

Moving Forward by Building on Strengths: A Discussion Document on Aboriginal Hospice Palliative Care in Canada

Prepared for the Canadian
Hospice Palliative Care
Association by:



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March 29, 2007



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Aboriginal Hospice Palliative Care in Canada: Gap Analysis Discussion Document

Executive Summary

The Canadian Hospice Palliative Care Association (CHPCA) has been funded by Health Canada to coordinate a national meeting for the purpose of discussing the current state of Aboriginal Hospice Palliative Care (AHPC) in Canada within the context of national developments in the field. The invited stakeholders came together in a common understanding of the past developments, the current state of affairs and priorities for future action. The process was not intended to be a formal consultation nor a comprehensive research project, both of which are needed in this field. The process for developing the papers did not involve community engagement or consultation which is a very serious limitation to the process of identification of strengths, issues and areas for action.

The content of the paper was developed through survey and interview processes that included fourteen knowledgeable individuals. In addition a two day national meeting was held with an additional group of stakeholders to further discuss the issues and findings and develop recommendations for moving forward. The Action Steps recommended are:

1. **Recognize and Nurture AHPC Activities underway in Communities** – We need to build on the strengths, commitment and current capacity active in communities as we move forward.
2. **Public Education and Awareness Building** – As part of national awareness work, all participants need to contribute to raising the awareness of the unique HPC requirements of Aboriginal communities.
3. **Leading Practices** – All participants have agreed to begin to collect and inventory leading practices in AHPC for sharing through the CHPCA website and the inventory related to this project.
4. **Local Capacity Building** – Local capacity building will be supported by sharing leading practices and providing access to the inventory of tools and resources. All participants will promote the coordinated sharing of resources. Get the community involved at all levels through innovative means such as “kitchen table workshops”, if necessary.
5. **Collaborative Training and Education** – Collaborate in the development and implementation of AHPC education and training initiatives, including the development of generic materials that can be customized by the community.

6. **Joint Working Group** – All participants not currently on the Joint Working Group will provide support to that process to the extent resources permit as it is seen as very promising.
7. **HPC Integration** – The hospice palliative care issues are part of many other aspects of health care delivery including continuing care; home care; mental health; suicide; diabetes and other chronic diseases and others. All participants agree to take steps to ensure the full life span; including hospice palliative care issues are included in program planning and policy discussions.
8. **Roster of Programs and Services** – Individuals in the communities do not always have access to current information on what programs and services are available and how to access them. A method of developing and keeping an up to date roster of programs and services as a “one stop shop” would be helpful to patients or clients, family members and care providers. The provision of information on problem solving and “system navigation” would also be helpful.
9. **Addressing Access Issues** – The identification of issues and problems related to access to programs and services in different geographic regions and circumstances need to occur and strategies to address these issues initiated if no current process is underway. The lead agency or agencies on this comprehensive and responsive mechanism needs to be identified.
10. **Common and Accessible Language** – The Aboriginal Hospice Palliative Care agenda is new on the national scene in Canada. In order to advance our collective capacity to coordinate and collaborate, we need a common lexicon of terms or commonly understood language as a foundation to mutual understanding. In addition, we need to consider the development of plain language documents to increase accessibility of the information.
11. **Investment in Cultural Competence at all Levels** – Cultural competence needs to be built at all levels in the system – relationships between individuals/families and care providers and between organizations and systems. A review of policies to assess how they contribute to culturally competent organizations and institutions need to be carried out.
12. **National Leadership and Funding** – The group assembled to discuss Aboriginal Hospice Palliative Care has suggested meeting annually to assess the progress and support National Aboriginal organizations, governments and non-government organizations in working together to advance AHPC in Canada. Funding shortfalls must be addressed if substantive progress is to be made. Advocacy and political leadership is needed from the community level and a strong business case needs to be built. One option is a joint position paper among national leaders in Aboriginal Hospice Palliative Care.

1.0 Introduction

The Canadian Hospice Palliative Care Association (CHPCA) has been funded by Health Canada to coordinate a national meeting for the purpose of discussing the current state of Aboriginal Hospice Palliative Care (AHPC) in Canada within the context of national developments in the field. The invited stakeholders came together in a common understanding of the past developments, the current state of affairs and the priorities for future action. The process is not intended to be a formal consultation nor a comprehensive research project, both of which are needed in this field. The process for developing the papers did not involve community engagement or consultation which is a very serious limitation to the process of identification of strengths, issues and areas for action. As the process moves forward, community input, validation and engagement is essential. The purpose of the first drafts of the background paper was to provide a starting point for dialogue among this invited group of national stakeholders, including Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK) and Métis National Council (MNC), with the intention of developing a collective sense of next steps.

This final paper represents the coming together of the background information with the results of the dialogue sessions held in Ottawa on the 19th and 20th of March, 2007. Part of the initial development of the background document includes a focus on gaps in the current delivery system for Aboriginal Hospice Palliative Care. The gap that exists between the programs and services currently available to most mainstream Canadians compared to what is available to Aboriginal Canadians is described using available information and the input of those interviewed. An equally important dimension of the current shortfall in Aboriginal hospice palliative care programs and services can be described by the disparities between the optimal future as defined by CHPCA in the two documents “A Model to Guide Hospice Palliative Care: Based on Principles and Norms of Practice” (2002) and “The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home”. The feedback received from the participants was clear in stating that we need to take a good honest look at the gaps and shortfalls in the current programs and services. Equally important is to ensure that we fully acknowledge and communicate respect to the commitment and capacity at the community level and the progress being made at all levels (local, regional, provincial/territorial and national).

The information provided in this report is from a brief survey of 14 knowledgeable individuals; a brief, high level review of nationally significant Canadian documents and publications and the results of the two days of dialogue with 16 participants of the national roundtable. The roundtable participants also established priorities for collaborative action to make improvements in AHPC programs and services for Aboriginal.

When using the term “hospice palliative care”, the CHPCA definition of “care that aims to relieve suffering and improve the quality of living and dying” will be used as the operating definition. For the purposes of this paper, the term “end-of-life care” is seen as

a component of comprehensive hospice palliative care. The term “Aboriginal” as defined in the Constitution of Canada, is inclusive of First Nation, Inuit and Métis people. This paper will focus primarily on First Nation and Inuit populations. Within each of these three groups, there is much diversity. Aboriginal people live in urban centres, rural communities and remote regions of Canada. Some Aboriginal communities are only accessible by air or roads over ice in the winter. Lifestyles also vary from those individuals living a life in mainstream Canada that have many characteristics in common with other Canadians. There are also groups of First Nation and Inuit people who live lives directed by traditional values and live grounded in a homeland that has been part of their legacy handed down by their ancestors.

2.0 Literature Review, Context and Background

The literature – both published academic articles and other documents is limited in the areas of Aboriginal Hospice Palliative Care. The literature review was not comprehensive but was successful in identifying a number of sources some of which have been summarized briefly and outlined in the context and background overview in the bullets provided later in this section of the report. Related literature in the areas of Aboriginal Health, Aboriginal Health Nursing, Cultural Competence and general Hospice Palliative Care have not been included in this overview.

In 2002, the National Aboriginal Health Organization presented a paper entitled “Discussion Paper on End-of-Life / Palliative Care for Aboriginal Peoples in Winnipeg at a national meeting convened to prepare a National Action Plan for End-of-Life Care. The paper defines key terms, describes the unique context of Aboriginal persons, families and communities, and identifies barriers to health services and specifically end-of-life / palliative care. Planning issues are also articulated in light of a limited number of telephone interviews completed with national stakeholders. Recommendations include the need for consultation with Aboriginal groups throughout the action plan development process; research and needs analysis work is needed which includes best practices. Policy modifications are needed, including further development of the Home and Community Care program funded by Health Canada. The needs of non-status and Métis people must also be recognized and responses developed. Standards of care, facilities and professional training are needed and a coordinating mechanism to resolve re-occurring jurisdictional issues and barriers to care are needed. The findings and recommendations of this report resonate with the outcome of the current process and the contents of this report.

In 2003, a meeting was held of the “Aboriginal End-of-Life and Palliative Care Coordinating Group” in Quebec City. The workshop participants included Aboriginal people from across Canada and was sponsored by CHPCA and Health Canada. Discussion was focussed on national initiatives; unique considerations in Aboriginal palliative care; sharing of protocols and best practices; and the programs, services and regional support services necessary to support hospice palliative care in the home. A presentation on the “First Nation and Inuit Integrated Palliative Care Model” by Laurel Lemchuk-Favel provided an overview of service requirements and related costs. Roda

Grey also presented a paper on work being done by the Inuit in this area. Terms of Reference were developed but a follow-up meeting was not held.

“Responsive Hospice Palliative Care with Aboriginal Clients in Rural and Remote Settings: Course Planning Manual and Courseware” (Hanson and Aherne, 2004) was developed by the Pallium Program in response to a recognized need to contribute to the development of capacity for cultural competent hospice palliative care with Aboriginal individuals, families and communities. The course is designed for community level care providers and includes flexible options for selection of resource material and multi-media supports (DVD segments and Power Point presentations) to support local trainers in using the material to develop local capacity.

In 2005, the Aboriginal Interest Group of the Canadian Hospice Palliative Care Association met. As with meetings in other years throughout the history of the Committee, updates were provided. Topics of interest included the training of community health aids in Alaska; accommodation for the family of a person dying in hospital; the Pallium Aboriginal Training of Trainers course; teams in palliative care; research being done at Lakehead University in partnership with two First Nations and the creation of a Manual to assist families and communities that has since been distributed. The issues and challenges identified echoed many of those articulated later in this document. The issues discussed included the relationships between patient and caregiver; difficulties in dealing with geographic isolation; problems with continuity and consistency of care; staff turnover; hospital environments unwelcoming to ceremony and lack of knowledge about specific First Nation and Inuit needs. Problems with confidentiality, dealing with complicated advanced care documents; lack of resources and accessibility barriers; jurisdictional “nightmares” and spiritual/religious complexities in working with families. Unresolved grief and the connection to the abuse of drugs and alcohol was also discussed. The appropriate translation of information from English or French to indigenous languages and from technical to plain language was also identified as a barrier to respectful care. The need for the further development of research models that appropriately respect and work with community realities and serve community priorities was articulated. The need to share success stories and learning between Aboriginal communities was underlined as a priority. Support was expressed for increasing cultural understanding within tertiary hospitals and building care homes for Aboriginal communities so that individuals may die close to home if they cannot die at home. The ability to respond needs to be cultivated through investment in cultural competence development at all levels in the system. (CPHCA, 2005)

The Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) Initiative has produced a series of documents outlining their process and the resulting competencies. There are six major competencies and numerous sub competencies. One of the identified competencies is “when graduating from medical school, students will be able to address psychosocial and spiritual needs.” The fourth sub competency is “demonstrate cultural, religious and Aboriginal sensitivity in addressing end-of -life care”. These were originally generic competencies and the reference to Aboriginal was added in later rounds. It is hoped that the related curriculum development will

include targeted education and training related to First Nation, Inuit and other Aboriginal peoples. (EFPPEC, 2006)

“Palliative Care in First Nations Communities: The Perspectives and Experiences of Aboriginal Elders and the Educational Needs of Their Community Caregivers” by Prince and Kelley (2006) is a breakthrough in academic literature as it is very true to the voice of the community in reporting on the results of community based research. The purpose of the project was to document current levels of awareness, understanding, and perceived access to palliative care among members of First Nation communities. The project also sought to understand community beliefs and values related to death and dying, the preferred place for receiving end-of-life care, and the educational needs of caregivers in First Nation communities. The recommendations emerging from the research are aligned with the direction taken in this process. The recommendations support the implementation of culturally appropriate palliative care education for community health and social service providers; support trained community health workers to develop culturally appropriate educational resources and educate community members; facilitate a community development process; assist local palliative care providers to develop protocols and guidelines; assist local providers to develop linkages to regional palliative care experts and services for consultation; assist in advocacy related to increasing the home death options and outline research to conceptualize a model for developing palliative care in First Nation communities that would be applicable in other areas of Ontario and Canada.

“Building Community Capacity: A Retrospective of Bereavement Services in Regina, Canada” (Melvin et al 2006) provides a 20 year retrospective analysis of developmental milestones associated with the Regina area community capacity in bereavement, including community based resources, clinical care and research. As Regina has a significant Aboriginal population, the paper took into account services directed toward Aboriginal populations. Aboriginal capacity building is seen as one area for future development of bereavement services. In addition, connection to Saskatchewan’s Aboriginal population and inclusion of traditional Aboriginal beliefs and approaches to healing and grief were also identified as a result of the research. The most commonly suggested future direction of service development is to address cross-cultural issues and diversity, specifically the unmet needs of Aboriginal peoples, rural communities and under serviced populations. Better balance between “western” models of grief and healing and traditional Aboriginal models was suggested. The third most common suggestion was for services that are, and that are seen to be genuinely community-based and supported.

“Caring for the Terminally Ill: Honouring the Choices of the People” is an excellent resource manual developed by a group in northwestern Ontario. The model of care provides for care in four domains: comfort, compassion, concern and choices. The manual provides very useful and practical advice in caring for the terminally ill in the emotional, physical and spiritual aspects of life. The resource material is focussed on the family and community as well as the individual at the centre of care.

“Issues in palliative care for Indigenous communities” (Maddocks and Rayner, 2003) is an Australian article and the results connect with Canadian realities. The authors identify that indigenous communities in Australia have a “common heritage of loss”; that death rates are higher; use of health care and palliative care is lower; cultural considerations that need to be respected include Indigenous understandings of disease causation, attributions of blame for sickness, the performance of ceremonies after death and the importance of dying on traditional lands. The involvement of Indigenous health workers in clinical care increases confidence in the healthcare system as a whole.

Hotson et al (2004) published a seminal article entitled “Understanding Death and Dying in Select First Nation Communities in Northern Manitoba: Issues of Culture and Remote Service Delivery in Palliative Care”. The purpose of the study was to delineate and describe the local palliative care services available to residents of remote Aboriginal communities in northern Manitoba; to identify attitude and beliefs about death, dying and palliative care in these communities; and to explore obstacles related to palliative care service delivery from the perspectives of culture and geographic isolation. The results included the identification of the pattern of many Aboriginal people dying in large urban centred many miles away from their communities and isolated from friends, family and culture although the overwhelming preference was to die at home. Culturally sensitive care requires that patients have access to family supports and traditional services, if requested. Geographic isolation required that patient-specific care plans be created for use in the remote community; effective lines of communication are established between remote healthcare providers and urban specialists; health care providers and family care givers be properly trained to fill their respective roles and that appropriate guidelines and resources be available in the community to support this type of care. The conclusion is that providing the equipment, supports and education necessary for home-based palliative care in remote Aboriginal communities can be an effective way of addressing the medical, psychosocial and spiritual needs of these patients. These results and conclusions are fully aligned with those of Prince and Kelley (2006).

The “Guidelines for Palliative Care Services in the Indian Health System” (U.S. Indian Health Services, 2006) is an interesting document as it substantiated the need for adaptation of mainstream services for Indian populations. The guidelines include structures and processes of care that support the use of an interdisciplinary team. The focus on communication and care planning is consistent with the findings of Hotson et al (2004). The inclusion of quality improvement processes has not been mentioned in other literature, but is fundamental to ensuring quality care over time. Pain and symptom management is also a priority as is the provision of age and culture appropriate information and bereavement services.

The context within which hospice palliative care is provided to Aboriginal people is the reality of hospice palliative care (HPC) in Canada. The shortfalls in the current HPC system affect Aboriginal Canadians as well. In some cases, the shortfalls are more dramatic and more difficult to overcome due to the challenges created by jurisdictional issues between governments; geographical location of Aboriginal communities; limited supply of well educated professionals and care providers; the lack of research in the field;

lack of educational resources for professionals and family care providers and limited access to health care options that are accessible, appropriate and culturally competent. Rather than focusing only on the problems and issues, the more positive approach is to include a brief review of significant advances over the past ten years that have provided a solid foundation upon which to continue to improve Aboriginal hospice palliative care in Canada. The following are only a few of the highlights that provide a strong starting point:

- ***Community Knowledge and Experience*** – across Canada, Aboriginal communities have built on the wisdom and commitment of the past to further develop good ideas and build innovative approaches to the design and delivery of hospice palliative care community initiatives, family oriented activities as well as more formal programs and services. Promising practices will be compiled in the months to follow.
- The ***Canadian Hospice Palliative Care Association (CHPCA)*** has been a significant leader in defining quality in the field. The process of development of “A Model to Guide Hospice Palliative Care: Based on the National Principles and Norms of Practice” and companion documents has set the stage for a national consensus on what constitutes quality care. The “Pan-Canadian Gold Standards for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home” set out gold standards for each of the four home care services funded by government: case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life. The gold standards are a response to the 2004 Health Accord in which the federal and provincial/territorial governments agreed to provide better care. CHPCA has had an Aboriginal Interest Group since 2001 and the level of participation among members is increasing. The interest group, chaired by Rosella Kinoshameg is an important resource for CHPCA as the association moves forward in further defining and responding to the unique hospice palliative care needs, issue and requirements experienced by Aboriginal Canadians.
- The ***Pallium Project*** is a community of practice with members from the academic, service delivery, voluntary sector and government leaders actively engaged in building Canada’s hospice palliative care capacity together. In 2003, the Pallium project was awarded 4.3 million from Health Canada’s Primary Health Care Transition Fund for Phase II which has included outreach education and continuing professional development, knowledge management and workplace learning tools, and service development, service delivery enabling (service readiness) and community mobilization and engagement. One of the many initiatives undertaken by the Pallium Project was the development of courseware to support Aboriginal Hospice Palliative Care (AHPC) continuing education entitled “Providing Hospice Palliative Care with Aboriginal Clients in Rural and remote Settings.” (2003)

- The ***Quality End-of-Life Care Coalition of Canada (QELCCC)*** is a coalition of 31 national organizations concerned about quality end-of-life care and they are committed to working together to achieve this goal.
- The ***Canadian Virtual Hospice (CVH)*** is an internet based resource that has been developed over the past four years and provides useful support and information for families and health care providers.
- The ***National Aboriginal Health Organization (NAHO)*** published a paper entitled “Discussion Paper on End of Life / Palliative Care for Aboriginal Peoples” (2002) that was also presented at the 2002 national meeting to launch the National Strategy on Palliative and End-of-Life Care. NAHO has remained interested and has been a national resource in the field.
- ***Aboriginal Nurses Association of Canada (A.N.A.C.)*** is a national organization of Aboriginal Nurses that has been active in the development of models for Aboriginal Health Nursing and Cultural Competence. The organization has a long standing interest in the area of AHPC and has developed documents and collaborated with other organizations in this area.
- ***Indigenous Physician Association of Canada (IPAC)*** is a national organization of Indigenous physicians that was formed in 2006 and there are several members with interests in AHPC.
- ***National Aboriginal Organizations (NAOs)*** - The Assembly of First Nations (AFN) is the national organization representing First Nation citizens in Canada. The AFN represents all citizens regardless of age, gender or place of residence. The AFN is actively involved in joint initiatives with Health Canada and Indian and Northern Affairs Canada to improve the current level of palliative care services that are available to First Nation people and seek measures to effectively address the needs of First Nation communities. The Inuit Tapiriit Kanatami (ITK) has demonstrated interest in this topic and have continued their work in advocacy and related background work to support taking action. It is not within the scope of this document to speak to the advances made by the remaining three national Aboriginal organizations (Métis National Council (MNC), Congress of Aboriginal Peoples (CAP) and the Native Women’s Association of Canada (NWAC).
- ***Government of Canada*** has also demonstrated leadership in identifying the issues as they relate to all Canadians:
 - The Canadian Special Senate Committee on Euthanasia and Assisted Suicide Report, “Of Life and Death” (1995) which recommended the development and implementation of national hospice palliative care guidelines continues, among other recommendations.
 - “Quality End-of-Life Care: The Right of Every Canadian” (2000) developed by the Subcommittee to update “Of Life and Death” of the

- Standing Committee of Social Affairs, Science and Technology of the Senate of Canada – Chair, Honourable Sharon Carstairs
- Canadian Strategy on Palliative and End-of-Life Care (2002) and the Progress Report of the Coordinating Committee: December 2002 to March 2004 (2005)
 - Hospice Palliative Care: Public Awareness Raising Framework (2006)
- ***Human Resources and Social Development Canada (HRSDC)*** implemented the caregivers benefit through the Canadian Employment Insurance (EI) Benefit. The benefit is available to employees who need time off to be with seriously ill family members. The benefit is available when all vacation and family leave available from the employer is exhausted and can last for up to six weeks.
- ***Provincial and Territorial Governments*** have also demonstrated leadership, some more boldly than others and few with specific reference to Aboriginal Canadians. One example being that the Province of British Columbia released “A Provincial Framework for End-of-Life Care” in May 2006 which references sensitivity to culture and ethical principles common to culture. The federal and provincial/territorial ministries signed an agreement in 2004 in which the First Ministers agreed that “End-of-Life care for case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life” is to receive first dollar coverage by 2006. Six components were identified that needed to be in place for a much needed comprehensive, coordinated and integrated set of end-of-life services for Canadians.
- ***First Nations and Inuit Health Branch, Health Canada*** have also made significant contributions:
- Home and Community Care Program implementation
 - Joint Working Group on Continuing Care Policy Development (Comprises of members from AFN, ITK, HC, INAC, and FN & Inuit representatives)
- ***Non-Insured Health Benefits (NIHB)*** which is funded by Health Canada provides for limited coverage for prescription drugs, patient transportation, medical equipment and supplies, optometric services, dental services and psychological services. Issues have been articulated in the scope and nature of the coverage. The pre-approval process for medical supplies and equipment is a major issue, particularly for the Inuit that may wait up to 6 months for approval for a piece of equipment or oxygen therapy needed immediately. Discharge planning and coordination of transportation for patients and escorts is a significant issue in parts of the country. Comprehensive assessment instruments and processes are lacking.
- ***Educational Institutions of Health Care Providers*** have engaged in a process to define competencies and educational requirements in the area of palliative

and end-of-life care. The “Educating Future Physicians in Palliative and End-of-Life Care” (EFPPEC) project is a joint project of the Association of Faculties of Medicine of Canada and CPHCA with funding from Health Canada. EFPPEC was established in 2004 and has as its purpose to bring education in palliative and end-of-life care to all undergraduate medical students and clinical postgraduate trainees at Canada’s seventeen Medical Schools so that they will graduate with competencies in this area by 2008. Canadian Association of the Schools of Nursing (CASN) has been sponsored by Health Canada’s Secretariat on Palliative and End-of-life care to gather nursing leaders together for a two day meeting in March 2007 to achieve consensus on nursing competencies for palliative and end-of-life care and discuss the status of nursing curriculum for palliative care in Canada. Other educational institutions and professional faculties may also be active in this area.

- ***Canadian Nurses Association (CNA)*** – the CNA and member provincial / territorial professional nursing organizations work in the areas of nursing standards and competencies. Support for high quality practice environments for nurses and within health care in general is a primary concern along with making policy statements on specific topics. Hospice palliative care is one area of growing interest for CNA.
- The ***Canadian Institutes of Health Research (CIHR)*** – CIHR is an umbrella organization of a collection of research institutes, including the Institute of Aboriginal Peoples’ Health (IAPH). These institutes are major funding agencies of health research in Canada. The CIHR funds the development of Aboriginal health research capacity through the development of the ACADRE network.
- The ***Social Sciences and Health Research Council (SSHRC)*** – SSHRC is the major funding agency for social science research in Canada.
- The ***Canadian Rural and Remote Health Research Society (CRRHRS)*** – CRRHRS is an organization of researchers and research partners with interests in health research in rural and remote areas.
- The ***Researchers Working Health and Related Areas*** have become increasingly interested over the past ten years in hospice palliative care in general and Aboriginal perspectives and issues specifically. A comprehensive review of the research is not within the scope of this paper, although a review of available resources is one aspect of the project as a whole and will be appended to the final report as an inventory.

3.0 Future Vision of Aboriginal Hospice Palliative Care

The CHPCA Model includes definitions of commonly used terms, values, principles and norms of practice, conceptual frameworks, clinical practice guidelines and measurement tools. These core components are to be interactive with research; advocacy/communications and marketing strategies; legislation and regulations; funding/service delivery models; patient and family outcomes; organizational development/function; educational competencies, curricula, exams; accreditation standards; and minimum and licensure standards. The model was the result of nine years of national consensus building that involved hundreds of participants.

In each aspect of the Model, there are common as well as unique considerations that need to be taken into account to move toward an optimal hospice palliative care system. The model is founded on an underlying understanding of health and illness. The definition of hospice palliative care, the values, principles and foundation concepts that underlie all aspects of hospice palliative care is also part of the context on which the model rests. We know that some Aboriginal individuals and families have an understanding of health and illness that may vary from the norm in Canada due to the cultural and historical context within which they live their lives. Developing and understanding hospice palliative care from a diversity of Aboriginal perspectives is in early stages and may require adaptations to the current work in order to be in harmony with Aboriginal realities.

The “Square of Care” which guides the delivery of hospice palliative care to patients and families may also need to be refined to take into account unique characteristics and circumstances of some Aboriginal families. The square of care as currently described takes into account demographics; culture; personal values, beliefs, practices and strengths; developmental state, education and literacy; as well as disabilities. This provides a strong starting point. The “Square of Organization” provides guidance to the organizational development and function which may also require change to speak directly to organizations that are governed, managed and staffed by Aboriginal people and serve Aboriginal families. The fifth component which guides implementation of the model may have to be redirected to respond to the current situation in First Nation and Inuit communities.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during illness and bereavement

Hospice palliative care aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth and self-actualization

(CPHCA, 2002)

This view of the ultimate aim of quality hospice palliative care is held in common by all Canadians. The methods through which care is provided to ensure the best possible experience for First Nation and Inuit people may be somewhat unique if methods are to appropriately and sensitively respond to the realities of the lives of individuals, their families and communities.

4.0 Current Capacity and Strengths

Current capacity and strengths provide a positive and powerful foundation for moving forces. In the terminology of the Appreciative Inquiry method, these strengths include “life giving forces” to nourish the system and in the words of the Elders “lift up” future efforts to enhance AHPC. Many strengths and recent advances were identified in section 2.0, background and context. In addition, survey respondents and roundtable participants were asked to identify strengths. The strengths that were identified included the following:

- **Understanding Aboriginal Hospice Palliative Care (APHC)** – There is a beginning understanding of what the components and processes needed for a system of Aboriginal Hospice Palliative care are. There is a long way to go. We have enough understanding of what it is for one respondent to say “there is no Aboriginal hospice palliative care. Having Aboriginal voices from many jurisdictions i.e. on reserve / off reserve / remote areas / small and large urban areas, hopefully will bring palliative care to First Nations peoples. There is no translation for the word palliative care in the Aboriginal language that I speak.” Another respondent added that the philosophy and goals of palliative care are very consistent with cultural values and community orientation, which makes it easier for First Nation people to understand. They also see the importance of the integration of palliative care into chronic and long term care as they want to support their elders to die at home and not leave the community for long term care institutions. In this person’s opinion, First Nation people are very motivated to engage in palliative care related initiatives. Specific work needs to be done to understand and document the views and perspectives of Inuit and Métis people as each group has unique conceptual frameworks, cultural considerations, perspectives and priorities.
- **Leading Practices** – There are good models in communities across the country but these local situations are successes for a variety of reasons including the financial and leadership commitment of the community. These programs are culturally appropriate and they use First Nation staff, traditions and culture to assist the First Nation palliative care client. The factors that support success and the effectiveness of the models need to be understood so that the knowledge can be disseminated to help other communities. In some cases, communities are in a financial position to use own source revenue to strengthen the programs and services, but many other communities do not have the resources.

- **Individual and Community Interest and Commitment** – Aboriginal people have always had genuine interest in supporting individuals that choose to die at home. There is a keen interest in learning more about death and dying at home and to focus on meeting the needs and desires of the “person”. Community members have always been and continue to be fully committed to providing the option of dying at home to all. Part of the challenge is lack of access to 24 hour, 7 days a week supportive services.
- **Local Capacity Building** – There has been success in finding ways to engage communities in respectful two-way dialogue that supports planning and implementation of local capacity building initiatives. In some cases, the work includes a research and/or evaluation component. Examples are the Inuit version of the Caregiver Handbook; University of Regina Cree Elder Participatory Action Research Project; Pallium Project Aboriginal Relations materials; North Western Ontario and Lakehead University initiatives and others.
- **Commitment to Making it Work in the Home** – There has always been a willingness on the part of families and care providers to make it work so that a person who chooses to die at home is able to die there. The support of community leadership, the availability of training helps everyone go to great lengths to respect the wishes of the individual. Traditional practices are becoming more acceptable in some places.
- **Hospital Programs and Services** – Hospitals are making advances in providing more sensitive and responsive care for all including the “Mileau De Vieux” or making hospital feel like home concepts. Development of educational materials in Indigenous languages and developing cultural and other support programs geared toward the needs of Aboriginal clients are examples.
- **“No Rules” Environments** – Some institutions are developing a “no rules” atmosphere where families can come and go anytime and allows for one person at least to be there at the bedside all of the time. The family is allowed to bring in food and share it with the loved one, coffee is available and their spiritual or religious support person is allowed to come in to carry out ceremonies. This environment can make the final days more comfortable for all.
- **Willingness to Learn to Provide Culturally Sensitive Care** – There is an increasing willingness on the part of hospice palliative care providers to develop cultural competence and find a way to provide culturally sensitive, culturally safe and/or culturally competent care.

5.0 Current Situation Analysis

The current situation needs to be understood in historical context. Aboriginal people have always taken good care of each other from the beginning of life to the end of life and beyond. The commitment to caring for the dying and the grieving members of community remains and is a strong foundation on which to build additional capacity. Significant progress has been made over the last decade and there are long standing and newly emerging advances and strengths in the current system that provides hospice palliative and end-of-life care to First Nation, Inuit and other Aboriginal people. Building on those advances and strengths, and an agenda for next steps need to be created. In order to do that, we look at the work left to be done. The purpose of this analysis is to bring together the thoughts of a group of knowledgeable and committed individuals to provide an assessment of the current situation, including a preliminary understanding of gaps in order to establish a national agenda to support additional research, the gathering of evidence to support our preliminary analysis and the development of strategies to move forward to a more positive future.

When asked how the gaps identified affected First Nation, Inuit and Métis people, respondents spoke from their own experience. There was a general sense that these gaps affected all three groups in different ways but personal knowledge and prevailing documentation better describes the situation in First Nation communities and on reserve. Little is known about the off reserve First Nation, Inuit and Métis realities faced when seeking care for a loved one in the midst of dealing with a life limited illness or dying. The impact of unexpected death, both traumatic and not so traumatic is another area where little is known for sure. There was a general sense expressed by those surveyed that the rural and remote communities were experiencing the most significant gaps and that we need to remember the needs of the family and community, not just the person at the centre of care.

The needs of remote, fly-in communities north of 60 and in the northern regions of the provinces are particularly acute as the health system that serves them is often limited in the capacity required to take on the care of a family dealing with a hospice palliative care situation. In these communities access to equipment, nursing, homemaking, education and expert medical advice is very limited or non-existent. Individuals in this situation are often transported by air out of the community and end up dying far away from home, family and community. Language and cultural barriers are often a problem in receiving adequate or sensitive care in these far away environments. The expense and the degree of difficulty moving physical and human resources to and from these communities is beyond the understanding of many that have not lived in these communities.

Marginalized populations in urban areas were also named as a group that often has a high level of complex needs and, in the case of the hospice for the homeless in Ottawa, 45% of the people served are Aboriginal. Small urban centres are often underserved as well. Barriers to care of marginalized people is important. In addition, one respondent identified that Aboriginal people may not access services even if they are geographically

available. The reasons for accessing or not accessing are difficult to ascertain as many agencies do not collect the ethnicity or first language of their clients or patients. We need to identify what “culturally appropriate care” is and realize it is not one approach, but a range of options available within the context of a culturally competent and responsive system.

5.1 Knowledge and Evidence

Optimally, practice is based or informed by evidence and the call for evidence and research agendas is also driven by individuals practicing in the field and their clients. As hospice palliative care is a relatively new field, there are many gaps in the research programs and the knowledge needed to inform policy development, program and service design and delivery. Aboriginal hospice palliative care is an even more recent development. The question about “what is unique about First Nation and Inuit individuals and families that may mean they require specialized approaches to the delivery of hospice palliative care?” has only begun to be asked and is not well answered at this time. In order to answer that question, we need to bring together traditional First Nation, Inuit and other Aboriginal knowledge and mainstream scientific or empirical knowledge. We need to understand what standards we bring to assessing “evidence” to support and inform decision making. How do we assess the quality of the evidence that comes from traditional Indigenous sources as equivalent to that of sound evidence emerging from mainstream research efforts?

Specific areas for future action related to knowledge identified by survey respondents include:

- **Knowledge to Support Education and Training** – If primary health care is seen as the underlying philosophy in all aspects of health care delivery, we have not fully supported the model through knowledge development, dissemination and related education and training.
- **Learning Essential Approaches to Palliative and End-of-Life Care (LEAP) with Aboriginal Cases** – The Pallium Project generated LEAP curriculum has been implemented nationally and feedback has indicated a need for cases customized for Aboriginal rural and possible urban realities.
- **CHPCA Home Support Worker Training Kit for Inuit People** – Nunavut has asked that this kit be reinterpreted, tested and appropriately deployed for Inuit Community Health Representatives and other local staff, to be delivered using the “Closer to Home” delivery strategy.
- **Woodland Cree Version of the Caregiver Handbook** – There has been some interest in looking at a Cree version of the resource, in at least one dialect although more consultation is needed.

- **Elders and Knowledge Keepers Video Work** – The Pallium Project would like to see the perspectives of various Elders captured in a teaching-learning video and has much “opportunistic” footage “in the can” waiting for an additional opportunity to move that initiative forward. This would take additional financial investment for final writing, scripting and post-production. The thoughts about using the end products include it being shown on APTN as a societal engagement piece.
- **Cultural Variation** – There is a great deal of diversity within Aboriginal communities and nations that has to be taken into account in generating appropriate responses.
- **Medical Terminology and Translation** – medical terminology has to be translated into plain language and First Nation / Inuit languages to ensure understanding.
- **Aboriginal Involvement and Leadership** – In addressing the knowledge gap, Aboriginal people need to be involved in all aspects of planning, research, policy and program design.
- **Professional Updating Mechanism** – There is a constant need for updates to support the further development of clinical expertise.
- **Knowledge to the Families** – Families need clinical and non-clinical information to support decision making, care giving and advocacy.
- **Cross Cultural Training** – Training needs to be provided to individuals to enhance cultural competence. The education needs to include the importance of family and community at end of life as well as information on traditional protocols for non-Aboriginal care providers. Information on how Aboriginal people view death is also essential. As one person said: “Death is not the enemy ... it is going to a better place and as children we were taught to accept death because we are all here to die.”
- **Norms of Practice for Aboriginal Hospice Palliative Care** – We need to develop norms of practice for Aboriginal palliative care which could be based on the CHPCA norms of practice and modify them as appropriate. The understanding of the differing views of patient autonomy within a collective culture needs to be one of many considerations. In developing the norms, we need to decide where the First Nation community “system” for palliative care should reside and culturally appropriate protocols and care plans used to navigate the system could be developed and modified for various regions of Canada.
- **Knowledge to the Process** – as there will always be gaps in the documented knowledge available, it important to have Aboriginal representation in decision making processes.

Specific ways to fill the knowledge gaps that were recommended include:

- **Good Practice Stories** – Gathering good practice stories to share among communities would be a great way to build “on the ground” competencies.
- **Focus Groups with Elders, Community Care Providers and Professionals** – Use focus groups to explore what is working and look at the evidence related to leading practice in areas of the country such as the Kenora/Rainy districts (Lakehead).
- **Community Based Research** – In the past, some researchers were seen as outsiders coming in to take information out of the community with no obligation to serve community needs and priorities. New methods of research used by Aboriginal and non-Aboriginal researchers teams that include university based and community based researchers are doing important work to develop and disseminate more knowledge to assist the development of the AHPC field.
- **Funding for Expanded Programs** – Funding is needed for research, for educational and training programs development and also for delivering quality programs and services. Evaluation is also essential if we are seeking to continuously improve the programs and services.
- **More Brokered Responses** – More knowledge development projects that include sponsors, technical experts, cultural brokers and most importantly clinical champions and clinical leaders from the Aboriginal palliative care community. An example is the process used by Pallium in the development of the first generation of the Aboriginal courseware.
- **Connecting Multiple Sources of Knowledge and Ways of Knowing** – There needs to be deliberate “integrative” strategies that include finding practical ways for Aboriginal Traditional Knowledge to co-exist in harmony with western biomedical pain and symptom management practice. In particular, in looking at the roles of pain and symptom management and traditional knowledge in dealing with the issues of heart and spirit that complicate end-of-life care such as existential suffering.
- **Values of the Collective in Knowledge Translation and Exchange** – Home based training and education sessions, community feasts led by leaders and disseminating messages through trusted networks as part of the social fabric of the community are ways of sharing knowledge that works with traditional collective values.
- **Dialogue Sessions** – Informal meetings with community people, community Elders, traditional Elders and other ways of creating a forum for dialogue are great ways to create knowledge to add Aboriginal input to existing palliative care models and learn from each other.

- **Research and Committee Work** – Research is very important and the basis for good policy decision making and development. Currently, there is a Joint Working Group that involves a number of stakeholders.
- **Community Based and Community Led Research** – Participatory action research that is guided by community members in regards to questions, procedures and analysis etc, can be used as well as other ways of gathering information. These processes can be used to develop the resources and programs in the local communities.
- **Video Taping** – Using videotaping to capture Elders and traditional knowledge keepers talking about protocol, sharing traditional teaching or telling stories is powerful and invaluable in training individuals who do not have the background.
- **Not Through Standard Mainstream Methods** – Knowledge needs to be captured by listening to the stories and through relationships and engagement with Aboriginal communities. Traditional Knowledge research is needed.

5.2 Jurisdiction and Policy

First Nation and Inuit people that are eligible for federal health programs are often caught in a jurisdictional muddle when attempting to access care. The two levels of government – provincial/territorial and federal both attempt to be the “payer of last resort” in attempt to control costs and shift as much of the burden as possible to the other government. Local First Nation and Inuit governments may end up caught in the crunch as they are left to help people the best they can. The need for “seamless hospice palliative care” that provides the best possible range of options to families with the lowest possible number of challenges and barriers is self evident. The current system does not provide seamless care and there are many situations in which First Nation and Inuit people in need of hospice palliative care “fall through the cracks” and end up with less than optimal health care and other related supports. The jurisdictional gap will be outlined further in the following section on policy gaps.

The lack of case coordination and management between FNIH related on-reserve primary care services and provincial/territorial acute hospital services providers, especially an “end-stage” illness is a serious gap articulated by survey respondents. The lack of coordination is seen in the poor discharge planning support from Edmonton, Winnipeg and Ottawa for the Western Arctic Inuit people whose illness has become life limiting and who return to their communities for the remainder of their lives. The lack of coordination may result in a gap in much needed pain medication as orders from pharmaceuticals for remote communities are processed in Yellowknife and shipped out.

At all levels of government, there are policy gaps that create problems related to hospice palliative care. An example of one attempt to fill a need, the federal government created the Caregivers Benefits through the Employment Insurance program. It was implemented

in 2004. The advancement provides some assistance to those eligible of EI, but fails to provide any support for the non-eligible people including unemployed or underemployed Aboriginal people, those involved in some aspects of the traditional economy and the self employed. With no EI coverage, the final safety net is social assistance. In many cases, provincial/territorial and First Nation/Inuit community policy is not developed or implemented in a way that is sensitive to the needs of family caregivers. The policy framework for health insurance hospice palliative care coverage by the provincial/territorial governments varies across the country, in addition, individuals being served by the federal government (inmates, RCMP, First Nation people living on reserve directly services by Health Canada etc.) also have gaps in coverage.

Palliative care is an uninsured service under the *Canada Health Act*, responsibility for the administration and provision of this service remains that of provincial and territorial governments. Each province and territory decides how they will provide services in their jurisdiction. Provinces and territories funding is through the general transfer provision of the Canada Health and Social Transfer (CHST). The CHST is based on a per capita formula and includes First Nations and Inuit living on reserve and within designated communities. Therefore, palliative care services are intended to be accessible and available to all Canadian citizens regardless of residency. However, the reality is that most provinces and territories do not provide palliative care to First Nations living on reserves claiming that the federal government has the jurisdictional responsibility.

FNIH's Home and Community Care Program (FNIHCCP) currently does not fund palliative care as a core service to First Nation reserves and Inuit communities. This results in the sporadic provision of palliative care across First Nation and Inuit communities. The inherent problem of these jurisdictional funding and policy gaps existing between provincial/territorial (P/T) governments and the FNIHCC program has meant that that First Nation and Inuit individuals requiring palliative care are often displaced from their communities to urban centres in order to receive the care they require.

The majority of Aboriginal (inclusive of First Nation, Inuit and Métis) people in Canada live in urban settings. In urban settings, the Aboriginal people access mainstream services offered by provincial/territorial governments. In some cases, hospice palliative programs and services targeted toward Aboriginal people and their unique needs and circumstances are available and in many cases, very little are available. Example of good practice include the First Nation Health Program at the Whitehorse hospital that includes staff, access to traditional medicine and healers and a ceremonial space with a kitchen to prepare medicine and sleeping quarters for families accompanying a person in their final journey. The Royal Alexandra Hospital (RAH) in Edmonton, Spiritual and Cultural Helpers are trained and made available at this and other hospitals in the Capital Health Region. The RAH also has dedicated ceremonial space, access to traditional medicine, healers and ceremony as well as providing assistance in attending ceremonies outside of the hospital. The St. Boniface Hospital in Winnipeg is also known for its Aboriginal programming. There is little information available on how these programs and services can be accessed by home care patients.

Specific jurisdiction and policy related issues identified by the respondents include:

- **Funding on Reserve** – Although the federal government has the responsibility for providing care on reserve, the level of funding is inadequate to support hospice palliative care (HPC) programs services or the related training for both formal and informal care providers.
- **Inuit communities** – Funding in Inuit communities has also been inadequate to meet the need but the jurisdictional landscape is different with the responsibilities of the Nunavut government. Inuit populations and communities also exist outside of Nunavut in Northwest Territories, Northern Quebec, Labrador and elsewhere in Canada. The arrangements for the delivery of health care to Aboriginal people differ between northern territories.
- **Functional and Practical Barriers to Care** – Jurisdiction, policy and mandate issues work as a functional and practical barrier to seamless transition across various service settings of care (e.g. home, hospital, hospice, long term care / continuing care and setting of marginalization (street or prison). Lack of good discharge planning to support transport from major centres back into remote communities create very difficult situations for families and local care providers.
- **Homecare as a “Grey Area”** – Home care is seen as a “grey area” as it is not an insured service like physicians and hospitals. The roles of the federal and provincial governments in home care remains somewhat unclear. Gaps and overlaps occur at the community level due to misunderstandings and lack of agreement between the federal and provincial government agencies. In some cases, the situations become more complex when services are funded by government and carried out by non-government agencies.
- **Communities Know the Needs** – Communities at the grassroots know what is needed and know what HPC model would best work for the people beginning from resources already in the community with additions from existing HPC models. As one respondent stated: “I do not see a difference, all governments have rules and regulations that create barriers to meeting the needs of First Nation people... First Nation people get lost in the cracks.”
- **Wait Times** – The wait times involved in accessing care, a hospital bed or advice from expert resources is a problem in delivering timely, high quality care.
- **Weekends, Evenings and Nights** – Home care models often work primarily on a 9-5 model from Monday to Friday and HPC needs 24/7 support to ensure comprehensive coverage.

- **Pay Equity** – The levels of remuneration for comparable jobs differ between the First Nation or Inuit, federal and provincial governments. This creates turnover and lack of continuity of care.
- **Jurisdictional Buck Passing** – Jurisdictional issues are a real problem. Jurisdictional buck passing leaves local First Nation communities without HPC services. Ontario has mandated that end-of-life strategies be carried out in each LHIN but it has not been clearly articulated whether or not First Nation communities are included in this mandate. One respondent suggested that palliative care needs to be clearly articulated as a component of the chronic disease management strategy.

Suggested methods for dealing with the jurisdictional and policy issues include:

- **Collaboration and Consultation** – Joint initiatives that fully engage national Aboriginal groups and local communities are essential to building appropriate strategies that will result in a stronger AHPC system in Canada.
- **Formal Agreements** – Following the necessary orientation, issues identification and discussion, develop formal agreements between non-Aboriginal health agencies and First Nations regarding service delivery and the process for access service and providing care.
- **National Strategy** – We need a national strategy directed toward on-reserve palliative care and palliative care in the northern Inuit communities and the funding needs to be identified to support the expansion of appropriate programs and services. Evidence is needed to support the decisions and data needs to be collected to demonstrate the lower costs and the enhanced quality of care.
- **Restructuring** – One respondent suggested a “total restructuring of policy and service structure as well as the education and training of providers of care at all levels.”
- **Reduce Rigid Policy, Policy Interpretation and Application** – To make room for the application of “common sense” and professional judgement in order to reduce unnecessary expenditures and improve patient and family care. One example is that a policy will allow a family member to travel in and out of a remote community several times to attend the bedside of a dying family member but will not pay less money for the individual to stay with the family member.

5.3 Education, Training and Skills

In the basic education of health care providers at all levels, palliative care is not well integrated into the curricula. There is limited curriculum time devoted to palliative care and the resources available rarely address specific First Nation and Inuit issues. In addition, the continuing education options available to care providers have been limited. The contributions of the CHPCA and First Nation people have been significant in recent years, with the addition of a small collection of First Nation specific resource material for continuing education of community care providers. These materials are listed in the Inventory developed in this project. The Pallium project has also made considerable advancement in developing continuing education materials and communities of practice to support professionals in gaining clinical skills in palliative care. In addition, Pallium has developed and piloted courseware specific to Aboriginal people. The Pallium courseware takes a relational approach to the development of skills. There is a relative absence of material for Inuit people. The Ian Anderson program at University of Toronto has also developed First Nation specific materials on a cross-cultural model. The lack of basic education and continuing education as well as the lack of knowledgeable mentors and advisors that can assist in the development of awareness and skills leads to a significant skills gap.

Nurses working with Inuit populations identified the lack of training for home care workers is a barrier to quality care. (Pallium, 2005) The training needs to include information on basic disease processes, skills in personal care, comfort measures and what to expect when they enter a home.

Education for staff/family/community in palliative care is required along with professional support networks to back up the person providing direct care. Education of First Nation health and social service workers in local communities is required which require curriculum and resources.

Public education is required that helps members of the public to support further understanding of palliative care and new resource materials are needed to support campaigns.

Specific areas for future action related to education, training and skills identified by survey respondents include:

- **Pain and Symptom Management Training** – Lack of specific training in pain and symptom management and how to ensure good management as people move between on-reserve and off-reserve institutions and care providers. This training needs to also address the lack of awareness and linkages between existing palliative care providers.
- **Palliative Care Education** – Palliative care education is required for primary caregivers, family members and the community. This needs to include improvement in the effectiveness of communication between all providers and

patients. Family members do not know what palliative care or “do not resuscitate” means. Information on what it means for a FN person to be preparing for the end of life journey needs to be shared. An example of a good beginning is the Pallium Aboriginal courseware. Lack of awareness of AHPC issues and/or confidence in speaking to these issues must be developed through this training. Modules could be delivered in communities to allied staff and families who need it. Traditional options could be included in the training.

- **Aboriginal Grief and Bereavement** – There is a very significant need for education and training to support enhanced skill development in this area among all health care workers working with Aboriginal people. Aboriginal people have a unique history and community and cultural context that often result in complex and complicated grief that requires sensitive approaches.
- **Orientation Training** – Very little is in place that addressed the “whole person” the context of the “whole family”. Therefore, organizations need to work with First Nation communities to develop an orientation program for non-Aboriginal health providers.
- **Training for Aboriginal and non-Aboriginal Care providers** – A range of training opportunities is required, including cultural competence, system navigation/case management, local service integration, better supports for families especially in the area of grief and bereavement related to expected and unexpected/tragic death.
- **Educational Opportunities for Aboriginal People** – More Aboriginal people need to be educated in the health professions so that they can serve Aboriginal populations.
- **Hospital Liaison Workers** – Aboriginal hospital liaison workers that could work with social workers, act as a patient advocate, provide visiting service to individuals in the hospital without family support and act as a resource for all staff would be a great asset.
- **Recruitment and Retention** – Recruitment and retention of staff affects staffing levels, the degree of familiarity and skills lost when experience staff members leave the organization and the quality of relationships with Aboriginal resource people and communities. The investment in orientation and training needs to be support by effective recruitment and retention strategies.
- **Collecting and Disseminating Stories** – The participants suggested that positive stories be collected and disseminated so that First Nation and Inuit people throughout Canada can learn from each others experience. An example is to examine to success story of the First Nation people of the Nass Valley in British Columbia as they have a strong model of self-governance and traditional caregivers are assigned to all individuals from birth. Clan structures and

traditional forms of governance are also being revitalized in the Yukon. The Vancouver Health Authority has six First Nation Liaison Nurses and that is working very well. One of their responsibilities is to do cultural awareness workshops.

- **Increased Numbers of Aboriginal Health Professionals** – Initiatives need to continue to recruit and retain more Aboriginal students in the health professions in order to have more individuals of similar cultural backgrounds serving their people.

5.4 Cultural Competence

Cultural competence is the human relational capacity to seek and find compassionate understanding within, between and among people with differing cultural backgrounds and perspectives. (Hanson, 2006) Cultural competence can be assessed at the individual client or patient relationship level, the organizational level or the system level. At all levels and throughout Canada the degree of cultural competence related to First Nation and Inuit people has significant gaps. In a hospice palliative care setting, the understanding of how the history of colonization and acculturation may affect an individual or family is fundamental to providing respectful and responsive care. Knowing what it means for an Inuit person to come to a larger centre from a remote, fly in village is important in understanding their needs and desires. Being able to inquire respectfully to gain the information and understanding necessary for culturally competent care is an important skill base, not well developed in our health care provider workforce. Organizations and the health system as a whole may unintentionally create barriers to culturally competent care through the articulation of policies and procedures. Even in the allocation of space within a hospital, the need for ceremonial and large extended family meeting space is rarely considered.

One survey respondent suggested that one method for individuals to develop cultural competence is that they “be immersed with our people since we are a collective body of people”. Cultural competence is needed at the individual practitioner level but also at the hospital (organizational) and system level. Family rooms need be available in all hospitals but there also has to be an understanding of the importance of extended families and the clan system.

The lack of culturally appropriate information on end-of-life care for individuals and families make it difficult to open up the dialogue on palliative care and even to plan for the future and talk about possibilities. Lack of education on the care of the dying that is culturally appropriate is a gap at the professional level.

Specific areas for future action related to cultural competence identified by survey respondents include:

- **Expected Death Protocols** – Need a protocol and process to defer the necessity of police attendance and autopsy with and expected death at home which reflects respect for Aboriginal customs and priorities.
- **Community Based Care** – Aboriginal people should be able to receive programs and services where they live at the end of life. The situations where people are unwillingly taken out of the communities to die without their families and their culture should be avoided.
- **Culturally Competent Care** – Many hospice palliative care providers off reserve would be hard pressed to provide a culturally competent service. One responded t suggested that non-Aboriginal regulated health care professionals consistently let their personal prejudices interfere with their duties in law and their professional “duty of care” which results in a consistently lower standard of care. There is a gap in the awareness of culture and what difference it makes to care. As one person suggested: “It is not safe to serve people one does not fully understand”.
- **Relational Capacity and Content Knowledge** – Cultural competence requires the development of a relational capacity to connect and learn and through that, content knowledge about the specific beliefs and/or practices regarding death may be shared. It is important to understand the traditions generally in order to know how to ask for the unique information needed to ensure appropriate care for an individual and family. As one person said: “Culturally competent care requires more than knowledge, skills and abilities. To reach the optimal level, there is a need to develop true understanding and respect. Even as we increase our knowledge in the views of Aboriginal people about health, there has to be recognition of individual differences as well as how those differences need to be respected.”
- **Knowledge and Skill** – As one person suggested “there are huge gaps in the knowledge and skill of local health service providers. These range from knowledge on how to do personal care at the bedside to pain and symptom management within an Aboriginal context. Local providers are highly motivated to learn given the opportunity and follow-up support.”
- **Infrastructure on Reserve** – Many care providers lack awareness of the infrastructure and in some cases, lack of infrastructure and resources in many First nation communities. This may lead to unrealistic care and discharge planning and disconnected care systems where people “fall through the cracks”.
- **Historical Context** – Many care providers lack awareness and appreciation of the historical experiences and multiple losses that are part of First Nation and Inuit history. The understanding of how this context impacts day to day care situations is also important for care providers to learn.

- **Responsiveness at Two Levels** – At the level of the organization, policy, programs and services need to be responsive to the general cultural and historical realities of the people they serve. In addition, these aspects of organization must have a built in imperative to listen to the needs and desires and the mandate and flexibility to respond if at all possible.

Suggestions made to build cultural competence include:

- **Education** – Both undergraduate and continuing professional education needs to include components to develop cultural competence with health professionals.
- **Training** – Ongoing training needs to be provided to assist in changing negative behaviours that undermine cultural safety.
- **Supported Personal Development for Reflective Practice** – Individuals that are competent in their own lives, are often competent in their relationships with others, no matter what race. Relational capacity is a human capacity that must be developed as a skill base that needs to be augmented through growing personal awareness and the cultivation of enlightened compassion.
- **Partnerships** – Enhanced capacity to relate and better support Aboriginal families can be developed through partnership with Aboriginal programs like friendship centres in urban settings.
- **Cultural and Traditional Teachings** - Traditional teachings to nurses, doctors and other care givers providing palliative care to Aboriginal clients assist in deepening their understanding.
- **Reducing Turnover and Recruiting and Retaining Aboriginal Staff** – staff that have had the opportunity to receive orientation and training and have developed relationships with Aboriginal staff are valuable. To reduce the loss of these valuable resources through turnover is very important. In addition, recruit and retain more Aboriginal staff to the HPC field.
- **Walking With the Community** – As part of the training have all nurses and doctors and other care giver take a cultural awareness course and travel to a community to experience palliative care in the community and stay through the death and attend the funeral.
- **Medicine Wheel Consultation** – Use the medicine wheel framework to consult with traditional healers. The medicine wheel is not a universal construct across Canada and between First Nation and Inuit groups, and therefore must be used appropriately.
- **Staff Grief Supports** – Supports for staff members grieving the loss of a patient or client needs to be available. Examples include a staff feast, Elder and/or clergy

support, prayers, cleansing and other ceremonies and more mainstream approaches to debriefing and collegial processing of grief. Unresolved grief is a factor in turnover and burnout and therefore, is an important area for action.

5.5 Health Care Service Delivery

The spectrum comprehensive hospice palliative care has only been recently articulated. The components of care and what it takes to delivery quality hospice palliative care is only begun to be fully understood in mainstream urban Canada. Once the focus is moved out of large urban settings to smaller rural and remote areas, the needs and appropriate health care delivery systems responses is not well understood at all. What we know is that in most First Nation and Inuit communities, there is next to nothing in the way of hospice palliative care specifically funded or mandated. The health centres and nursing stations have resident or visiting physician services and nursing services that provide generalist care, including care of those nearing end of life. The ability to take those services into the home is limited in most locations. Many people die in hospitals away from their home community and family, which is not the desire of most people.

The Home and Community Care program, funded by FNIH and delivered under agreement by communities, provides some home based care, but funding levels make it difficult to include the care required as a component of supportive services. In many communities, there is an informal extension of the mandate into palliative care, but with no funding, the inclusion of unfunded services undermines the sustainability of the system and overextends existing staff. The transportation of individuals from home to community based care as well as transportation out of the community due to lack of available care in the community is covered for eligible people by the FNIH non-insured health benefits program. The issue is not the cost as much as the disruption of the peace of the dying process and the family and community connections that can be very supportive to individuals at the end of life. The lack of access to hospital or palliative care beds can often override the preferences of the family and community. The lack of access to drugs, medical equipment and supplies can also be a problem if care is based in the home or outside a hospital. The availability of emergency drugs and access to pain medication on an emergency basis can be severely limited in rural and remote locations.

Practical, end-stage clinical support, including timely palliative pain and symptom management support is often lacking on reserve and in rural and remote settings particularly. Nurses serving Inuit populations have indicated serious gaps in the palliative end-of life care system in the smaller communities. (Pallium, 2005) There is also a gap in access to hospice palliative care facilities on reserve.

The shortage of beds resulting from in-patients having to access services outside their home area can mean a long wait for a bed when needed although most want to return to the community at the end. In some cases the timing does not work and individuals do not make it home for the last stages.

Human resources and funding, support system, equipment, best practices related information, palliative care information in Aboriginal languages are all gaps identified by survey respondents. The lack of funding related to palliative care on reserve, mentioned by more than half of the survey respondents, results in the funding being spread too thinly which means the service delivery within the whole program is reduced. There is a gap in the professional support available to families and front line care providers within communities. This gap is made more difficult due to the inability of the medical system to be able to adapt resource, equipment, funding and education to meet the needs and realities of the individual patients and communities, said one respondent.

There is also a gap in the structure through which palliative services are delivered. Palliative home care, for example, requires visits that are schedules, or involve people needing to wait at a certain place. Palliative care institutions often have policies and procedures that are not flexible enough to accommodate extended families. The dying people and their families are caught in a system that does not see dying as a natural part of our human existence, which does not fit with the culture of many Aboriginal people.

The respondents identified another gap in the lack of infrastructure in the local communities i.e. health professionals, pharmaceuticals, home care programs, equipment such as hospital beds and other assistive devices needed for the dying patients. Access to expert resource people and consultants on speciality fields of palliative care is part of the infrastructure requirements identified.

Specific health care gaps identified by the survey respondents include:

- **Staffing levels** - Inadequate staffing levels result in the lack of time to share information and educate the families.
- **Pain and Symptom Management and Rehabilitation Services** – Due to staff shortages and funding issues – the capacity to provide comprehensive pain and symptom management in the home is limited. In addition, rehabilitation services which are very important to the quality of life at the end of life are often denied.
- **Medical Equipment, Devices and Supplies** – This is a concern across Canada for all communities but for aboriginal communities it appears to be a major block due to this falling under federal jurisdiction in most cases. As one person stated: “no medical equipment, supplies and devices are available for palliative care which is made even more problematic taken together with the lack of financial and human resources. The federal government, as a funding source and provider should follow the gold standards as well. Home care funds are being redirected to pay for equipment, devices and supplies which further erodes available funding. The cost of transporting these items also an important issue in remote communities. It is rare to have a hospital bed available in remote communities which can make care difficult. There is a need to find practical alternatives for short term implementation when other options are not possible.

- **Training and Equipment Maintenance** – Families need training in order to use the equipment safely and effectively. The equipment stored locally may not be maintained due to lack of local skills.
- **Lack of Timely Access to Pain Medication** – In rural and remote Aboriginal communities there may be barriers to timely access to pain medication. It may be due to pharmacy services being provided by another community at some distance from the local community and also due to lack of security of the pain medications kept in the home. Funding sources to cover all necessary medication can also be a problem. The lack of authority for nurses to order pain medication or authorize and change in medication can be a problem if there is not around the clock physician back up.
- **Local Stock of Medications** – The home and community care program needs to have the financial resources to make medications available locally. The non-insured health benefits program will only pay for medication dispensed to an individual. With pharmacy services provided from out of the community, changes in the dosage of medications can take up to 10 days to implement which could seriously compromise the physical well being of the patient.
- **Funding to Support Traditional Healing** – There are limited resource available to support the use of traditional healing and Elder services.

Suggestions for addressing health care gaps include:

- **AHPC Infrastructure Investments** – The lack of infrastructure in FN communities (and Inuit communities) needs to be addressed slowly and steadily with education, training and funding for improved service. The training needs to include pain management knowledge and skill development for professionals and lay or family care providers.
- **In-home Drug Coverage and Access to Equipment** – Provide financial support for drugs administered in the home in the same way coverage is provided in hospital in order to support home death. The required equipment also needs to be made available and equity established between status and non status individuals and between those living in different geographic regions of the country.
- **Support for innovation** – Innovative programs need to be funded and supported and shared with other communities.
- **Sharing Good Practice** – Good practices for supporting the journey need to be documented and shared.
- **Pallium Project Phase III** – The Pallium project has begun to build a “wish list” for a funding request for Phase III that will include financial, relational

(partnerships) and project management investments to continue to make contributions to the enhancement of HPC across the country, including additional work in AHPC.

- **Advanced Care Directives** – provide support for the development of advanced care directives for Aboriginal people. The care planning needs to prepare the individuals and families to deal with the issue of organ donation and transplantation.
- **Grassroots Consultation and Planning** – First Nations need to be included in setting up best practices for their communities.
- **Continue JWG and CHPCA Work** – Continue the Joint Working Group Committee work and this work on the identification of gaps, issues and options in AHPC currently led by CHPCA and funded by Health Canada.
- **Act Now** – Do not take too long as this has been studied long enough – the AFN and HC need to get provincial/territorial buy-in to gain their commitment to addressing priority gaps.
- **Study the Alaska Model** – The Indian Health Authority has a model whereby they send PC professionals in to Inuit community for expert PC consults and to assist local workers and families in the management of palliative care. They are achieving home deaths.
- **The 2004 Health Accord** – The federal government needs to be held accountable for the funding of health care to all jurisdictions as well as their direct service delivery role in caring for First Nation people, those in the RCMP, military and inmates of federal penitentiaries, many of whom are Aboriginal.

5.6 Funding

The lack of funding for hospice palliative care is a problem throughout the health care system. Costing work completed by Laurel Lemchuk-Favel and Francesca Vehoeve “First Nation and Inuit Home Care: Analysis and Costs Based on an NCE Model” (1999) provided a beginning look at the cost of the gap in home and community care in First Nation communities. We know there is a substantial shortfall in the healthcare delivery systems in general and specific hospice and palliative care programs and services in First Nation and Inuit communities. In addition, there is a lack of dedicated funding for Aboriginal specific programming in major hospitals or hospices serving Aboriginal people.

The specific gaps related to funding named by respondents include:

- **On Reserve Hospice Palliative Care** – Hospice palliative care must be explicitly and adequately funded under home care programs with new funding

increases. It is difficult for communities to manage without additional funding. Families and communities need programming and service support to do what they have been doing for generations. One respondent indicated that “there is no funding available at this point for on reserve palliative care” and another said that “major and serious under funding is occurring at present”. A third responded just responded with “huge” in response to the question of “how would you describe any funding gap that you are aware of in the funding available for Aboriginal hospice palliative care. A final person stated that “I don’t see any palliative care programs in my area that are specific for Aboriginal people.

- **Better Use of Existing Resources** – One respondent made the argument that there is much that could be done within current primary care capacity in communities with additional investment in training and development. In order to look at increasing funding, a more considered analysis of staffing loads, support requirements and staff requirements for the end of life. There are reports of individuals being sent out of the communities in the north by medevac near the end of life as the RN resources in the community cannot keep up with the support requirements and meet the other community primary care needs.
- **Other Rationing of HPC Service** – There are gaps in service for all palliative care services for everyone. In Saskatchewan, for example, the amount of service that can be provided to any palliative patient is related to functional status. There are many in the home care programs that would benefit from PC and it is not available.
- **Funding for Community Development** – Community development to support local teams is needed. One project in north western Ontario proved successful.

Approaches to address the funding gap suggested include:

- **Joint Working Group (JWG) Activity** – The multi-stakeholder JWG is looking at the funding gap and developing a business case for continuing care in attempt to secure more funding for the continuum of care. HPC is identified as a “second level” service under the First Nation Inuit Home and Community Care Program and it needs to obtain the status of “essential services”. The estimate that a 15-25% increase to HCC budgets is needed.

5.7 Family and Community Resources and Capacity

The system of hospice palliative care depends on the capacity of social support networks, volunteers, family care providers and friendship groups to provide informal care. In some cases, those supporting individuals and families requiring hospice palliative care require training and other support to ensure the quality of care is optimal and the care providers do not end up ill or depleted due to lack of support. The lack of awareness, understanding of palliative care and/or comfort in discussing death and dying is a barrier to community education and capacity building.

Rates of poverty and other risks are higher in Aboriginal populations in Canada. As result, families may not have the capacity necessary to meet the needs of a loved one facing the end of life or bereavement. As identified by the RN Needs Analysis (Pallium Project, 2005), lack of knowledge about caring for those completing their journey is a significant challenge. Literacy levels can be a problem in more remote settings and the security of medication has been identified as an issue with both First Nation and Inuit communities. Unresolved issues with previous loss – both the loss of individuals passing away as many other historical and cultural losses may get in the way of a family or community member's ability to care for their members. This may result in family dynamics that may be complex and challenging. Tradition must be followed and the family may lack the skills to make their needs known to the hospital or home care staff in order to negotiate the time necessary to sit with the person after the end, for example. Other language and cultural barriers can create problems for families attempting to access care from non-Inuit care providers. RN Needs Analysis (Pallium Project, 2005)

Specific areas for future action related to community resources and capacity identified by survey respondents include:

- **Recognition of the History of Community Service** – Communities have served communities in the past and the system to care for one another has broken down in recent years, in part due to the effects of colonization. Outside commitments such as jobs, family and academic work can be barriers to taking on traditional care giving roles. Therefore both volunteers and paid support workers are needed.
- **Build on Strong Communities as Powerful Models** – Some communities, often in remote areas have not lost the ability to rally around those individuals and families in need. Family and community members take turns being there during and after the death and stay as long as needed after to assist in anything that needs to be done. These communities need to be held up as powerful examples of how the traditions work well if they can be either not lost or sufficiently recovered.
- **Current Capacity** – The adults in the community are not often able to care for the dying without supportive services due to gaps in their personal skills and capacities. The youth have not always been taught how to respect and care for Elders. Community capacity varies a great deal from one to another. Very few trained informal or family caregivers.
- **Respite Care and Support** – Families caring for dying loved ones at home need respite services. In addition, they need resources to assist them in delivering adequate care.
- **Lack of Knowledge and Comfort with Death and Dying** – Many times people have a strong discomfort in dealing with death and dying and there is a lack of knowledge about what to expect in the dying process.

- **Lack of Support for Conflict Resolution Support** – Both Aboriginal and non-Aboriginal approaches may be viable options for families with conflict and issues to resolve related to the care of a loved one. The traditional view of balance, peace and harmony as the situation within which a dying person needs to be provided loving support can be seriously compromised by unresolved conflict. The time pressures for decision making and the ethical issues that may need to be addressed provide complexity to the conflict resolution process.
- **Trained Health Care Providers and Case Managers** – There are a limited number of health care providers often playing multiple roles which is a significant community capacity gap as they are not fully available to train and support other health care workers or informal care providers. To support families in maintained their confidence, a case manager for them to access for all kinds of support including “system navigation” is essential.
- **Geographic Mobility** – The pattern of “moving around” that is part of the lifestyle of some Aboriginal people can create a challenge in organizing informal care and support.
- **Transportation Support** – Moving the patient and family around the community to access care and support as well as the possibility of needing financial assistance to travel out of the community for periods of time is a reality in rural and remote communities.
- **Drug Security** – Drugs that may be subject to abuse may not be secure in the home or in the community. Finding methods to secure paid medication and other drugs is essential for ensuring good care for the patient and to make sure the drugs are not abused with the connected danger to the community.

Suggestions for building capacity include:

- **Volunteer Programs** – More formal volunteer programs with good training and support would be an asset.
- **Community Engagement** – Developing capacity needs to be localized and will happen best if there is respectful community engagement with local community Elders and other leaders. A “one size fits all approach” would not work.
- **Networking with other Caregivers** – Families with experience caring for a dying member may be helpful to other families going through a similar experience.
- **Appreciation and Accommodation of Varying Beliefs** – Aboriginal people have a broad range of beliefs about death and dying and some belong to a wide variety of mainstream religious organizations while others follow and even wider range of more traditional teachings. There may be very significant diversity within

one family. This diversity needs to be understood within the context of a trusting and open relationship and appropriate responses developed to support quality AHPC.

- **Provision of Additional Care Providers** – There needs to be a capability within a future AHPC system to send additional people into a community to provide basic care if the local workers do not have the necessary capacity.

5.8 Basic Needs

In order for individuals and families to care for loved ones in the home, basic needs related to housing, food, clothing, income and other basic needs must be met. We know that poverty rates are higher among First Nation and Métis people in Canada and many families live in overcrowded and unsafe houses. As identified by the RN Needs Analysis (Pallium Project, 2005), the nurses working with Inuit populations identified lack of housing as a primary concern and a major challenge for someone choosing to complete their journey in their home community. The struggle that some families have to meet basic needs may mean a greater risk of burnout as there is less energy to invest in care for the loved one. In addition, cost related to the use of more electricity, feeding a patient at home and the additional cost of feeding back up care providers can be a serious constraint in homes where poverty is a fact of life.

Specific basic needs gaps identified include:

- **Homelessness and Hospice Palliative Care** – Individuals in urban areas and in rural or remote areas may be homeless. Aboriginal people make up a significant portion of the homeless population in Canada. Without a home, there is not home based care possible. Projects, like the hospice in Ottawa are under development in some urban areas and hold significant promise.
- **Infrastructure, housing and potable water** – Lack of adequate housing space and potable water is an issue for home dialysis and support a home death.
- **Overcrowding in homes** – With 3 or 4 generations and a large number of people living in an overcrowded home, the home may lack the safe and peaceful environment necessary to properly care for the dying.
- **Basic Income** – The lack of a sufficient income to meet the basic needs of the family, particularly in area with high unemployment and high cost housing, food and utilities (remote northern communities) can be a very significant barrier to the provision of quality care in the home.

5.9 Aboriginal Specific Palliative Care Guidelines and Protocols

The nurses involved in the RN Needs Analysis (Pallium Project, 2005), identified the lack of specific protocols as a problem. Managing symptoms like pain and shortness of

breath can be challenging in the absence of protocols. The turnover of medical and nursing staff in many facilities and programs serving Aboriginal people makes the need for protocols more critical to support quality palliative end-of-life care. In addition, the lack of formal arrangements with the RCMP can often result in the police attending an expected home death. In Northwestern Ontario, an agreement has been negotiated which is working well.

5.10 Grief and Bereavement Support and Services

The support requirements for individuals, families and communities that are in a process of dealing with loss are also beginning to be recognized and addressed. The recognition of some of the specific requirements of First Nation and Inuit people is also emerging, although little is known about what the most effective strategies for to support Indigenous people to deal with their backlog of grief related to their personal and collective history triggered by new grief associated with recent loss.

Lack of support for grief and bereavement that is culturally competent was mentioned repeatedly. Most communities and individuals in communities have experienced multiple, often traumatic deaths. These same individuals are often asked to provide support for others who have experienced deaths in their families and communities. The caregivers require support to deal with their grief so that they may help others. Community owned and led and professionally supported grief, bereavement and healing capacities, particularly to address complicated, complex and compounded personal, family and community grief is a significant gap identified by survey respondents. This includes access to Elders in all settings, including urban hospital and home care settings, and provision of space for extended family members to grieve together. Barriers to extended family sitting with the dying person are common with the strong message to family being “you are in the way” and “there are too many family members”. This demonstrates a lack of understanding of how Aboriginal people view death and how it is the worst situation for a loved one to be removed from their home to die in a hospital alone.

Specific areas for future action related to grief and bereavement support and services identified by survey respondents include:

- **Grief and Bereavement** - There are no formal hospice programs that are cultural competent or inclusive of First Nation or Inuit perspectives throughout most of Canada. Most hospice programs are focussed on mainstream culture and lacks cultural content. Few resources are available. Grief work needs to happen at a community level, not just through individual counselling strategies. This is a number one priority for training and education and help with the management of grief has been identified as a high priority by FN people across the country.
- **Community Capacity** – None of the respondents were sure who is doing this work in Aboriginal communities, but there is a need to expand the capacity to deal with new grief and also to deal with how the “grief events build one on

another without resolution or assistance in coping”. This creates a backlog of grief that is added to historical and cultural loss experienced by Aboriginal people. Many FN people are suffering from cumulative grief where each death triggers more and deeper suffering. No supports are available at the community level and services provided off reserve are not usually culturally appropriate.

- **Planning for Support** – No support groups are active and they are needed before and after the death for community members, family and healthcare workers. The network of support should be a priority for palliative care work from early in the process. We need to ensure all communities have access to spiritual, social and psychological support. Structured care planning is essential.
- **Enhanced Ability to deal with Loss** – The ability of individuals, family and community members to support people who are dying in large part will reflect their own comfort with death and dying. An important component of that is the ability to deal with loss and grief. Many communities have faced multiple, often traumatic deaths and have not had the time or resources (grief counselling, trauma support etc.) to appropriately deal with these losses. This backlog may “freeze” the individual or community into inaction often assessed as apathy. Any palliative care training needs to include “care for the caregiver”.
- **Personal Capacity to Be Supportive** – As one respondent stated: “some workers are not comfortable in giving support to the grieving family. They lack the warmth needed at this time of sorrow. It is an issue that each individual must work out for themselves. They need to find themselves before they can help others.”

Specific initiatives or approaches suggested by respondents include:

- **Build on University of Regina Work** – the paper “Building Community Capacity: A Retrospective of Bereavement Services in Regina, Canada” (2006) provides a very useful beginning at articulating the issues and identifying a way forward.
- **Social Workers and Other Services** – Use of social workers in health care settings to support grief and bereavement processes can be very helpful. The families should have options available to them and financial subsidies if necessary to support access to appropriate and effective services.
- **Grief and Trauma Counselling** – Ensure the allocation of specific funding for the development of palliative care / mental health services to support counselling and support, starting with children.

6.0 Values, Principles and Action Steps

6.1 Values and Principles to Guide Action

The roundtable session was very successful in articulating values and principles to guide future action in this area. The Elders sitting with the group were inspirational in their messages about the best way forward. The values and principles that emerged from the discussion were as follows:

- **Begin with a Vision** – the vision of the future of providing the best possible Aboriginal hospice palliative care for individuals, their families and the community need to lead our action.
- **Honouring the Commitment of the People** – the commitment of the Aboriginal people to support those facing life threatening or life limited illness has always been part of the culture and needs to be honoured in moving forward.
- **Compassionate Response** - the system that is developed need to built on the need to respond quickly and compassionately to hospice palliative care related wishes of the individuals and families to the extent that is possible.
- **Respecting Historical and Current Capacity** – the capacity of the community now and always needs to be respected and preserved as the foundation of community response.
- **Share Our Knowledge and Experience** – Aboriginal people and those people providing services to them have developed a great deal of helpful knowledge and experience that needs to be shared through stories and promising practices.
- **Build on Cultural Knowledge and Traditional Teachings** – cultural knowledge and traditional teachings from many different Aboriginal traditions are rich with guidance and advice to support wise action.
- **Build Integration, Partnerships and Collaboration** – working with the resources from all jurisdictions and all parts of the formal and informal health care system needs to be the basis for best use of resources to meet the needs. Integrating AHPC into all other programs areas is also important.
- **Work with all Determinants of Health** – many social and environmental determinants of health affect the HPC realities of families and communities. Comprehensive and effective responses need to be inclusive of these considerations.
- **Community based and directed research** – building our base of evidence and other knowledge is important to develop the arguments for adequate and stable

funding and effective programs and services. The research needs to be directed by the Aboriginal communities.

- **Specific Targeted Engagement Initiatives for FN, Inuit and Métis communities** – each group and many sub-groups have distinct needs and requirements. It is important to have individual strategies developed with full community engagement with each group.

6.2 Action Steps

The interviews and roundtable discussions informed the following suggested next steps:

1. **Recognize and Nurture AHPC Activities underway in Communities** – We need to build on the strengths, commitment and current capacity active in communities as we move forward.
2. **Public Education and Awareness Building** – As part of national awareness work, all participants need to contribute to raising the awareness of the unique HPC requirements of Aboriginal communities.
3. **Leading Practices** – All participants have agreed to begin to collect and inventory leading practices in AHPC for sharing through the CHPCA website and the inventory related to this project.
4. **Local Capacity Building** – Local capacity building will be supported by sharing leading practices and providing access to the inventory of tools and resources. All participants will promote the coordinated sharing of resources. Get the community involved at all levels through innovative means such as “kitchen table workshops”, if necessary.
5. **Collaborative Training and Education** – Collaborate in the development and implementation of AHPC education and training initiatives, including the development of generic materials that can be customized by the community.
6. **Joint Working Group** – All participants not currently on the Joint Working Group will provide support to that process to the extent resources permit as it is seen as very promising.
7. **HPC integration** – The hospice palliative care issues are part of many other aspects of health care delivery including continuing care; home care; mental health; suicide; diabetes and other chronic diseases and others. All participants agree to take steps to ensure the full life span; including hospice palliative care issues are included in program planning and policy discussions.

8. **Roster of Programs and Services** – Individuals in the communities do not always have access to current information on what programs and services are available and how to access them. A method of developing and keeping up to date a roster of programs and services as a “one stop shop” would be helpful to patients or clients, family members and care providers. The provision of information on problem solving and “system navigation” would also be helpful.
9. **Addressing Access Issues** – The identification of issues and problems related to access to programs and services in different geographic regions and circumstances need to occur and strategies to address these issues initiated if no current process is underway. The lead agency or agencies on this comprehensive and responsive mechanism needs to be identified.
10. **Common and Accessible Language** – The Aboriginal Hospice Palliative Care agenda is new on the national scene in Canada. In order to advance our collective capacity to coordinate and collaborate, we need a common lexicon of terms or commonly understood language as a foundation to mutual understanding. In addition, we need to consider the development of plain language documents to increase accessibility of the information.
11. **Investment in Cultural Competence at all Levels** – Cultural competence needs to be built at all levels in the system – relationships between individuals/families and care providers; organizational and systemic. A review of policies to assess how they contribute to culturally competent organizations and institutions need to be carried out.
12. **National Leadership and Funding** – The group assembled to discuss Aboriginal Hospice Palliative Care has suggested meeting annually to assess the progress and support National Aboriginal organizations, governments and non-government organizations in working together to advance AHPC in Canada. Funding shortfalls must be addressed if substantive progress is to be made. Advocacy and political leadership is needed from the community level and a strong business case needs to be built. One option is a joint position paper among national leaders in Aboriginal Hospice Palliative Care.

Appendix 1: References

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