

# **Towards Culturally Responsive Care in the Community: Ethnicity and Early Intervention in Dementia-Related Decline**

## **Final Report to the Pallium Project**

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# **Towards Culturally Responsive Care in the Community: Ethnicity and Early Intervention in Dementia-Related Decline**

## **1.0 INTRODUCTION**

This subproject was based on four inter-connected components: (1) Canada as a contemporary multicultural nation; (2) the reconciliation and renewal underway with the First Nations people; (3) the health care shift to patient-centred practice; and (4) the rising rate of dementia within an aging population.

### **Cultural Issues**

Research-oriented analysis of dementia-related issues is relatively rare in Canada. While studies on the co-relation of cultural differences in the identification, treatment and institutionalization of dementia and Alzheimer's disease patients have been undertaken in other jurisdictions, notably in the UK and the USA, thus far, no study of this sort has been done as part of primary health care renewal efforts in western Canada. We set out to work within Northern Alberta, thus providing an essential building block for informing dementia-related care as part of Canada's primary health care renewal investment, especially as it intersects as an end-of-life care concern associated with extended, progressive, life-limiting illnesses. By using Northern Alberta as an applied community-based laboratory, much of the early learning from this work will be helpful in informing work in other jurisdictions in which the Pallium Project operates. It also has the potential to seed a western Canada hub for future multi-site work with other Pallium Project collaborators spread throughout Canada.

### **Professional Education Issues**

From the perspective of building cultural competence among professionals, few projects have undertaken the educational development necessary to achieve this. In a multicultural society such as Canada, primary care professionals (i.e., especially community-based RNs and family physicians) need to be aware that dementia is essentially a Western construct in terms of its status as a pathology (Patterson, et. al. 1999). In many cultures, this diagnostic label does not even exist (Pollitt, 1996). In making diagnoses, cultural sensibility must be a factor taken into consideration.

Implementation of the "Canadian Consensus Guidelines for Dementia" is likely to be a challenge for many family physicians as there is variable understanding in our aging and culturally diverse population. Primary health care professionals generally need to have a better understanding of how various cultures view the disease (dementia), including its impact on family caregivers and the community. We need to create a short- and medium-term context where primary health care professionals will be better able to collaborate in assessing, treating, managing and developing culturally appropriate community services.

## 2.0 STUDY PURPOSE

This subproject had two main goals:

1. to determine how ethnicity and culture operate as variables in recognizing, caring for, and treating dementia, especially as it increases in prevalence as a chronic progressive life-limiting illness; and
2. to develop collaborative responses for more effective community-care of this phenomena as a population health concern in Canada.

The research team began its study by examining the explicit cultural components of dementia in four distinctive ethnic groups in Northern Alberta - Indigenous, French, Chinese and Muslim. We found that several important features predominated the discussion of dementia among these four groups:

- a. **First Nations peoples**, especially the Cree, still have viable language and cultural systems in place. We worked with a group of Cree seniors at the Elder's Lodge in Wabasca, Alberta. Dementia is a controversial issue in the community.
- b. **French communities** have been a bedrock of European immigration to Northern Alberta, with several family-clusters dating back to the fur trade period. Although the pressure to assimilate has been great, especially in the early days of English administration, these communities have retained their French character and culture. Places like St. Isadore, Guy, Falher and MacLennan all have viable cultural organizations that can provide reliable data on the cultural dimensions of the Francophone population. We worked through the Services in French, for the Peace Country Health Region who identified people from across these communities to participate. The distinctive perspective the Francophone community presented on dementia-related issues could not have been predicted.
- c. **Chinese immigrants** are well known throughout the northern part of the province beginning in the 20th century; however, since the 1980's, the Chinese population has boomed. With this development have come many elderly, often as retired relatives of migrating children. Some of these people understand very little English and rely upon their close relatives for information and translation. We found that Edmonton has two parallel Chinese immigrant communities, one based on Mandarin, the other based on Cantonese. While these are not mutually exclusive, there were sufficient differences in migration and type of community that we split the Chinese into two groups. We found striking positions on dementia within these communities.
- d. **Muslim immigrants** have been part of the complexity of the North from early times, with Lebanese Muslims one of the earliest on the continent. Significant numbers came after the end of the Second World War, and many of them settled in Lac La Biche. Presently, percentage-wise, Muslims in that town constitute the largest per capita group of any city in North America. We found a well-organized community, with a mosque and cultural components firmly in place. We were surprised at both the assimilation of the community, as well as its distinctive position on dementia-related issues.

### **3.0 METHODOLOGY**

#### **3.1 Study Design**

We developed culturally-sensitive questionnaires for each of the participating communities. We translated the questionnaire for the Francophone community into French, but for each of the other groups, we relied upon community-based facilitators, who either verbally translated the material themselves, or arranged for someone else to do so. We met with each facilitator at least once, outlining the purpose of the study and answering any queries. We then met with the facilitator and a select core group from the community to review our analysis when the questionnaires were complete. All participants were quite happy to be involved in the study and it would appear that the study itself has prompted some to raise questions about community involvement in dementia awareness. This activity completed Phase 1 of the subproject.

With participants from the four communities, Phase 2 of the study involved identifying the principal issues of the groups relative to dementia. Consequently a methodology involving community questionnaires, community meetings and ethnic resources provided the foundations for our study. Once this was in place, we explored through workshops how and to what extent these issues are currently addressed among health care professionals and health care workers in Northern Alberta.

#### **3.2 Participants**

It became obvious very early on that the communities differed considerably in their cultural makeup; for example, Muslims insisted that the elderly males of their society reflected the views of both male and female within the community, this being their traditional religious role. Thus Muslims self-identified with distinctive religious doctrines relative to aged parents. On the other hand, Chinese reliance on religious values was more muted. These nuances are reflected in our analysis of the data. We were not able to get similar cohorts across all groups for the simple reason that these sectors do not exist the same way throughout the various ethnic groups. Then, too, First Nations people recoil at being regarded as 'ethnic,' so wording became an issue. Finally, considerable variance in meeting with consensus groups was the norm in this research. We just were not able to standardize the cohort as one might have wished in an ideal situation.

#### **3.3 Methods**

##### **Step 1 – Conduct Literature Review and Bring Cultural Issues into Focus**

This step was completed and as part of the deliverables for this study and was included in the interim report March 28, 2006 to Pallium.

##### **Step 2 – Framework Development**

We developed a set of operating principles deriving from the selected ethnic groups and constructed a list of areas in dementia treatment that will need to be addressed by the health care profession. From these principles were crafted a set of cross-cultural concerns and distinctions relating to dementia's identification, treatment, care and institutional configuration. We received valuable feedback from the ethnic groups concerning these principles during the consensus group meetings.

### **Step 3 – Stakeholder Engagement**

We organized working sessions with select cultural brokers within each of the communities to seek their input on the principles that would be placed in the questionnaires. Combined with the resources of our team, we were able to identify crucial areas for each of the groups. This provided us with an important finding: we could not use a uniform questionnaire for all groups. We therefore had to design a uniform questionnaire and then modify it for each group. To make sure we were culturally-sensitive in this important area, we checked back with representatives of each group. When we were negotiating with communities, we also discovered issues relating to the questionnaires...for example, one group preferred to have questions relating to language highlighted. However, to develop their counsel on question strategies would have skewed our timelines. In one case, we found the time lines for developing a community-based partnership too great to fit within this project's timelines. In short, these sessions allowed us to refine our ethnic understanding of the dementia structure within each group so that an ethnically-sensitive model could be articulated. Finally, it is worth noting that all groups wanted copies of our final analysis and findings so they can use them for further activity within their own ethnic group.

### **Step 4 - Design/Build/Test Knowledge Translation Products**

As part of phase 2 of the study, we provided health care professionals with a series of workshops and grand rounds based on the findings, so that the professionals may address some of the perceived areas of information and perhaps lacunae. At the same time, their judgment on how effective the procedure and materials allowed for a correction and sharpening of the results. Also, as part of phase 2, we started the process of developing videos portraying common ethnic cases and ethnically-sensitive scenarios for practitioners. These will be available for us in the new year.

### **Step 5 – Exit Surveying**

In this step, we administered a follow-up questionnaire to health care professionals to address the effectiveness of the operation, with questions designed to determine how ethnically-sensitive outcomes will have an impact on the local health care practice.

## 4.0 RESULTS

### 4.1 Summary of Consensus Group Findings

As noted in the interim report (March 29, 2006), each community provided us with a person from their community who acted as mentor and mediator for the group. That individual then chose from 10 to 20 seniors to form a consensus group. The responsibility of the consensus group was to meet together and answer the questionnaire that was prepared for them. Separate questionnaires were developed for each ethnic community (**Appendix A**). When that task was completed, we received the answers, studied them, then met with the mentor and one or two members from the consensus group to determine if there were any questions that posed a problem. When this activity was complete, we placed the material in a profile of the group's perceptions. From this data we then selected the issues or issues that were of obvious concern for the group.

The results of this process revealed a wide range of cultural and ethnic conceptions on end-of-life and dementia care. Among those, we have selected a few here to comment specifically upon (the entire package was appended to the interim report, March 29, 2006)

1. Language issues have much more weight among the various ethnic groups than we had anticipated. Our evidence seems to indicate that where dementia is an issue, an acquired second language ability may deteriorate to the point where the senior returns to his/her native language rather abruptly. This isolates the patient even more, since it is unlikely that health care workers have been apprised of the language shift. The same phenomenon may also appear with a stroke or with some kinds of heart disease.
2. Cantonese-speaking patients have different perceptions of end-of-life than Mandarin-speaking Chinese people do. One of the principal differences is in life experience. Chinese Cantonese-speakers have been in Canada much longer. They are more likely to have parents and extended families in Canada, while Mandarin-speakers from mainland China are more likely to be alone in Canada. This means that the earlier immigrants also identify more closely with Confucian familial values, while the Mandarin-speakers, born and raised under communist rule, have fewer convictions deriving from that traditional religious culture because of government policy.
3. Quite unexpected was Francophone attitudes towards resuscitation protocols. The senior members of this community were quite willing to learn more about living wills, etc., but they had not had the information brought to their attention before. On the other hand, their sons and daughters, now well into middle age, were reluctant to talk of these matters. Generally, senior Francophones were quite happy to allow their belief in God to carry them towards their end on earth and, therefore, they did not want resuscitation protocols to be carried out. They also seemed to be mindful that such resuscitation seldom returns the individual to their former state of existence, and hence they were far less likely to ask that they be resuscitated. On the other hand, perhaps the coming generation is reluctant to accept the task of maintaining French culture in Alberta, and this colours their attitudes towards discussing these matters with their parents.

4. The Sunni Muslims of Lac La Biche come from a long tradition of close community cohesion. Based on the Qur`an's explicit statement that it is the responsibility of children to care for aged parents, most Muslims in that community regard the failing health of the senior population to be the moment when they must accept their religious responsibility. In their view, it is neither the responsibility of the health care system, nor the government, to care for elders. In cases where a failing senior must be cared for, the responsibility devolves upon an unwed daughter or the wife of the eldest son. In effect, then, we should expect to find seniors either living at home with a daughter or in the home of their son as they become incapacitated. What appeared most problematic, however, was the limited formal training skills for those who are designated caregivers to the elderly, and the increased potential for caregiver stress. Elder care requires the development of special skills that might be provided by professionals and the system.
  
5. We had thought that, like other First Nations peoples, the Bigstone First Nation elders (Wabasca) would be attracted to traditional medicine, which might offer some assistance to them. We had also anticipated that extended families would be minutely involved in seniors' lives. Both notions appeared to be wrong. In the first place, these members of Treaty 8 held steadfastly to the perception that the 'medicine chest' had been promised in treaty negotiations—and they had accepted that for many major problems Western medicine was likely more successful than traditional medicine. Hence, there had not been wide-spread maintenance of medicine man and herbal traditions. Secondly, since they had suffered under residential schools, not many had extensive networks of relatives left to assist them; rather they had to rely on close family members to come to their aid in crisis situations. The Cree tradition emphasized the independence of each person, and hence it was only seen as respectful to allow the senior to work out issues on their own until relatives were informed that the seniors could no longer do so. That was seen as the appropriate moment to intercede. This applied despite the reality that the Reserve was huge with little communication or transportation system available. Also, it was noted that death is not discussed, since it is an issue seen to reside with the spirit world and its interactors. It definitely was not something the ordinary person thought competent to talk about, even when faced with it at close quarters.

In all of the consensus groups, it was unanimous that health care professionals needed to have a better understanding of how various cultures viewed end-of-life issues. There is anecdotal evidence that senior women patients receive less care, probably because traditionally, they are caregivers to their families and ill relatives before caring for themselves. The result is that professionals respond to matters brought to their attention and do not anticipate that the senior woman may be hiding their own problems. Furthermore, we have found that end-of-life matters bring ethnic and religious variables to the surface. Professionals need to better understand how culture impacts family caregivers and community involvement. If cultural competence was stressed, professionals could better assess, diagnose, treat and manage culturally-appropriate services.

## **4.2 Culturally-Responsive Care Workshops**

Armed with the results of the Consensus Groups, we then launched into Phase 2 of the study. The goal of this aspect of the project was to utilize the results of Phase 1 to create workshops that could be presented to professionals to help them to extend their cultural competence. As we examined these goals, we surveyed several possible self-evaluations of cultural knowledge and selected materials that we felt would assist the professionals that served these communities to become more sensitive to the issues.

### **4.2.1 Goals of the Workshops**

Phase 2 began with the selection and articulation of the goals of the workshops. Specific issues of each group played a role in helping us fashion what would be presented to the professionals who worked with each of these groups. Consequently, the workshops were shaped with the following features in mind:

1. The workshop would be held at a site near to the data-gathering locale—that is, we fashioned the workshop so it would be directly relevant to professionals dealing with that community.
2. Prior to each workshop, a self-administered questionnaire allowed the professional to evaluate their own sense of cultural competence...a pre-workshop questionnaire was sent which asked professionals to answer questions addressing cultural awareness dealing with patients, caring for and treating dementia/end-of-life care patients in their communities.
3. Each workshop would end with an evaluation of the value of the workshop for the professional in that community...i.e. an exit evaluation.
4. Each participant in the workshop was issued a certificate indicating that they had attended the cultural competence workshop.
5. Three months later, a further evaluation would be solicited from those who had attended to determine how relevant the knowledge gained had been in serving the community, and how their own cultural competence had improved. (This material is only now being received and will be evaluated when it is completed. We will also compare responses with the pre-workshop questionnaires.)

### **4.2.2 Learning Objectives of the Workshops**

The objectives of the workshops were designed such that health care professionals would be able to:

1. Understand and apply their knowledge of community values to the health care communities that they serve;
2. Understand and apply their knowledge of end-of-life issues and care-giving responsibility in the community that they serve;
3. Understand and apply knowledge of their community's views in the use of advance directives;
4. Understand and apply their knowledge on other relevant issues arising from the interviews (e.g. the language problem).

The Workshops were presented to health care professionals in each of the communities as follows:

<b>Community</b>	<b>Location</b>	<b>Date</b>
Francophone	McLennan, AB	June 3, 2006
Chinese	Edmonton, AB	June 14, 2006
Muslim	Lac La Biche	June 24, 2006
First Nations	Wabasca, AB	June 29, 2006

Attendance ranged from 15% to 86% of those invited; those who attended indicated that it would be helpful to hold a further workshop for those who could not attend because of work, business and other commitments. This remains a possible scenario.

#### **4.2.3 Cultural Competency of Health Professionals**

Clinical Competency Questionnaire is enclosed in **Appendix B**.

#### **Cultural Knowledge and Skill of Health Professionals**

**Table 1** reflects the importance placed on this kind of knowledge by the professionals. We note that 56% felt that social-cultural issues were very important in geriatric cases, that 80% perceived that racism prejudice and discrimination had either somewhat or a great deal of impact on their patients, and that over 92% felt comfortable in caring for patients with limited English skills. It is also instructive that over 70% took non-verbal cues when dealing with culturally-diverse populations. **Table 1** also indicates considerable skill level in the area of providing culturally-sensitive education and prevention (items 5, 6) but that eliciting information about folk healing and alternative healing strategies is much more difficult (items 3, 4). It was probably not surprising that more than 75% regarded themselves as somewhat to quite a bit skilled in providing culturally-sensitive end-of-life care (item 9), since a fair number of the professionals work in situations in which their colleagues are ethnically diverse.

**Table 1: Clinical Cultural Knowledge and Skill of Health Professionals  
(Pre-Workshop Survey)**

Health Professionals' <b>KNOWLEDGE</b> about ...	<b>Knowledge Level n=41 (%)</b>		
	<b>Not At All/ A Little</b>	<b>Somewhat</b>	<b>Quite a Bit/Very</b>
1. Demographics of diverse racial/ethnic groups	22.0	43.9	34.1
2. Sociocultural characteristics of diverse racial/ethnic groups	19.5	48.8	31.7
3. Health risks experienced by diverse racial/ethnic groups (n=40)	17.5	42.5	40.0
4. Health disparities experienced by diverse racial/ethnic groups	24.4	34.1	41.5
5. Sociocultural issues in: Geriatrics Psychiatry (n=37) Women's Health (n=37)	9.8 32.4 18.9	34.1 35.1 40.5	56.1 32.4 40.5
6. Ethnopharmacology	53.7	31.7	14.6
7. Different healing traditions (n=40)	30.0	40.0	30.0
8. Historical and contemporary impact of racism, bias, prejudice & discrimination in health care experienced by various population groups in Canada	19.5	48.8	31.7
<b>Health Professionals' <b>SKILL</b> in dealing with ....</b>			
1. Greeting patients in a culturally sensitive manner	7.3	36.6	56.1
2. Eliciting the patients perspective about health and illness	17.1	34.1	48.8
3. Eliciting information about the use of folk remedies and/or alternative healing modalities (n=40)	37.5	25.0	37.5
4. Eliciting information about the use of folk healers and/or alternative practitioners (n=40)	40.0	30.0	30.0
5. Performing a culturally sensitive physical examination (n=39)	25.6	38.5	35.9
6. Prescribing/negotiating a culturally sensitive treatment plan (n=40)	30.0	35.0	35.0
7. Providing culturally sensitive patient education/ counseling (n=39)	23.1	33.3	43.8
8. Providing culturally sensitive clinical preventative services (n=39)	25.6	28.2	46.2
9. Providing culturally sensitive end-of-life care (n=39)	23.1	25.6	51.3
10. Assessing health literacy (n=39)	20.5	43.6	35.9
11. Working with medical Interpreters (n=39)	20.5	41.0	38.5
12. Dealing with cross-cultural conflicts relating to diagnosis/treatment	29.3	39.0	31.7
13. Dealing with cross-cultural adherence/ compliance problems (n=40)	22.5	47.5	30.0
14. Dealing with cross-cultural ethical conflicts (n=39)	30.8	43.6	25.6
15. Apologizing for cross-cultural misunderstanding or errors (n=38)	28.9	36.8	34.2

## Professional Comfort Level in Dealing with Cultural Issues

Over 92% of health professionals felt comfortable in caring for patients with limited English skills (**Table 2**) .... this conflicts with information that we have received from patients who point out that communication with professionals is almost always in English and they feel uncomfortable about their limited skills. It is also the case that some diagnoses are based upon oral communications, and patients may not be diagnosed well if it is based upon their responses to key questions in English. It is also instructive that over 70% took non-verbal cues when dealing with culturally-diverse populations (item 5). Care-givers are also aware of beliefs that impact on health care (item 4). Comfort levels are dramatically different if a colleague expresses derogatory ethnic remarks than if a patient does the same (items 11, 12).

**Table 2: Health Professionals' Comfort Level in Dealing with Cross-Cultural Encounters/ Situations (Pre-Workshop Survey)**

Health Professionals' <b>COMFORT</b> with ...	<b>Comfort Level Percent</b>		
	<b>Not At All/ A Little</b>	<b>Somewhat</b>	<b>Quite a Bit/Very</b>
1. Caring for patients from culturally diverse backgrounds	12.2	9.8	78.0
2. Caring for patients with limited English proficiency	7.3	22.0	70.7
3. Caring for a patient who insists on using/seeking folk healers or alternative therapies (n=40)	12.5	35.0	52.5
4. Identifying beliefs that are not expressed by a patient or caregiver, but might interfere with the treatment regimen (n=39)	17.9	41.0	41.0
5. Being attentive to nonverbal cues or the use of culturally specific gestures that might have different meanings in different cultures (n=40)	27.5	30.0	42.5
6. Interpreting different cultural expressions of pain, distress, and suffering	22.0	31.7	46.3
7. Advising a patient to change behaviours or practices related to cultural beliefs that impair one's health (n=39)	30.8	35.9	33.3
8. Speaking in an indirect, rather than a direct way, to a patient about his/her illness, if this is more culturally appropriate (n=39)	28.2	41.0	30.8
9. Breaking "bad news" to a patient's family first, rather than to a patient, if this is more culturally appropriate (n=36)	27.8	36.1	36.1
10. Working with health professionals from culturally diverse backgrounds (n=40)	10.0	17.5	72.5
11. Working with a colleague who makes derogatory remarks about patients from a particular ethnic group (n=39)	48.7	28.2	23.1
12. Treating a patient who makes derogatory comments about your racial/ethnic background	43.6	25.6	30.8

## Importance to Professionals of Cultural Training

Professionals who signed up for the workshop clearly regarded the issues raised to be important, since over 95% thought them to be somewhat to very important in dealing with patients, but were less convinced when it came to colleagues, medical students and staff (**Table 3**). An impressive 97% had awareness of their own ethnicity, while 100% thought receiving training was either somewhat to very important. The amount of training received highlights the importance of workshops on cultural competency—with university education generally seen as lacking, but neither medical nor residency training regarded as adequate, but continuing professional education much more positive.

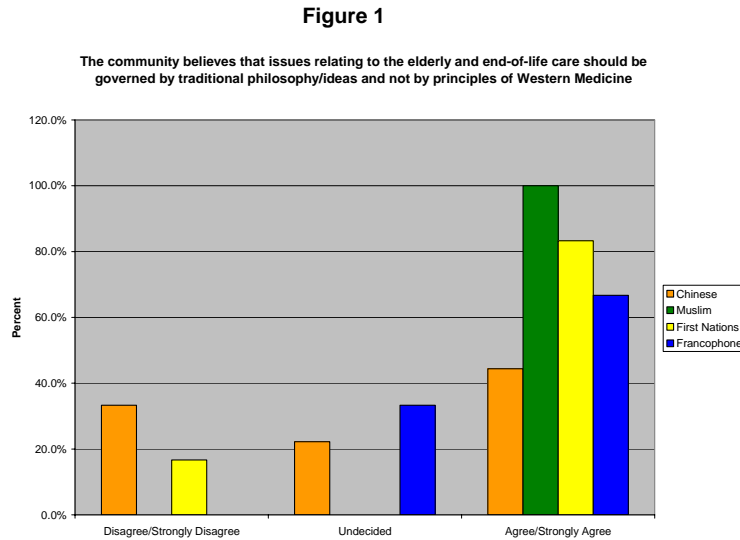
**Table 3: Health Professionals' Attitude Toward and Training in Cultural Issues (Pre-Workshop Survey)**

	<b>Level of Importance</b>		
	<b>Percent</b>		
<b>Importance of sociocultural issues in interaction with...</b>	<b>Not At All/A Little</b>	<b>Somewhat</b>	<b>Quite a Bit/Very</b>
Patients	4.9	14.6	80.5
Health professional colleagues	7.3	29.3	63.4
Residents/medical students (n=39)	10.3	28.2	61.5
Staff	4.9	29.3	65.9
<b>Awareness of your own...</b>			
Racial/ethnic/cultural identity (n=39)	2.6	7.7	89.7
Racial/ethnic/cultural stereotypes (n=39)	2.6	10.3	87.2
Biases & prejudices	7.7	15.4	76.9
<b>Importance for health professionals to Receive training in cultural diversity or multicultural health care</b>	0.0	14.6	85.4
<b>Amount of training in cultural diversity health professionals previously received in...</b>			
College/post secondary education (n=35)	45.7	34.3	20.0
University (n=29)	55.2	31.0	13.8
Medical school (n=14)	57.1	28.6	14.3
Residency training (n=16)	56.3	25.0	18.8
Continuing professional education (n=36)	30.6	30.6	38.9

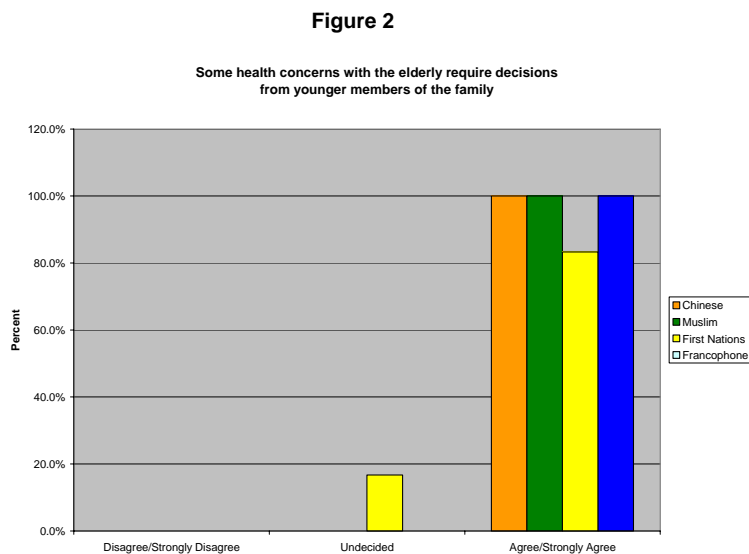
#### 4.2.4 Results of Pre-Workshop Questionnaires to Professionals

Pre/Post Workshop Questionnaires are enclosed in **Appendix C**.

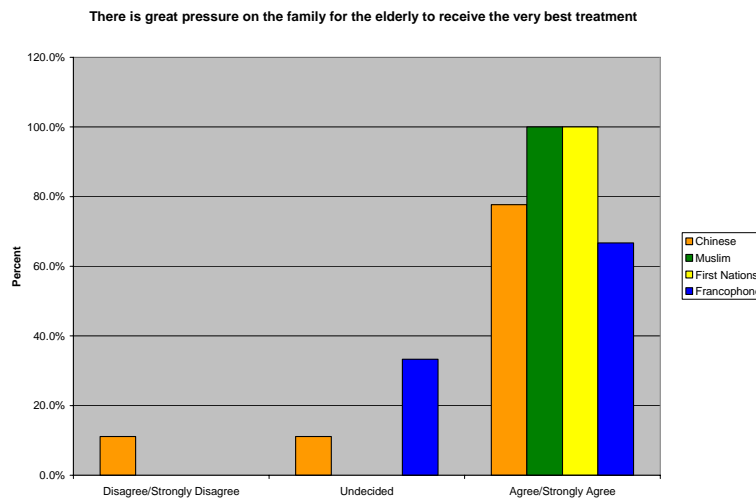
**Figure 1** illustrates that end-of-life issues may not be entirely mediated by Western ideas. Only health professionals providing care in the Chinese community were clearly divided on this issue.



The responses obtained in **Figure 2** were anticipated, but we surmised that in **Figure 3**, some Chinese had no family here so the question might be seen by their professionals as vitiated. These findings also indicate how committed the younger generation is to the best care, since professionals clearly encounter this feature themselves.

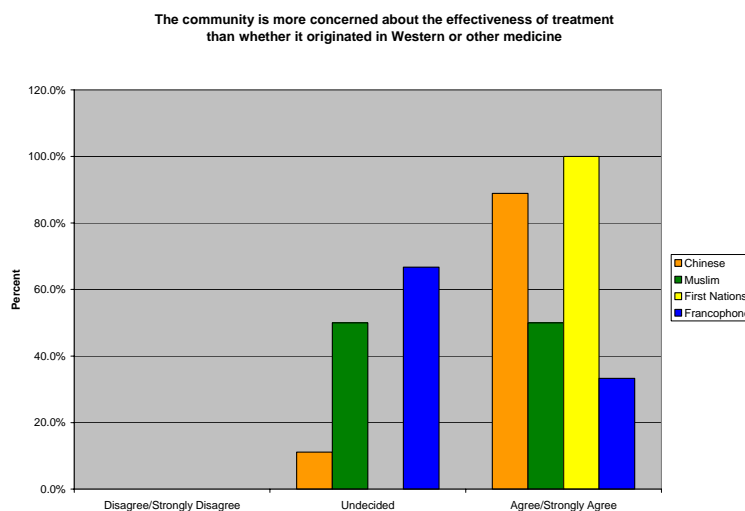


**Figure 3**

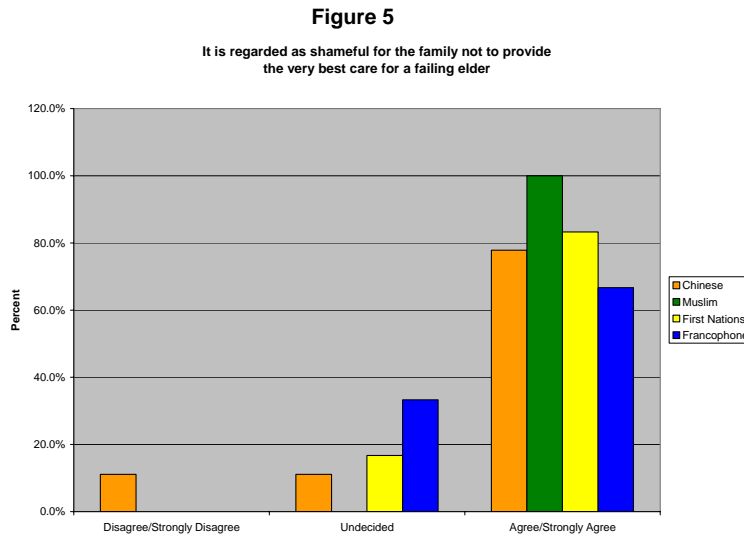


Professionals who work with Chinese and First Nations communities are clearly aware of what might be termed “alternative medicine.” What is striking is that First Nations consensus groups indicated that they themselves used little of traditional medicine (**Figure 4**) because of their conviction that medicine was promised in the treaty. There would appear to be some conflict in these results that requires further study and perhaps information to professionals.

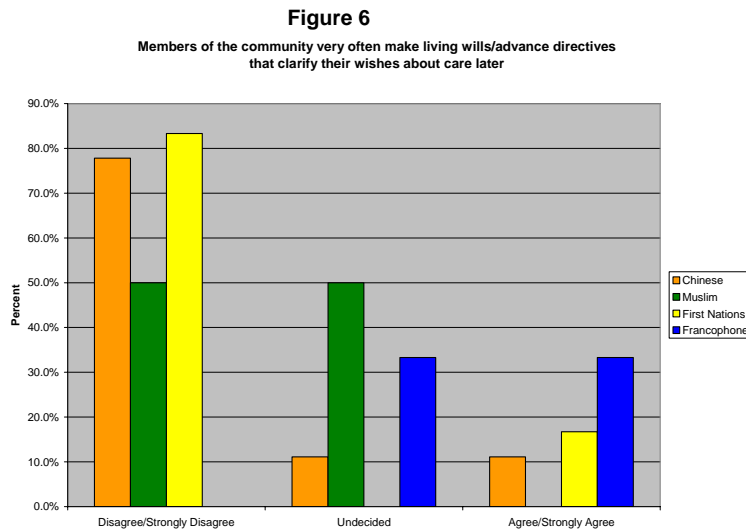
**Figure 4**



**Figure 5** is a further reflection of Muslim responsibility; obviously it is a feature that professionals are aware of.

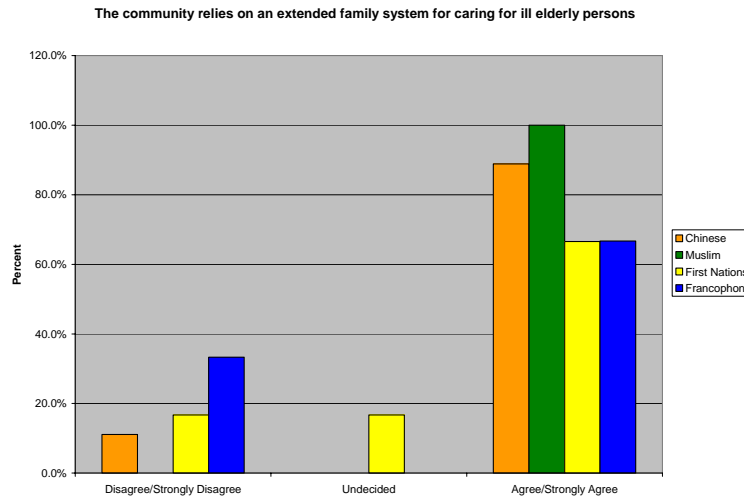


**Figure 6** indicates that much work needs to be done in introducing advanced directives to ethnic populations. Professionals seem to be aware of how little impact advertising and information has made on the population.



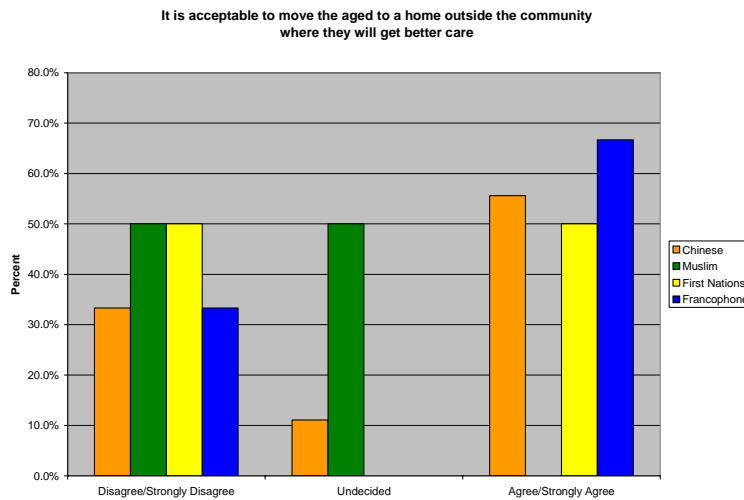
**Figure 7** indicates the importance of the family for ill elderly persons; professionals serving Muslims obviously are aware of their distinctive views.

**Figure 7**



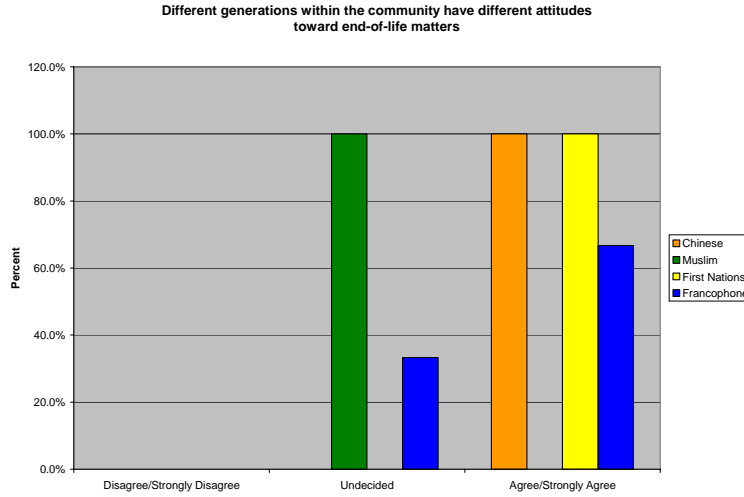
It would appear that professionals have not heard the concerns of ethnic groups for locally-based care (**Figure 8**). Almost all our consensus groups argued for locally-based care, because of the importance of the community to senior well-being. The issue of isolation from community is much stronger than the professional community appears to be aware.

**Figure 8**



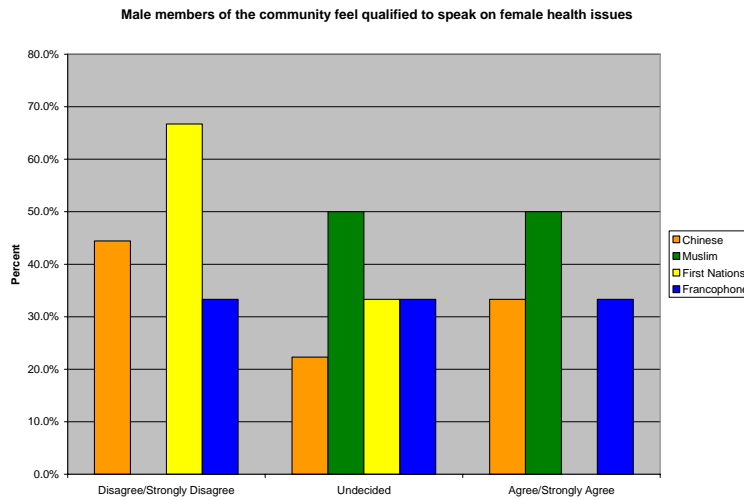
Health professionals caring for Francophone and Muslim communities are not sure about differences about generational values (**Figure 9**).

**Figure 9**



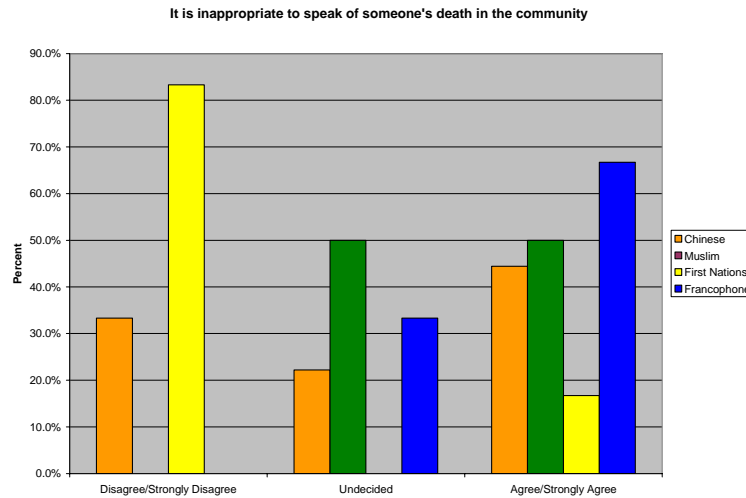
Professionals appear to be somewhat unsure about the role played by males in health care matters; **Figure 10** shows Chinese and Francophone professionals almost equally unsure.

**Figure 10**



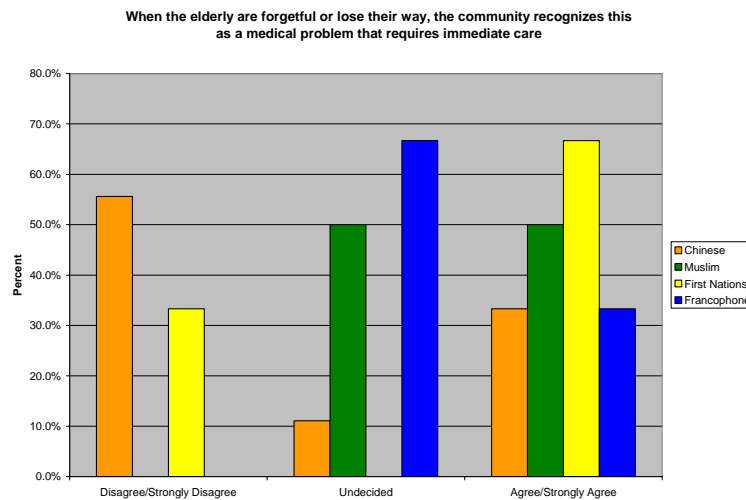
Professionals in First Nations communities are sensitive to the issue of speaking about the death of someone in the community, (**Figure 11**) since after someone’s death it is a measure of respect to acknowledge the passing. It is almost evenly divided, however, in the Chinese community, indicating some confusion on the issue. That it is a contentious issue in the Francophone community seems evident from these results.

**Figure 11**



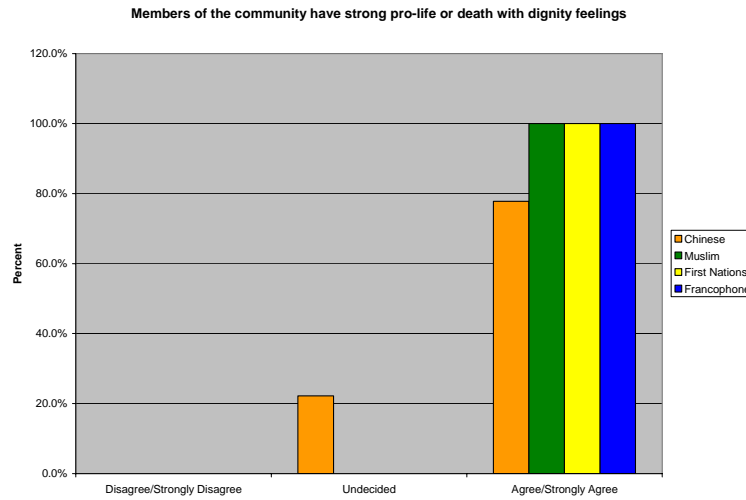
The recognition of dementia as a medical problem was anticipated based on the results from the consensus groups, especially regarding First Nations people (**Figure 12**). The professionals’ views regarding the Chinese patient were somewhat surprising.

**Figure 12**



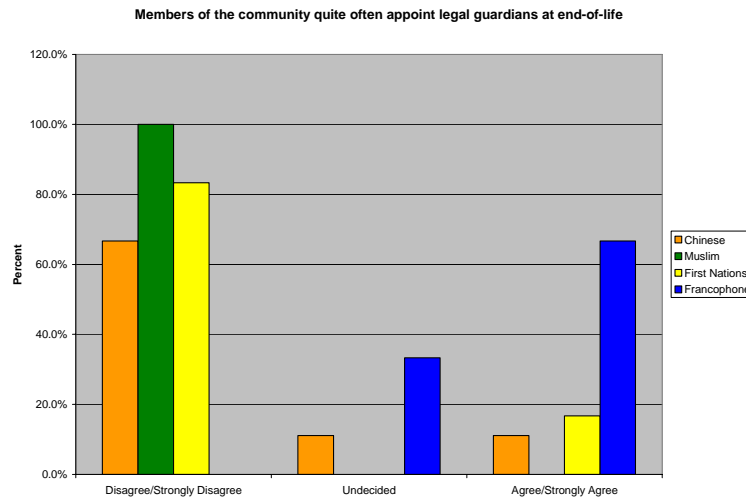
**Figure 13** illustrates that professionals are aware of the pro-life and death with dignity issues in all ethnic communities studied.

**Figure 13**



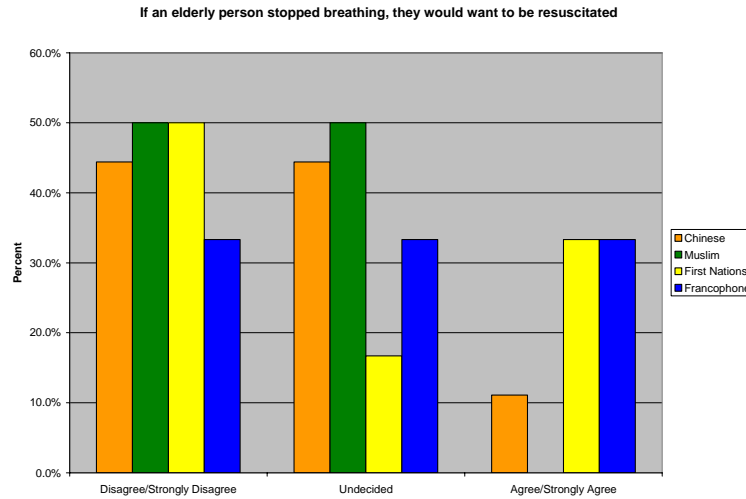
**Figure 14** indicates that health care professionals are aware of the problem of appointing legal guardians; the Francophone community seems to be the one community most aware of the issue.

**Figure 14**

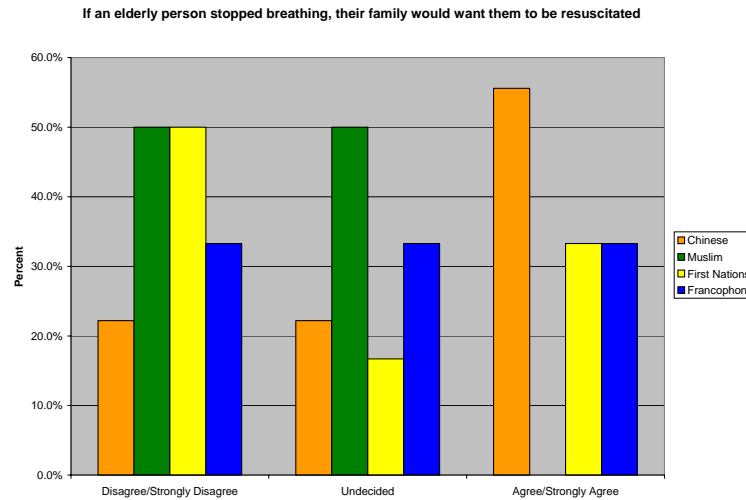


Almost all professionals believe that all major senior groups would not want to be resuscitated, (**Figure 15**) yet almost none of the ethnic communities studied participate in advance directives. There would appear to be much difference of opinion between the professionals and the next generation who will be making the resuscitation decisions, (**Figure16**).

**Figure 15**

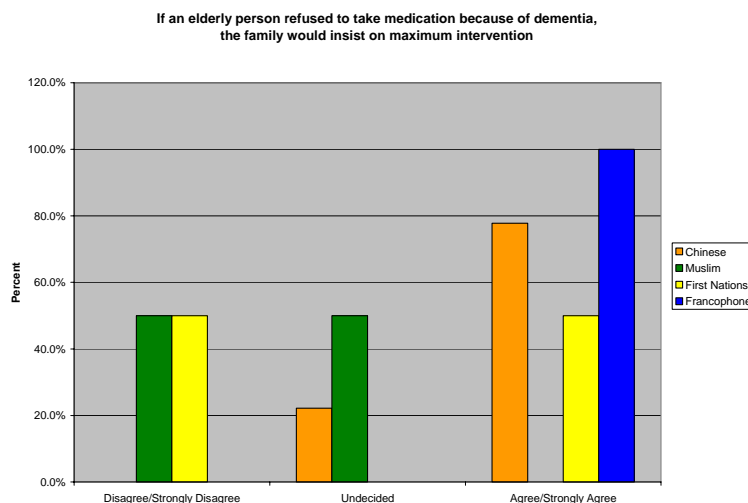


**Figure 16**



**Figure 17** represents a cultural difference impacting on professionals. Only for Muslims do health professionals have a clear idea of what the family would want or would likely want done; while they are split on First Nations people.

**Figure 17**



#### **4.3 Developing Post-Workshop Information for Communities and Professionals**

Based on the study findings, we have undertaken the last of our information activities, viz, the construction of eight videos, two for each ethnic group. We contracted to produce four cultural scenarios, reflecting a key issue for each ethnic community in the form of an informational script (**Appendix D**). Each of these will be translated into the language of the group and played by amateur actors. The idea is to present to the community one solid result of the study that is a crucial one for their understanding. In addition, we contracted to produce case studies for a video for professionals based on the findings of each group (**Appendix E**). These will be produced (in English) using semi-professional actors. We anticipate each video being from 5 to 10 minutes long. At this point, we have contracted to produce a pilot for the two scripts based on our research in Lac La Biche.

The themes of each of the scripts are:

1. Chinese Cultural Scenario: Personal directives and code/no code  
Case Study for Professionals: Family contentions at end-of-life (In Cantonese-Chinese)
2. Muslim Cultural Scenario: Muslim care-giver stress for dementia case (in Arabic)  
Case Study for Professionals: End-of-life decision-making for Muslims
3. First Nations Cultural Scenario: Use of Ventilator for a ceremonialist.  
Case Study for Professionals: Informed consent for end-of-life case (In Cree)
4. Francophone Cultural Scenario: Living Wills or personal directive (in French)  
Case Study for Professionals: Dementia with delirium and broken hip.

## **5.0 DISCUSSION**

The outcomes from this study fully support that ethnicity shapes both end-of-life and dementia care issues in Northern Alberta. The expectation that is placed upon health care facilities and practitioners differs across the spectrum of religious and ethnic groups, and cannot be predicted. Cultural competence is also an issue that is gaining ground among health care professionals, underlining the fact that practitioners have encountered difficulties with cohort of patients and see the need for additional resources and training.

Some points to be highlighted include:

1. Public awareness of resuscitation protocols and living wills is very limited. Provincial and Non Government Organizations (NGO) that have tried to elicit public support seem not to have made much impact, with serious ramifications for hospitals and care of the elderly.
2. Dementia is not always identified as a disease, either because ethnic sensitivities do not allow it to be recognized or because life-cycle perceptions characterize end-of-life existence in different ways
3. There is considerable ethnic resistance to centralizing facilities for palliative or dementia cases, and ethnic groups insist that the community-based model provides the most adequate way to handle a rising population.
4. Attitudes toward end-of-life issues are determined more by close cultural beliefs than by a universal “Canadian” perception, and this fact has direct implications for health policy. It also has immediate significance for health care providers who are on the front lines of dealing with the issues.
5. Language is an issue of far greater importance than we had anticipated, both for diagnosis and for care. Much more research needs to be done in this area.
6. Health care professionals are sensitized to cultural issues at a basic level because they work with ethnically-diverse colleagues. This provides them with an entry into ethnicity as a factor in health care. Our data indicates a high degree of ethnic awareness among participating professionals.
7. Professionals are very much aware of the paucity of information in dealing with ethnic groups and health. Medical training and professional training has not kept up with the changing demographics of Canadian society and the practitioners of North Alberta are very much aware of this problem.
8. Educational videos may help alleviate some of the lack of information evident in Northern Alberta among these target groups and their health care professionals.

There are some limitations to this study, which could either be remedied by further study or at widening the research to include other groups. There is some evidence that end-of-life crises damage second language ability, undermining unilingual medical service ... more research should be done to see if this applies across all ethnic groups in the province. The catchment group we studied was small, so we do not know if our findings can be generalized to all ethnic

groups. There is evidence of a disconnect between the skill and knowledge of the professionals and the expectation of the various communities. Many professionals consider that they know how ethnic groups will react to issues, when, according to our study, in some regard they do not. We have no way of knowing whether there are contrasting perceptions based on urban/rural differences; we do not know if rural Chinese have the same perception of these issues as Edmonton-based Chinese. The number of professionals we engaged was limited, so we do not know the general level cultural competence might be among Alberta professionals. Almost all ethnic groups believe that health care professionals need additional ethnic-awareness training, especially with regard to geriatric and dementia areas. Due to the limitations of our study, we were unable to determine whether this perception is found or not. Finally, Alberta is now a multi-cultural Mecca, with Calgary becoming one of the most ethnically-diverse cities on the continent, and Edmonton is rich in ethnic difference. Much more research in the interaction of medicine and culture of this kind would seem to be urgent if health care is to keep up with economic and social developments in the province.

## **6.0 FUTURE STUDIES**

Our research has covered only four distinctive groups; there are many others about whose needs and perceptions are unknown, including second and third generation Ukrainians and Scandinavians, to name only two.

While the professionals we worked with show important dimensions of cultural competence, more research needs to be done to determine the level of competence among practitioners at large. Certainly our ethnic groups did not think it adequate, and professionals themselves indicated the relatively sparse training they had received in medical school and professional organizations on the issue. More work would appear to be required in training professionals in ethnic sensitive areas.

Our study did not emphasize comparison between groups to determine priorities among the issue at end-of-life care. More research might alert us to greater commonalities across ethnic groups on dementia, for example, than we have been able to determine.

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Mary-Ellen Perley of MEPTheatrical authored the scripts for the cultural scenarios and case studies for health professionals.

Omar Mouallem is producing the pilot for the scripts.

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Earle H. Waugh, Ph.D.  
On behalf of the Research Team.