixon-Woods, the principal architect of the candidacy model, and her colleagues (Dixon-Woods *et al.* 2006*b*; Stokes, Dixon-Woods and Williams 2006). Bourdieu criticised Goffman's interpretive interactionist theory for its over-emphasis on individual agents; in his structuralist theory of practice, he emphasised instead the economic, cultural and symbolic *capital* available to people in different social spaces. Following Hallett (2003), however, Dixon-Woods and her colleagues argued that the two theories shared a concern with the issues of rules, (symbolic) power and practice, and that each was necessary to account for and link the micro, meso and macro levels of analysis and to provide a holistic picture of society (Stokes *et al.* 2006; *see also* Guruge and Khanlou 2004).

Dixon-Woods *et al.*'s (2005) critical interpretive synthesis of vulnerable groups' access to care drew upon substantial and diverse qualitative and quantitative evidence from many disciplines as well as policy documents and political statements (the latter focused on the United Kingdom). The analysis was guided by a focus on equity and the need to understand fully how access is achieved by these groups in a health-care system such as the United Kingdom National Health Service (and that available in Canada) that is free at the point of access. The reviewers' 'dynamic, recursive and reflexive' questioning of the ways in which the problematic of access had been constructed formed a key part of the synthesis and a significant role in theory generation. The resultant candidacy model is intended to be a 'midrange' theoretical account that balances explanatory scope and empirical applicability. The authors define candidacy as:

The ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services.... [It] is a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, including how 'cases' are constructed. Accomplishing access to healthcare requires considerable work on the part of users, and the amount, difficulty, and complexity of that work may operate as barriers to receipt of care. The social patterning of perceptions of health and health services, and a lack of alignment between the priorities and competencies of disadvantaged people and the organization of health services, conspire to create vulnerabilities (Dixon-Woods *et al.* 2006*a*: 11).

The definition recognises both the validity of all knowledge and its coconstruction and the operation of symbolic power in relationships. The authors go on to partition this complex construct into seven dimensions: the first six can be viewed as transition points at which a person's candidacy for care must be negotiated, and the seventh captures the broader environmental context relative to which the negotiations take place (Table 1). I argue that this model accounts most fully and systematically for the phenomenon of access and the way in which vulnerabilities arise in relation to it. In the original report, Dixon-Woods *et al.* (2005) referred to EMS separately but briefly as a vulnerable sub-population of older adults; ethno-cultural minorities and older adults are considered as separate populations. The BACEMS data expands our understanding of the negotiation of candidacy by EMS, particularly in Canada.

## **BACEMS:** data collection and analysis

The BACEMS action research project sought to identify the barriers that EMS experience in accessing continuing care services in Greater Vancouver. In the Metropolitan Area in 2001, more than one-quarter of the elderly population was ethnic minority, and among them more than 85 per cent were of Chinese, South Asian or Filipino origin (Statistics Canada 2001). The research was initially targeted at Punjabi seniors with whom I have conducted research for more than 15 years, and whose comments concerning change in filial relations gave rise to the research question. In 2001, Punjabi was second only after the Chinese languages as the non-official (not English/French) mother tongue spoken by more than 60,000 British Columbians (BC Stats 2002; Vancouver Coastal Health 2005). 'Family class' immigrants aged 50 or more years (Citizenship and Immigration Canada 2005) are a potentially vulnerable subset of EMS (Koehn 1993). Their numbers are greatest amongst immigrants from India (BC Stats 2006). Punjabi seniors thus account for a relatively large and especially vulnerable portion of British Columbia's EMS population, yet they do not have access to extended care facilities in their own language.

The Vietnamese and Hispanic populations were identified by health-care providers working in Vancouver's three most ethnically diverse Community Health Areas (CHAs) as including comparatively many seniors with high levels of unmet need. Vietnamese was the second most commonly spoken non-English language in one of these CHAs. In Vancouver, the Vietnamese constitute a mid-size ethnic minority population.<sup>3</sup> The Spanish-speaking or Hispanic population is relatively small – about half the size of the Vietnamese in Vancouver

> - and extremely diverse. There are nonetheless several Spanish-speaking seniors' groups based in various multi-cultural centres throughout the city. These seniors were included in the study to avoid the bias of excluding smaller populations that might have had exceptional problems.

Focus groups were the primary means of collecting data, and were supplemented by participant observation (e.g. attendance at social events, long-term involvement with seniors from each of the communities in a cross-cultural seniors group) and three in-depth interviews with family care-givers (secured through the snowball technique). Six focus groups were held with 56 seniors from the Punjabi, Vietnamese and Hispanic communities, and another four focus groups brought together 26 community health-care and multi-cultural service providers. The health-care provider sample was drawn from the three ethnically diverse CHAs noted above. This multi-disciplinary group included case managers, nutritionists, physiotherapists, community-health nurses, occupational therapists, social workers, and an adult day-centre worker. Multi-cultural service providers working with the three target populations in various settings and who were of the same ethnic background as their clients were also included. The seniors were recruited through their participation in ethno-specific seniors' groups. Certified medical interpreters were used to facilitate each interaction with seniors to reduce the extent to which their statements were modified to serve competing agendas (Sasso 2004; Bowen 2001).<sup>4</sup> All the interviews and focus-group discussions were taped and transcribed in English and then systematically organised into inductive themes. <sup>5</sup> To validate the researcher's interpretive steps, themes were presented to each of the focus groups, and collectively during two follow-up stakeholder workshops attended by 51 and 23 participants.

#### Results and discussion

### Identification of candidacy

The first step in gaining access to health care is determining that you need and deserve it. Dixon-Woods et al. (2005: 216) found that the desire to protect individual and cultural identity, which seniors and immigrants may perceive as threatened by health-care providers and practices, could be a barrier to access. For 'many older people', this identity centres on the ideal of 'being healthy, independent and active' and 'responsible and unselfish' in their use of services. While this is true of the BACEMS sample, the culturally-constructed identities of EMS differ from the mainstream (Anglo) sample to which they refer. Matthews (1993), Guruge and Khanlou (2004) and Grewal (2005) have all pointed to the importance of exploring interdependence and families as systems in research with ethnic older adults, particularly with reference to service access. The comments of the BACEMS seniors and service providers described the dynamics in immigrant families that contributed to the failure of EMS to identify their candidacy for medical attention. The process of migration, particularly when elders are sponsored, tends to reverse their role and status within the

<sup>&</sup>lt;sup>3</sup> In 2001, Vietnamese speakers numbered 6,570 in Vancouver and 12,295 in British Columbia (Vancouver Coastal Health 2005).

<sup>&</sup>lt;sup>4</sup> Space limitations preclude the more detailed discussion of methodology developed by Koehn, Cormier and Sachova (2004), but interested readers are directed to the methodological papers by Chiu and Knight (1999), Fontana and Frey (1994), and Temple and Edwards (2002).  $^5{\rm The~qualitative~data~management~software~\it QSR~Nvivo^{\circledR}}$  was used (Richards 1999).

family and contributes to considerable inter-generational tension and the positioning of elders as dependent. This in turn reduces the likelihood that seniors will identify their own candidacy for care.

In all three communities, seniors and service providers agreed that inter-generational tensions can make co-residence extremely difficult. The extent to which seniors actually coreside with their adult children varies among the communities, with Punjabi seniors the most likely to do so, and Hispanic seniors the least likely. Many more of the Punjabi seniors, as compared to the Vietnamese or Hispanic participants, were recent family class immigrants. These seniors are financially dependent on their sponsors and hence ineligible for pensions and other social supports for 10 years. This arrangement reinforces dependency on adult children and increases the seniors' vulnerability. Women are especially likely to be housebound by their obligations to care for the sponsors' young children (Koehn 1993). While some seniors engage in menial labour, their limited income provides little flexibility to live independently (Dempsey 2004). The difficulty of negotiating unknown territory with limited English and the shame that this would bring on them and their families further prevents most from doing so. The seniors interviewed for this project interpreted their situation as it relates to health-care access in different ways. For some, the heightened independence of younger women in Canada, and the greater likelihood that they will work outside the home and prefer a nuclear-family living arrangement, is interpreted as selfish and robs them of the opportunity to be cared for in the way that they have provided care for their own elders. As one Punjabi senior said:

In the old days, people used to say they should have their own mother-in-law and sister-in-law, but now the views are changing, especially of the young generation, because they do not want to do anything for the others. ... Children are not willing to take the responsibility. ... No one has the time and everyone is selfish, no? ... Only dollars, dollars, dollars; that's it.

Others spoke of the pressures that accrue to their children as immigrants in Canada and their desire not to increase their burden by making demands on them, such as taking them to medical appointments. As one Hispanic senior said, 'In this country, the whole family's busy. The whole family is working. So we can't depend a lot on them, because each one has his problems and his work'. Another inhibitor is fear of institutionalisation by their children. As a Hispanic senior said, 'The majority of us ... we're afraid sometimes to ask for help, because [our children] would say, "Okay, now you have to go to the hospital "....In a nursing home, you have to struggle a lot. It's not easy'. As a consequence, many seniors are reluctant to ask for their children's assistance unless they are critically ill. This precludes access to more preventive measures and chronic disease self-management. A health-care provider said of her EMS clients, 'If they're isolated or they don't have good communication with their family, for whatever reason, in the cultural group ...especially the widows and widowers ...they [might say] "oh, my kids are working". My observation is we get them in a crisis.'

#### **Navigation**

Once the decision to seek care is made, people must invest a great deal of effort and many resources to find their way to and through the health-care system. The literature on immigrants and seniors in Dixon-Woods *et al.*'s (2005) review identified the importance of information about the system, of social support and of practical resources such as language. The recency of many of the immigrants' arrival also influences their ability to navigate health-care systems. Knowing where to go and what is available presents challenges for many immigrants, and the efforts of older people to obtain appropriate care can be stymied by the discontinuities among 'the exhausting range of overlapping professionals involved' in their care or produced by the fragmentation of services that they need to access for their various ailments (Dixon-Woods *et al.* 2005).

Consistent with findings from other studies of EMS (Lindesay *et al.* 1997; Sadavoy, Meier and Ong 2004), many of the BACEMS seniors were unaware of the range of available health and interpretation services and the means of contacting the regional health authority. Some of the service providers we interviewed offered what Johnson *et al.* (2004) referred to as 'culturalist' (othering) explanations for this lack of knowledge. As one health-care provider said, 'often they're very kind of shy, humble sort of people and they're not in the habit of asking for things. So when they need these health resources they don't even know where to go'. Health-care providers in the sample admitted that their prior assumptions about cultural norms had been challenged. One provider recollected:

[I remember] clients [who] because of language and culture, it would have been useful to refer to the temple or some services or somebody in their broader community, but because of pride or shame or whatever, that this is a terminal disease, [they] don't want anybody to know. So they were isolated and we couldn't bring in other people. ... It's a common feeling, that shame; they don't share weakness, and whether they're a big family or not, you can't get past that until they enter the hospital.

As Katbamna *et al.* (2004) found in England, it is essential to determine what resources are actually available to people; stereotyped assumptions about the social supports of ethnocultural care-givers and recipients can have a profound impact on the formal services that are provided. The BACEMS findings support Dixon-Wood *et al.*'s (2005) conclusions that while immigrant communities often rely on family, friends and community for assistance with information, transportation and interpretation, in order to access medical care, help from informal networks is not always reliable or acceptable. The BACEMS participants told us that EMS rely primarily on their children to provide them with the information they need to gain access to health services; yet some children do not know very much about the services themselves, particularly if they are relatively recent immigrants. Others choose to keep this information from their parents because they do not want them to attend programmes outside the home, particularly when they are needed for domestic services and child-care. This information deficit was mitigated in some cases when the seniors were able to attend ethnospecific seniors' groups that regularly invited speakers from the health authority to provide information in their own language.

Taking time off work to transport elderly parents to medical appointments can be difficult for immigrants with limited resources, and using public transport can be especially challenging for EMS. In addition to the usual concerns that seniors have about the cost of different transport options, recently-arrived sponsored seniors are further disadvantaged. As a service provider pointed out, 'a lot of [sponsored] seniors don't have the income but they're not eligible for bus passes'. Moreover, without English, negotiating transport and communicating with care providers can prove impossible for EMS, lending weight to the argument that language is more salient than ethnicity in determining the initial health-care access of immigrants (Bowen 2001; Gerrish 2001). Service providers in the BACEMS study pointed out that most EMS experienced difficulties learning English if they did not speak it prior to immigration. Limited access to English-as-a-second-language classes (Friesen and Hyndman 2004) and low levels of literacy in some communities combine with cultural norms to increase the dependency of seniors on their families and hence limit independent access to services.

The language issue is not limited to new immigrants; not all seniors who have been in Canada for many years speak English. A Hispanic service provider noted that, 'a lot of [Hispanic] seniors have been in the country for 20 years, they don't speak English, they don't have services in their language'. Other service providers commented that some of their clients were losing the ability to speak English as they age. As in England (Ahmad and Walker 1997), both the EMS and health-care providers interviewed complained that very few health information pamphlets have been translated into minority languages. The participants also pointed out that many EMS, particularly women, are not literate in their own language, and hence called for the use of more appropriate educational media such as radio or television for the communication of health-related messages.

#### The 'permeability' of services

To describe the unhelpful features of health-care services' organisation, Dixon-Woods *et al.* (2005) used the metaphor of a membrane through which those seeking a service must find their way to gain access. Services that have low 'permeability' (*i.e.* require referrals, or have restricted access hours) require high degrees of agreement on candidacy between users and providers, impose qualifications on candidacy and require the mobilisation of many resources. While there is variation by service and by ethnicity, the literature on ethnic minorities indicates a tendency to use general practice relatively frequently and specialist services relatively infrequently. The inconsistent provision or non-provision of interpreting services is also a prominent theme in the literature. In this study, many Vietnamese and Punjabi seniors commented that they were able to access general practitioners (GPs) who spoke their language, but Hispanic seniors were disproportionately disadvantaged in their efforts to access services because of the scarcity of Spanish-speaking GPs. The GP is often the senior's only connection with health-care services and determines whether or not the senior is eligible for HandyDART transportation services for passengers with physical or cognitive disabilities. Given the minimal assistance they receive for interpretation, many

<sup>6 &#</sup>x27;HandyDART is a shared-ride public transit service. It uses specially equipped vehicles designed to carry passengers with physical or cognitive disabilities who are unable to use public transit without assistance ' (http://www.translink.bc.ca/Transportation\_Services/Accessibility/handydart.asp) [Accessed 28 August 2008].

seniors are forced to choose among these few GPs; too often their practices are more than an hour's bus ride from the patients' homes. Choice is also hampered because no central registry identifies the languages spoken by GPs.

None of the Vietnamese seniors and only a few of the Hispanic seniors said they were aware of the current availability of interpreters at hospitals and other provincial health services. Vietnamese seniors said that when they consulted specialists or went for tests and screening procedures, such as X-rays, they either relied on improvised sign language or used friends or family members as interpreters. Occasionally, someone is hired for this purpose. A Hispanic senior who spoke English complained that she was unable to understand her ear specialist who used technical jargon that she could not comprehend. A South American trained physician/service provider commented that many Hispanic seniors shared her experience. He added that the doctor-patient relationship is more distant in Canada than Hispanic seniors are accustomed to, and that the time allocated for a doctor's consultation is very short.<sup>7</sup>

The Vietnamese and Hispanic seniors said they avoided using family interpreters because they did not like asking them to take time off work and they liked to be independent. Moreover, lacking knowledge of medical terminology, family interpreters tend to be imprecise, leaving the senior uncertain as to the diagnosis. Even worse, they may purposely decline to interpret sensitive information, for example, when the senior is terminally ill. The health-care providers who were interviewed admitted that they could not make an accurate health assessment without the use of English, but using an interpreter was seen as 'a very last resort'. As one said, 'management kind of discouraged us several years ago from paying for interpreter services if we could find another way'. This can compromise the care they are able to provide. Another comment was that, 'without an interpreter, you miss the subtleties...everything else we can manage in sign language but really trying to explore somebody's pain... you're literally just on the surface, you're not exploring how they feel'. Another health-care provider added, 'probably their care isn't quite as good, and partially that's because they can't understand what you're trying to say'.

Several studies of ethnic-minority groups analysed by Dixon-Woods' team (2005) also pointed to people's unwillingness to use services deemed to be of lower quality because of poor communication by health services and cultural dissonance, particularly at the microlevel of interaction (see also Policy Research Institute on Ageing and Ethnicity 2003). The analysis of organisational issues for older people similarly pointed to the need for 'comfortable' services that allow for choice and continuity of care providers whose cultural and social backgrounds were most closely aligned with their own. Service providers and seniors alike remarked that, when residents have access to their own language and food, they are happier, able to provide mutual support, and eat better. Health-care providers cited a new multi-level care facility for Chinese seniors as a positive example. A Vietnamese senior

<sup>&</sup>lt;sup>7</sup>Koehn's presentation of these findings to medical residents and fellows evoked comments that GPs have approximately seven minutes to converse with a patient; the remainder of the 15 minutes allocated by the Medical Services Plan to a doctor's visit is spent examining and documenting the patient's status and care plan. Whether the GP makes proper use of an interpreter or speaks the language of the patient, this interaction and translation for the chart, takes considerably more than the allotted time. New funding models for GP visits are thus central to the more flexible service delivery models needed for EMS as well as mainstream seniors and those with chronic disease who are likewise constrained by short physician visits and communication difficulties (*e.g.* Ostbye *et al.* 2005).

commented on the importance of language compatibility: '[in] retirement homes or any place, if there is no one that speaks our language, we get lonely and we get sad and we just want to go home, because we want to be around people who speak our language'.

Other participants supplied numerous examples of friends' or family members' discomfort with living in 'English-speaking predominantly white' extended-care homes. One Hispanic care-giver spoke of a senior whose profound loneliness once placed in a home with no Spanish-speaking staff appeared to have hastened her death. Without access to Punjabi-speaking staff or interpreters, an elderly woman became frustrated and disruptive, switching nursing homes three times. An elderly man who was 'marooned' in a facility without other Punjabis around him became depressed. A Punjabi family care-giver could not make use of adult day-care facilities for his mother because she experienced difficulties with language, food and the activities offered. One care-giver performed numerous services for her elderly family members living in an extended-care home as well as for others whose families were unable or unwilling to spend as much time with them. Although the nursing staff included enough Punjabi speakers to ensure that one would always be available for the Punjabi residents, the facility director would not accommodate the request.

Intimately tied to religious precepts as well as lifelong custom, food represents much more than nutrition for many seniors (Koehn 1999), but unless their families are able to provide meals they rarely get the food they need in medical and long-term care facilities. Many seniors prefer to go without and hence compromise their health. Aziz and Campbell-Taylor (1999) noted that lack of attention to cultural food preferences is one of several factors that contribute to the malnutrition of seniors. A Punjabi family care-giver said of his father's experience in the geriatric ward of a hospital located more than 30 kilometres from his home:

He will not take any of their food, so whatever came from them went straight into garbage. ... He used to take this breakfast ... and then [we provided] the other two meals, lunch and dinner. And I and my sister took turns ... we'[d] take meals for him at the mealtimes, you know, and make sure he eats that.

This man nonetheless believed that the current cohort of young-old people were unlikely to receive the same level of care from their families. He said, 'there's no way our children will ever take care of us, or even provide any meals for us in the care home or hospital, because as it is, they already are not eating Punjabi food themselves'.

Ethnic minority seniors in care also require some means of satisfying their spiritual needs. It is not customary in the Sikh or Hindu religions, for example, for religious practitioners to visit members of their congregation in hospital. Instead, people stay connected with their faith through religious radio or television programmes or by reading holy books. Typically, however, facilities do not provide radios tuned to these stations, and in shared rooms other residents complain about the noise. Participants suggested that special chips could help seniors to tune into ethnic stations, which along with arrangements to contain the sound would go a long way to ensuring the contentment of EMS residents.

Sadavoy, Meier and Ong (2004) maintained that appropriate models of service delivery for EMS must be more ethnically sensitive and flexible; 'access ports' with on-site, trained cultural and language interpreters and outreach to community agencies are one example. Seniors and service providers in this study endorsed a comprehensive diabetes prevention programme targeted at Vietnamese people that was funded by Health Canada for two years. Vietnamese seniors claimed that the programme effectively taught them about preventive and self-care techniques and familiarised them with the health authority in general, but like many such programmes, its continuation is threatened by insecure funding.

## Presentation and adjudication<sup>8</sup>

For both immigrants and older people in general, the process of presenting well in order to demonstrate the authenticity and legitimacy of a claim to candidacy is complex. Language incongruence between the health-care recipient and provider, as discussed, clearly limits the ability of the recipient to make a credible claim. The 'adjudications' that health professionals make about their patients are the ways in which they categorise patients, and thereby refer them to specialist and screening services based on the patient's presentation and the professionals' assumptions (Dixon-Woods *et al.* 2005, 2006*a*). In this process, the practice of 'othering' is especially salient (Johnson *et al.* 2004). Although research in this area is sparse, the domain of mental health has been fruitful for exploring how 'people are classified (categorised) and subsequently investigated, referred or treated (disposed) '(Dixon-Woods *et al.* 2005: 151). The presentation of mental health symptoms is potentially influenced by stigma, discrimination and social control, all of which have been found to inhibit the presentation and recognition of symptoms of mental illness by both immigrant and older patients (Conrad and Pacquiao 2005; Polyakova and Pacquiao 2006).

The prevalence, symptoms, course and outcomes of illnesses vary substantially by culture (Kirmayer 1989; Kleinman 1987; Littlewood 1990). Cross-culturally, there are various idioms of distress; symptoms viewed as depression in one culture may be interpreted as soul loss in another (Littlewood 1990). For example, some EMS that experience depressive symptoms related to the experiences of immigration, settlement and racism identified their mental health issues as 'stress' or 'spiritual crises', in part because the terms depression and anxiety are not customary in their home countries (Ahmad et al. 2004; Marwaha and Livingston 2002; Sadavoy, Meier and Ong 2004). The insensitivity of research instruments derived from western nosology has further contributed to the under-estimation of depression among immigrants (Krause et al. 1990), particularly among women who lack social support, and experience poverty and criminal assaults (Williams and Hunt 1997). Appropriate referrals are thus not made because of the failure of health-care providers to recognise culture-specific presentations of illness; yet over-generalisation of these tendencies results in stereotyping that can have the same effect. The difficulty is compounded in later life by the differential presentation of health problems and increased co-morbidities. Gender can also play a role, with older women being less likely than men to seek medical help for depression (Bruce et al. 1999, as cited in Dixon-Woods et al. 2005).

<sup>&</sup>lt;sup>8</sup> This clustering of two dimensions aligns with Dixon-Woods and colleagues' presentation of their analysis of materials on ethnocultural minorities in the earlier (2005) report. The definitions provided in Table 1 follow the format used in the later (2006) article.

<sup>&#</sup>x27;Presentation' is equivalent to 'appearances at health services'.

It has also been suggested that the characteristics of health-care providers are also relevant. There is evidence that under-referral to mental health services by Chinese-speaking physicians in Canada (Chen and Kazanjian 2005) and by South Asian physicians in Britain (Ineichen 1990) has contributed to the under-utilisation of mental health services by their patients, most of whom are of the same language group. Similarly, the role of differential *expectations* of health care by recipients and providers can influence referral patterns (Janzen *et al.* 2006). Ageist or racist attitudes held by providers may manifest in judgements about the ability of the older patient to convert interventions into persistent benefits that justify the investment.

Several Hispanic seniors interviewed for BACEMS felt that their GPs or specialists had not taken their complaints seriously. One reported that she felt like a 'guinea pig', having repeatedly received medications for blood pressure with adverse side effects. Another said, 'I also have a heart problem, and also have high blood pressure. And I went to a specialist and the specialist said, "well, I can't do anything [for] you, because you're too fat, so you better take these pills to lose weight". And a few days later I had a stroke. 'Without additional knowledge of her presentation and the physician's response, it is hazardous to interpret these comments. Dixon-Woods *et al.* (2005) argued that in order to advance our understanding of presentations and adjudications, we need research that makes comparisons between groups, and that reports of behaviours need to be complemented by observations.

#### Offers and resistance

Research on offers of medication or treatment and their uptake is virtually absent in the literature on ethno-cultural minorities and limited to preventive treatments among older adults. Dixon-Woods *et al.* (2005: 226) suggested that this may be because few reliable data capture this process: 'Most offers occur in private following a process of adjudication and negotiation with health-care providers'. Case notes are notoriously 'unsystematic and often unreliable' and the accuracy of self-report measures is contingent on the patient's understanding of the health-care system; it can be difficult to keep track of who offered what when dealing with a large number of health-care practitioners or language challenges.

The BACEMS data provides food for thought in this domain. Cultural values such as shame, family honour, filial duty and respect for elders may colour the way in which some EMS interpret the provision of care by non-family members. Home care may be refused because they perceive that it conveys messages to others about their own ill health, family problems, or a lack of status and respect within their families, who are stigmatised in the community. A health-care provider commented on how cultural ideals held by both the seniors and their children can interfere with their acquisition of home care: 'On the adult children's part, it's ...how other family members [and] friends would view their decision [to secure home care] because that would bring shame to the family'. This service provider invoked a cultural explanation for the refusal of offers. Conversely, some seniors reported that incorrect assumptions about the availability of family support by service providers can result in the withholding of offers of service. As a Punjabi senior said:

The way the thing seems to be structured is that people who are more responsible, or who feel more responsible for their near and dear ones, the elder ones, and that

they care to spend time and effort and money to help, to look after them – the government says, 'well, that's fine, you go ahead and do it '. And the others, if they don't, then the government steps in somehow.

The following example of the repeated refusal of offers to place an elderly Vietnamese woman in a long-term care home by family members is similarly open to multiple interpretations. A case manager told us that while this woman resided with her son and grandchildren, all members of the family worked and nobody was able to provide sufficient home care:

The care-giving family ... they have tried three times to place her and I'm saying until you get over your guilt you're not going to place her. ... I put in as much home support as the system allows but they can't get over the guilt of letting go and putting her in a place because not one family member in this Vietnamese family can [stick to that decision], because of the culture values there. ... And so it's a real big dilemma and it's been going on for a year-and-a-half. ... I will wait-list her, but every time we get to that clinic it always breaks down and she's back [with the family].

Similarly, a Punjabi-speaking case manager expressed her frustration at not being able to provide a better service to her elderly Punjabi client because the family members were unwittingly depriving their elderly father of optimal care in their concern to fulfil filial obligations. The case manager had offered support subsequent to his discharge from acute care, but the family did not seek help, despite his declining health and incontinence, until they reached a crisis situation. She said:

Their perception was that nobody could do that work for their father. [They thought] 'it's only us that could do it'. They were not aware of the total service and my feeling was that maybe in the hospital they thought they understood it fully. Eventually that person was placed [in a care facility]. ... The assumption that we have too ... [is that] that they know exactly what we're talking about and exactly what a home support worker can do.

In this case, the health-care provider acknowledged that the scope and nature of services available was not apparent to family members who were accustomed only to doctors and nurses offering limited medical support in their home country. The influence of various dimensions of access already discussed, such as lack of appropriate information about the service in a format readily accessible to the families, the lack of 'permeability' of available services and previous experiences of discrimination were not considered in their explanations of these refusals.

#### Operating conditions and the local production of candidacy

Local conditions that influence the production of candidacy range from proximity to services to provincial policies, the effects of which can be profound. An example of the latter is that the 'first available bed' policy in British Columbia disproportionately jeopardises bids by EMS to establish their candidacy for care. This provincial policy has raised the criteria for admission to residential facilities, such that only seniors with 'complex care needs that cannot be adequately met in their home or a supportive living environment'

are eligible for admission (Government of British Columbia 2002). Additional criteria for admission include established residence in British Columbia, Canadian citizenship or permanent resident status. Recent immigrants are disadvantaged since they cannot always fulfil the latter two criteria; although there are provisions indicating that these can be challenged by people in need.

More controversial, however, is the priority access clause that determines that, 'Clients with the highest need and urgency, whose care needs cannot be met with home support or other supportive care, have priority access for the first available, appropriate bed'. While in theory this may sound equitable, in practice it disproportionately disadvantages EMS who may be placed in facilities where they are far from staff, residents and family members who can provide familiarity, interpretation services and culturally-appropriate food. An extreme case was reported by a case manager called in to speak to a Punjabi man who, based on the 'first available bed' policy, had been placed in a Jewish care home:

The liaison [case manager] told me that this [Punjabi] client has got some kind of mental health issues, and asked if I could talk to him. ... They said: 'He's refusing to eat. He's not eating. He tends to stay in his room – doesn't socialise, and he is crying all the time. There could be some mental history here'. Sometimes if they will talk to him and he will say, 'Just leave me alone' through gestures. And they thought, 'Oh, he's violent, he's an angry man'. So here I go and his first reaction is, 'Can you leave me alone? 'And I said in Punjabi, 'No, I'm here to talk to you'. He got up from the bed, he sat up and he started talking to me, and I just listened. He was telling me, 'I don't want any medication, I don't want anything. Please take me out of here. I could live anywhere. Leave me in the temple. Leave me anywhere'. And he was trying to touch my feet [a gesture of supreme respect for an elder]. This was an extreme case. ... He was in an island, totally.

Fortunately, the case manager was able to relocate this man into a facility with other Punjabi residents and staff that was closer to a Sikh temple where he was taken for weekly visits. Another health-care provider confronted with a similar case described the policy as 'inhuman'. Ideally, EMS and their families would be counselled to plan ahead for elective placement in an ethnically-appropriate facility, although we know this to be challenging for many seniors (Sörensen and Pinquart 2000).

### **Conclusions**

The candidacy framework brings to light the complexity of attaining access to health care, and illustrates the involvement of many different stakeholders and the need for diverse strategies to surmount the barriers. The BACEMS data provided insight into some of the dynamics at play in the different candidacy domains for EMS. The family dynamics that result from migration, immigration policies (*e.g.* the dependency imposed on parents sponsored as Family Class immigrants) and global social trends, such as young women's increased participation in the workforce, have a profound influence on the senior's decision to seek care. Role and status reversals that erode the senior's position in the family and their own self-esteem, the isolation of seniors who provide care for young grandchildren, and the vulnerability of seniors who are financially or socially dependent on their sponsors

undermine the ability of EMS to access appropriate care in a timely manner. Additional research is needed to understand more fully how this dynamic plays out in different cultural groups. Solutions that enable and empower EMS must not increase friction within their extended families.

The challenge of navigating services is considerable for EMS, in part because of these family dynamics and their dependency on family members. Lack of proficiency in the host country's language challenges immigrants of all ages, but is especially problematic for EMS who are most likely to lack language or literacy skills and who experience higher rates of disease morbidity. Further research should identify what resources are in fact available to EMS to enable them to navigate through the health-care system. The evidence supports the need for professional interpreters and the inappropriateness of using family members for this purpose but it is not specific to EMS. And health decision makers continue to frame interpretation services as a 'last resort'. 'Permeable' services for EMS are staffed by health-care providers who speak the same language or have readily available and consistent interpreters sensitive to the need for seniors to establish enduring relationships with healthcare providers. Use of interpreter services precludes consistency and the development of trust. For EMS to feel comfortable with long-term care, facilities need to be sensitive to the language alignment of residents and staff and to provide options that enable residents to speak with peers in their own language, eat food that is consistent with their cultural and religious mores and life-long custom, and to access appropriate religious services. Research that compares the quality of life of EMS residents in ethno-specific long-term care versus majority facilities is needed.

The little of the BACEMS evidence on presentations and adjudications supported Dixon-Woods et al.'s (2005) argument that research on these micro-level interactions is the key to understanding referral and retention patterns. An emphasis on recognising cultural variation in the type of symptoms, course and outcome of illness without 'othering' or resort to culturalist explanations is critical. The BACEMS research offered many examples of the refusal of offers of medical care. The candidacy frame-work ensured that explanations of refusals took both cultural specificities and othering practices into account. EMS and/or their families may refuse home-care services, home-support nursing or placement in a longterm care residence because of the cultural stigma that acceptance of outside help invokes and/or because they perceive or experience discrimination in their efforts to secure such services; the two are not mutually exclusive. British Columbia's residential-care access policy clearly exemplifies how the efforts of EMS to establish candidacy are contingent on local structural conditions such as policies and the availability of resources. Research to evaluate the impact of specific policies on EMS is required, as are studies of geographical influences on access to care by this sub-population. Exploring the BACEMS data in the candidacy frame-work facilitated more insightful interpretations of our findings relative to the literature on ethnocultural minorities and identification of future research needs on EMS and health-care access.

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Table 1
Characteristics of the seven dimensions of candidacy

| Dimension                      | Characteristics  |
|--------------------------------|--|
| Identification                 | Differential recognition of symptoms as needing medical attention.  Vulnerable populations are more likely to manage health as a series of crises.  'Evidence of lower use of preventive services and higher use of accident and emergency facilities, emergency admissions and out-of-hours use' (Dixon-Woods et al. 2006: 12).                           |
| Navigation                     | Awareness of the services on offer; known to be reduced for vulnerable populations. Mobilisation of practical resources, <i>e.g.</i> time off work and transportation, which are typically less readily available to vulnerable populations.   |
| Permeability of services       | Services are more or less accessible ('permeable') depending on the qualifications of candidacy required to use them ( <i>e.g.</i> a referral) and the degree to which resources need to be organised.  Less permeable services 'demand a higher degree of cultural alignment between themselves and their users' (2006: 12).                              |
| Appearances at health services | Credibility once the client has presented at a health service depends on his/her competence in formulating and articulating the issue for which help is being sought.  |
| Adjudications                  | Judgement calls made by the health professionals who clients initially consult.  'Professional perceptions of the cultural and health capital required to <i>convert</i> a unit of health provision into a given unit of health gain may function as barriers to healthcareIn addition, perceptions of social "deservingness" may play a role' (2006: 13). |
| Offers and resistance          | Resistance by patients to referrals and/or offers of medication.   |
| Operating conditions           | 'Locally-specific influences on interactions between practitioners and patients'.  'The perceived or actual availability and suitability of resources to address [a claim to] candidacy' (2006: 14).   |