Alberta Health Services
Capital Health

CARITAS HEALTH GROUP

**The Palliative & End of Life Care Institute:**

A Summary Report of Findings from key informant interviews and
two additional focus group sessions (August – October 2008)

## EXECUTIVE SUMMARY

Palliative care specialists are faced with increasing requests for palliative care provision for all patients regardless of diagnosis. There is evidence to suggest the current scope of care is not adequately meeting the needs of neither patient nor health care professional.

The Palliative and End of Life Care Committee has been created with the goal of assessing the needs of the terminally ill and addressing issues facing this population. Additional focus groups and eight key informant interviews were conducted to strengthen the development of a business plan for a Palliative and End of Life Care Institute (PEOLCI). Consultation with these individuals provided further support of the necessity to strengthen and link palliative care with specialties outside of cancer. The PEOLCI will bring added value if it creates comprehensive, integrated initiatives that meet the needs of cancer and non-cancer patients and address resource inequalities. Moreover, infrastructure must be created to expand professional knowledge and responsibilities and allow for further research to explore patients' needs, and the role of specialist palliative care services and relationships with other disciplines. All these activities will work to realistically address current inequities: financial, social and otherwise for those patients and families living with and facing a terminal illness.

## A. INTRODUCTION:

> *Getting end of life care "right" lies at the heart of what it means to be a civilized society, and thus prioritizing this area needs no apologies (Murray, Sheikh, 2008).*

Health care practitioners must forge ahead and remove barriers than hinder the extension of palliative care beyond cancer. Strengthening current clinical work and research, developing models and facilitating relationship building can deal with challenges such as prognostic uncertainty, funding difficulties, lack of expertise by palliative care physicians in non malignant diseases and a weak evidence base regarding appropriate models of care (Murray, Sheik, 2008).

As part of the Palliative & End of Life Care Institute (PEOLCI) business planning process, a needs assessment was completed using both focus group sessions and key informant interviews. In June 2008 formal palliative care providers were asked to provide input into the development of a Palliative and End of Life Care Institute. The opportunity to interview these individuals presented itself during a prearranged Annual General Meeting hosted by the Regional Palliative Care Program. Further input was then required from those individuals outside of palliative care, particularly those involved in the broader category of 'End of Life (EOL) care'.

Key informant interviews are qualitative in-depth interviews, which facilitate the collection of information from a wide range of experts (Marshall, 1996) who have first hand knowledge — including community leaders, professionals, or residents. These experts are generally in a position of responsibility and influence. Criteria for choosing an ideal key informant include (Tremblay, 1957):

a) *Role in the Community*: His or her formal role should expose him/her to the information being sought.
b) *Knowledge*: In addition to having direct access to the desired information, the informant should have absorbed the information meaningfully.
c) *Willingness*: The informant should be willing to communicate his/her knowledge to the interviewer, and to cooperate.
d) *Communicability*: The informant should be able to communicate their knowledge in an intelligible manner.
e) *Impartiality*: Personal bias should be at a minimum and known to the interviewer if present.

Key informants can provide insight on various topics and provide solutions and recommendations to problems or issues. They are important tools in the evaluation and planning of community health programs (Eyler et al., 1999). Telephone interviews and face to face interviews are two common techniques used to conduct key informant interviews. These types of assessments can provide information complementary information to that obtained from other population based surveys, like focus group surveys (Eyler at al., 1999).

There are many advantages and disadvantages to utilizing key informant interviews to collect information (Tremblay, 1957), (Curt et al., 1990), (Kumar, 1987), (Kumar, 1989) (Margoluis, Salafsky, 1998).

| Advantages: | Disadvantages: |
|---|---|
| • Detailed and rich data can be gathered in a relatively easy way in a relatively short period of time;<br>• Opportunity to establish rapport and trust<br>• Ideas and information can be clarified on continual basis;<br>• Can easily be combined with other techniques;<br>• Can raise awareness, interest, and enthusiasm around an issue;<br>• Relatively inexpensive;<br>• Provide flexibility to explore ideas and issues not anticipated in planning the study or project. | • Limited reliability and validity because of informal sampling techniques, individual biases, difficulties in recording and analyzing data;<br>• Information obtained may be difficult to organize or quantify;<br>• Scheduling interviews with busy respondents is challenging;<br>• Those not asked to participate may become resentful being left out;<br>• May be difficult to generalize results to the larger population and may need to utilize other qualitative and quantitative methods unless interviewing a large number of key informants. |

The use of key informants is used in many fields of study: anthropology, sociology and psychology. It is also an increasingly utilized technique in health care research (Marshall, 1996).

## B. METHODS:

Twenty potential key informants were identified representing a diverse set of individuals directly or indirectly involved in palliative and end of life care in different sectors of the health care system. The Palliative and End of Life Care Working Group and Steering Committee narrowed the final list of informants to eight, ensuring the timely completion of the consultation while maintaining variety of perspectives. The eight individuals represent essential health care

disciplines relevant to end-of-life: pediatrics, cardiology, oncology, geriatrics, nephrology, neurology, primary care, and administration. Further, these health care professionals and administrators are opinion leaders within their respective jurisdictions.

Two additional focus group sessions were included. One consisted of individuals involved in community care services[1] and the second, administrative support staff working in various settings of the Regional Palliative Care Program.

Interviewees were initially contacted via email and provided with a letter requesting participation, an interview guide, which provided background information on the PEOLCI business plan process and a summary of previous focus group sessions held at the Regional

[1] Focus group participants represented the following areas of care: home care, supportive living, facility living and rehabilitation.

Palliative Care Program Annual General Meeting[2]. The email was followed by a telephone call to arrange a convenient time to meet. All eight key informants were interviewed by telephone. Interviews were tape recorded and transcribed. All interviews were conducted by the same individual. Goals and objectives of the consultation were reviewed at the beginning of the interview. Anonymity was guaranteed to each informant to ensure complete disclosure. Informed consent was formally obtained from each informant followed by the interview itself.

A semi-structured interview schedule was utilized to determine informants' experiences/perceptions of care provided in end of life. Interviews were conducted to determine: What is currently working? What is not working? and how a PEOLCI would benefit them and the patient population they serve.

[A copy of the invitation, guide, and two page background will be added as appendices to this report.]

## C. FINDINGS:

All informants were very enthusiastic and eagerly communicated their opinions during the interview. Discussions were rich and provided information from various perspectives: clinical, historical, managerial and political.

Information obtained from the key informants and two additional focus group sessions validated and augmented data obtained from prior focus group sessions with formal palliative caregivers. While eight interviews may be viewed as limited, saturation or recurring major themes that were stated and reinforced suggests that additional key informants would have burdened the consultation process. The process of consultation however is necesssary to gain consensus and build important relationships. Other potential informants however will have an opportunity to participate through review of the draft business plan.

### *C.1. What is working?*

a. Capacity:

A number of specialties have committed resources for dedicated 'palliative care' or 'end of life care' staff. The Department of Cardiology (Heart Function Clinic) for example received funding for a part time palliative care nurse. The Department of Nephrology hired a spiritual counselor who is dedicated with dealing with end of life issues. They also secured funding in April 2008 for a palliative care nurse; unfortunately the monies were subsequently revoked. The Pediatric Palliative Care Program received funding for an additional palliative physician starting in 2010.

[2] Participants included individuals who work in the area of palliative care. The Summary Report is available upon request.

b. Establishment of Linkages and Networks:

*"Providing more choice to the family about the setting of care"*

Home care staff was highly praised during numerous interviews and was described by many specialties as a "*huge source of support*". Another interviewer commented, "*The home care girls are just beautiful. There is no problem there at all."*

The pediatric palliative care team has strong links with Children's Services Homecare in the city of Edmonton. Since the inception of the pediatric palliative care program the lead clinician has been able to educate the Children's Services Homecare team and other clinicians. There has been a dramatic shift to providing end of life (EOL) care services in the home, rather than acute care, and empowering local health care providers and building a team around a child, with a lot of input by telephone between the health care team (home care – nurse – oncologist- primary physician). Edmonton is the only city in Canada that has a dedicated pediatric palliative care team with a nurse on call 24/7 for all children in the region and differs from other centers that do not have coordinated after hours care for dying children.

Another initiative benefiting palliative care health professionals and indirectly patients is the Alberta Health Services Alberta Cancer Board's (AHS ACB) establishment of the Psychosocial and Palliative Oncology Network (PPON). The principle of that network is to try to link people who practice palliative oncology or psychosocial supportive care for cancer patients in any community in Alberta and link them across the province and benefit them from the expertise available in Edmonton and Calgary, where highly developed tertiary and secondary programs in palliative care and psychosocial support exist. Linkages are multiple: helping with the development and dissemination of standards and material, standards of practice and guidelines that would support the community practitioner, and educational activities. Initiatives range from face to face, telehealth, and use of all other media that is available.

c. Regional Palliative Care Program (RPCP) and other clinical services:

The RPCP is seen to be a very strong model of how a regionally based program can work. The program is highly regarded as one that is strong collaboratively and one that has brought about a system wide approach to palliative care. The program has developed a reputation for dealing with difficult issues such as human resources, physician recruitment, provider coverage.

Many have witnessed the strong research and education activity from this group; one that is strong in both an academic and organization applicability perspective. It is felt that "*the kind of research completed by the palliative care program is applicable to clinical areas and does influence clinical practice – this is very positive and should be continued."*

Positive comments were made in terms of the formal education to providers but also in the types of education that is made available to the broader community that is accessing the palliative care team resources in the region.

*"[The RPCP has] good communication and a good approach to education"*.

Clinicians in other specialties appreciate being able to access their palliative care colleagues on a consultative level, in person or by telephone, to be able to assist them, guide the specialties through situations where they are having difficulties in areas such as symptom and pain management, reasons for side effects and other alternatives that they are not as comfortable with, including things like methadone. The Palliative Care Team has been a "*wonderful resource for them*".

Prior to the inception of Alberta Health Services, palliative care service delivery was the responsibility of the health regions. Palliative care is an important component of cancer control, and as such, although the AHS ACB did not have the mandate to deliver palliative care to the population of Alberta, the organization remained very interested in palliative care. Its role was to help palliative care research and to help support integration, program development and, in terms of service delivery, expert consultation for patients who were otherwise attending the Alberta Cancer Board Pain & Symptom Clinics at the Cross Cancer Institute and Tom Baker Cancer Center. Once a patient requires more palliative care services, care is transferred and linkages are made with the regional programs available.

d. Past Research Infrastructure Support:

There has been a strong history of provincial support and partnership for palliative care researchers. The Alberta Cancer Board Palliative Care Research Initiative was established with core funding from the AHS ACB between 2000-2005. This provincial research initiative was administratively housed in the Medical Affairs and Clinical Oncology (MACO) division, which is a provincial division versus a site based division. Dr. Vickie Baracos emerged as the lead of that initiative that brought palliative care researchers together in Edmonton, Calgary and other parts of Alberta. A lot of momentum that was gained at these sites has been helped by this initiative. Currently, research is no longer under provincial structure; an informal structure in Edmonton and in Calgary now exists.

e. Technology:

Many of the specialty areas already utilize technology in their clinical practice, particularly telehealth. As many programs are regional and provide coverage not only to the Edmonton and environs, but beyond to northern Alberta and parts of northern British Columbia, the Yukon, NWT and in some cases rural Saskatchewan.

f. End of Life Care Needs Assessment in Two Specialties

Two specialty programs completed or are in the process of completing surveys with patients looking at their needs, expectations and preferences for end of life care.

Through their research, the pediatric palliative care program learned that the most important thing for family when receiving palliative care is keeping the family together, one half of participants would consider hospice or respite care, but their primary desire is to have the child to die at home.

A clinician and researcher in the Department of Nephrology received funding from CIHR and will be looking at characterizing the whole dying experience for her patients. It is suspected that most of their patients are having aggressive care right up until the very end that may not be necessarily appropriate, with resource utilization being inappropriately high. They question whether they could change their clinical pathway resources and place more emphasis on palliative care, with more resources in areas they think is more appropriate.

g. Satisfaction:
i. Patients, families and Informal Caregivers: Many specialties do not formally survey their patients or families on their satisfaction level with care received. Anecdotally, they feel that the services provided are valued and that "*satisfaction on the whole is high because people are very aware of what it would be like without any services and are so grateful for what they get.*"
ii. Formal Health Care Providers: Satisfaction is high with the consultative services provided by the RPCP. Satisfaction and awareness is growing with other sites. For example, health care professionals at the Stollery Children's Hospital are more knowledgeable about the services and benefits of the pediatric palliative care program.

### *C.2. What is not working?*

a. Bereavement & Psychosocial Support:
Most of the specialty areas do not provide formal bereavement services or resources (eg. bereavement program, caregiver support groups) for their patients' families. It is certain that "*there is a lot of need in that area, [it is] imagined that family physicians are dealing with [it] now."*
Another gap that was highlighted is the lack of sibling support. Resources and programs are available for siblings of dying children in the acute care setting, this, however, "*falls apart when the child is at home*". There is work being done to try and incorporate this service in the community to be provided both during and after the disease trajectory.
One informant commented that at times patients and families are identified and referred to palliative care for these types of services. Specialties are aware that this is the gap in their service, but they cannot provide it. One interview questioned if integration of psychosocial services between palliative care and the specialties would work; she doesn't think it would. She believes there is a role with disease specific support groups because there are some unique aspects to each illness. She suggested a bereavement service that one could collaborate with specialties and various staff, eg. nurses who have experience dealing with patients with specific diseases.
A couple of respondents also suggested the role and the need for untraditional therapies, such as music and art therapy. At this time there is a dearth of empirical research literature supporting the use of such therapies in end-of-life care. There is a need to create an evidence-based approach in this area as such therapies are becoming more common not only in hospice and palliative care programs, but also other settings of care.

b. Capacity:
A majority of the respondents are managing their current levels of infrastructure support for end of life care but it is "*not ideal by any means.*" Barriers to moving EOL programs forward include the lack of staff or lack of integration of their staff with the palliative care community, with much of the EOL care provided hinging on particular clinicians, their interests and research which are not currently sustainable.

One respondent commented on the need for increased nursing support for the patients and families, as far as nursing or attending hours. He stated:

> "*it becomes a limiting factor. Sometimes it is borderline whether the informal caregiver is able to help take care of patient at home. The threshold for that can be increased if there could be more home support at some stage, ie. if one had more staff hours in those cases. The PEOLCI can make comments around the amount of home care services provided to terminally ill clients which will affect the need as to whether patients need to go to hospice or not.*"

Currently, there are programs that patients can access, but the scope of services provided does not include in house nursing support, or enough support that they would be able to palliate at home, especially at the very end of life.
Another informant commented that their needs and the patient needs are well maintained in the acute care setting. She questioned resources available when the patient goes home, *"it's knowing do they really have resources so that they can manage. It's the follow up from home care that we struggle with and not referring to palliative home care"*. There is uncertainty regarding the availability of resources if people "*wish to die at home to be able to maintain that wish with adequate resources from their end, comfort needs for the care giver with bereavement and or equipment.* "

Yet another respondent commented that home care is not an option for heart failure patients. *"A lot of patients have needs relating to management of their heart failure as well as palliation of symptoms, [eg] they need intravenous diuretics and we have a lot of trouble arranging for diuretics at home. If the patient doesn't die quickly in [the] hospital then we have to look at placing in them in hospice, [and it is] hard to get into these places with end stage heart failure, so the patient ends up on the ward"*.
Ideally clinicians would like to see patients die at home if that is their preference and to have the home care support that they need. If the patient needs to be in hospital then they would want them to be in more pleasant surrounding versus in acute care room. An austere hospital environment is not viewed favourably. An "*ideal suite would be like a [maternal delivery] theme suite – a comforting environment"*
Long Term Care (LTC) Institutions were identified as being "*singularly unprepared for that to the extent that a patient was withdrawn from her LCT institution for the express purpose of dying"*.

> *We have lots of LTC institutions here that are serving the needs of an aging population with increasing burdens of disabilities. We are saving more people with higher levels of dysfunction, not just cognitive, but physical. So they are in these large institutions and there is a good willing staff there but there are tremendous inconsistencies in their skill and comfort level with EOL issues.*

Areas of dissatisfaction have to do with how slow everything is, lack of knowledge of specific diseases within and by the team caring for the patients, which varies. Certain units within the city have gained a lot of experience while others are new. One respondent commented that *"home care has challenges with staffing in terms of consistent staff, nurses to do assessments. More [of my] patients have had to go to acute care because home care has the money but not the person power to keep the patient at home"*.

> *Keeping patients at home when they are dying, not sending them to ER, or to the hospital is a huge value, which has been undervalued in my eyes, regionally and by the system. We just don't get the support despite the fact we can save a lot of money and do what is right.*

There is also a problem with continuous coverage from the primary care field for the palliative care patients that are at home. Alberta Health Services Capital Health established a Physician Support to Home Care Program that is available to palliative home care nurses on weekends and evenings when situations arise when an attending primary physician is not available. They are called in as a default in such situations. The informant interviewed stated "*there are some concerns around that. The reason is that [we] have a medical payment system where everyone gets paid for being on call, except for family physicians, and there is some resentment for that and as such some people are not taking responsibility for that*".

The RPCP provides consults when requested by the family physician. As a result, they are perceived to not take other calls, "*despite that they are on call and are getting paid on call to deal with issues that have to do directly with primary care*". A gap therefore exists for home care patients that do not have a family physician. The Physician Support to Home Care Program has been identified as an alternative although and their low reimbursement rates are viewed as being inadequate.

There has been a dramatic reduction in the number of pharmacies that provide subcutaneous medications and clysis on weekends and after hours. As a result, clinicians are then unable to complete a drug rotation. Pharmacies are suffering a financial loss in this area as they often draw up medications only to have the patient die. The informant expressed the need for a mechanism to ensure after hour pharmaceutical provision in a timely fashion for those family physicians who look after their patients at home. *"There needs to be some serious discussion between the College of Pharmacy and the region."* He feels that those pharmacists who provide the service need to be subsidized. There needs to be some sort of financial and contractual arrangement with the pharmacists across the city that would support the palliative care client, the physician and the home care nurse that are looking after these people at home.

There is also a need for administrative support. Full time support is required to keep an up to date inventory of current resources and opportunities within the region and city of what is out there: clinical services, education and research.

c. Education:

Educational opportunities have been requested for staff outside of palliative care because staff feel "*a great need to be much more competent, aware and skilled in the issue of end of life.* Despite caring for geriatric or end of life patients, comments were made that health care professionals still struggle, particularly with symptom management, with pain being the biggest issue. One informant stated she would like more information on such things as drug interactions and the ramifications of using particular medications.

d. RPCP Criteria – Referrals from Non Malignant Population:

*"Palliative care is accepted in cancer and conceptually in other illnesses, but not practically in other illnesses".*

One informant passionately spoke about her patients and serving their palliative care needs. She stated the central intake system is not working for them, that the needs of her patients are not being met by the program as it stands and that defining palliative care pertains more to cancer patients than anything.

> *"When we talk about defining palliative care it is defining the criteria by which patients can access palliative care, whether it is a 3 month or 6 month life expectancy or whatever program, defining that for [my] patients is just really, really difficult, probably for many patients but it is not like cancer patients that have this clear dying phase where they have this dramatic decrease in functional ability in the last 3 months that clearly demarks that final phase. [My] patients don't have that, they have this entry reentry pattern, frailty pattern of just lingering, unexpected death, so many of these patients don't actually meet the criteria of hospice or submitting to palliative care services based on definitions. I find that somewhat repulsive that these patients have these tremendous needs but based on a lack of knowledge of life expectancy they are not eligible. I think that definitions should be on needs basis not just life expectancy."*

This issue for health care professionals of identifying "*when that end of life is really facing you versus are we going slowly down*" is prevalent for non cancer populations. Palliative Care clinicians, however, have provided some "*wonderful models making it clearer for health care professionals to have palliative care involved sooner rather than later to make EOL so much better than it is now."*

Another informant spoke about liaising with the hospital consult team for inpatients and said, there are "n*o palliative care physicians that we can refer our outpatients to"* the *"[RPCP] that's*

*for cancer patients, they don't deal with [our] patients"*, we *"can't draw on them for a resource right now"*. She stated it would be very beneficial if they had a palliative care physician in her specialty as a backup for outpatients.

Medical consultation and referral is often a barrier to patients accessing palliative care services. Physicians are not referring their patients to the palliative care program because there is uncertainty of what palliative care is about, what role palliative care plays as it exists today, resulting in specialties being "*somewhat narrow in their focus of palliative care*". A respondent commented I am "*not quite sure what an appropriate referral would look like, what to refer for.*" "*The only reason I would refer to palliative care for is "where do you want to die?" and if it is a home base I talk about options and will transfer to GNCH, or involve Palliative Home Care."* It is "*really unclear at this point how palliative care as it exists can be much help and what they are prepared to do."*

There is also unwillingness, by the medical team, to say that the patient might die which slants everything including familial expectations, and builds the idea that everything is treatable and possible. "*How do you bring up [palliative care] with families*." Education and experience will take us beyond this. One informant commented that a clinician's experience with the palliative care program seems to affect referral, once they see how the system works they are more likely to use it again.

e. Defining Palliative Care:

Staff are not always aware of best practices in palliative care. One informant shared an instance where she has written out orders on a surgery floor and a nurse has said "I'm not doing that, that's killing them". The informant suggested that the primary role of a palliative and end of life institute is to develop algorithms to ensure comfort to dying patients and their families. She thinks it is very doable but believes you have to have a central place rolling it out to everyone so each institution is not reinventing the wheel. "*There is potential for ongoing leadership for this kind of initiative. It's been done all over the world, we can bring it in and translate it to the local milieu"*.

The stigma surrounding palliative care also impact patients and their familes. Patients equate palliative care interventions with dying, probably more so in cancer population. Although, as health care professionals know, palliative care should equate to symptom control, irrespective of the patient's disease trajectory. An informant commented on level of understanding for different generations of patients. Older patients do not understand the term 'end of life care', or even 'frailty' or 'vulnerability'. These are terms used by health care professionals. *"[Patients] may not like the terms because they feel that people are giving up on them, whereas if it is symptom control improvement to improve quality of life in your senior years, that just means to them that there is someone there that is willing to help them through until they die."*

One informant very much subscribes to the view that palliative care should apply much earlier in the trajectory of cancer and other illnesses:

> *"…traditionally one thinks that active care stops and palliative care begins, but there should be substantial overlap and by the time patients are having troubles and symptoms that's the time for palliative care even if you haven't given up on life extension or the potential cure. Research and education particularly [can facilitate this], also a change in understanding and culture so that people do understand that palliative care is broader than EOL care."*

f. Lack of Research Infrastructure in some specialties:

Many respondents commented on the limited resources available to them to complete palliative and end of life care research. One informant stated she would have to put the infrastructure in place by herself and that is daunting. When she has been successful at doing research it has been because someone else has had the infrastructure and resources.

There is an incredible network here in Edmonton of knowledgeable people and its tremendous research background, but it's not readily available to specialties outside palliative care and thus not as visible. "*We need to have a meeting place, we need to be collaborating and educating"*. An informant commented that there is a large unanswered need in stroke and more research on EOL issues in stroke is required.

g. Unmet Needs of the Patient and Families:

Financial burden, particularly those with ongoing complex chronic illnesses. Financial concerns are significant for many patients as a large number are elderly and at or below the poverty line. Once the patient leaves the acute care setting and is receiving care in the home it becomes a societal cost and an out of pocket cost for patients and their families which obviously impacts patients tremendously. Once informant commented

> "*it's no good saving the system money by avoiding aggressive procedures and putting palliative care in place if the burden is put on the patient and the patient cannot afford it. Many of the patients also live by themselves, don't have family close by, are elderly, often don't have spouse, or the spouse has passed away. Providing EOL care for these patients is really, really difficult. It can linger for months and they have tremendous burdens during that time. I would like to see financial program to help cover costs."*

h. Establishment of Formal Linkages & Networks

A key informant stated that some of the greatest difficulties she and her colleagues face is the lack of formal links with palliative care. The only links that exist are those that were established personally and those have been weak at best for the last couple of years. Interactions and interest in engaging in formal networks was initially promising, but "*the scope of the problem is felt to be overwhelming. It's not something that [palliative care] can take on when you look at the sheer number of [her] patients and their need for palliative care resources. It goes beyond what a consultative service can provide."*

***C.3. How would a PEOLCI Help?***

a. Provincial Focus

One informant stated that he hopes the PEOLCI would have very much a provincial focus with the concern for patients in the province who need palliative care present and future and how to identify them, reach them and serve them. Another informant said the PEOLCI should be specific in terms of what can be done that will help with the direction of improving access, streamlining care, and providing more cost efficient care.

> *"You need to have that 'stand out', it kind of gets watered down when we are providing care in all these other facilities and settings and the problem is… the people in these facilities have other priorities and sometimes palliative and/or older care gets put to the bottom, it shouldn't but it does. If you can just raise the profile and it gets risen there when you are affected by it with a loved one who is dying or dealing with EOL issues, but until then, it is most often ignored, older people just aren't considered to be the top priority in this population and the problem is there is a lot of care and expertise that is needed and time, and they should get what they deserve. The RPCP has an excellent reputation and the PEOLCI would raise it to the next level."*

b. Clinical Care:

The Institute would be beneficial if it does things that bring

> *"added value to [health care providers] to be able to provide better and more comprehensive care that keeps people out of hospital and hospice… some sort of background structure that helps in the grassroots provision of palliative and EOL care".*

A couple of informants feel isolated when it comes to palliative clinical care.

*"Right now we are not delivering palliative care, we don't know how to do it and don't have anyone to go to. Fostering communication and having someone who can give clinical advice on case by case basis. We need that clinical support not to provide clinical care but to be a back up from our clinicians."*

Key informants offered and requested the development of a number of clinical initiatives from the PEOLCI to:

1) Provide funding so specialties can add physicians and nurses who are more specifically trained in palliative care to look after patients with non cancer illnesses.

2) Provide more in/out patient services and options for patients with non cancer illnesses. Baring that the Institute could channel the funding into the specialties and then 'they' would provide care in their home institutions.

3) Act as "*consultants with very targeted educational interventions that are relevant to the practitioners in that area*". Interventions would be either continuing to consult with certain patients that are identified by specialists as requiring EOL consultation, or training certain nurses who deal with EOL population – specific skills on how to deal with symptoms relating to disease process.
   *"[The Institute would] reach out to existing services and try to enhance them."*
4) Facilitate the development of home care and hospice services for non malignant patient populations. "*Acute care very full and not a good place to die if it is a predictable death."*
   *"The Institute would have to be integrated with all other disciplines and this could be achieved by providing capacity to do work through consultants, home care and hospice services."*
5) Create a clinical policy/ agenda for the non malignant population. The PEOLCI could partner with various departments and provide resources to initiate clinical end of life programs. Specialties can thus liaise with Palliative Care in a more meaningful fashion to begin discussions to link clinical pathways, redefine access criteria to RPCP, hospice and home care services, and investigate and resolve other issues specialties face as well.
   "*The Institute would benefit in terms of interaction, it would really help change how we deliver clinical care, [and] we would really want clinical ties as well.*

6) To continue to advance standards of care, to make sure that access issues are being dealt with , to streamline the processes of care and access to the system and to try and find ways to ensure that the right amount of palliative care service is available to different groups right across the system.
7) Provide a center / in patient component with specialized staff and surroundings that provide the right kind of suitable care. Specialties can then refer individuals with t EOL issues who are struggling and cannot be maintained at home or whose symptoms are not well controlled and they really are struggling in the acute care setting, This would allow for patient flow through – to get people to the most appropriate service that meets their needs. This process would also provide more caregiver relief, and education for the specialties.

8) A toll free 1800 number that could offer oncall services. This would be useful for multiple areas as burn out is an issue with many specialist teams – *"[they] cannot go out and be there for everyone."*

c. Central Location:
There was no consensus among the key informants regarding the necessity for a 'bricks and mortar' Institute. Informants favouring a physical institute were more likely to have identified gaps and needs in their service. Informants working in environments with fewer resource constraints were more likely to favour virtual partnerships.

The four individuals opposed to the physical construction of an institute cited the following reasons:

⇒ A building isn't required for administrative, communication, educational and research networks.
⇒ Where palliative care services are carried out is so excessive and varied across the region, how would it fit into people's everyday working life?
⇒ We are in an era where a bricks and mortar institute will be fairly difficult to achieve, but we can use today's technology to achieve very effectively, the creation of a virtual institute which could be achieved much sooner than a bricks and mortar one. To begin with you will have a big fight over where the bricks or mortar building will be located, Edmonton or Calgary.
⇒ It does not impact various health care providers directly. Groups and networks can collaborate very well without a separate building. If you can get the money great, but it is not seen as essential. It would be preferable to place money into the provision of care.

*"Go BIG or go home"*

The others felt an overwhelming need to have a central location for the PEOLCI to:

⇒ Facilitate communication, much of which is based on good will, collegiality, a willingness to work - that depends on relationship. Relationship is built face to face. It is not to say one cannot have success with distant relationships, online and remote communication, but things do not come to fruition the same way, relationships are not as strong.
⇒ Provide clarity, people have a better idea of what this structure can actually provide them. Sometimes, more support can be garnered for one facility that could be seen as unbiased. Having something virtual with people spread out all over these locations does not necessarily foster integration, collegiality, collaboration.
⇒ Provide an opportunity for people involved in palliative and EOL care, to get together, perhaps with family, to be able to congregate for the purposes of education and research.
⇒ Provide more resourceful use of infrastructure support - research and administration.
⇒ Be a hub for organizing various activities and draw people together. It is helpful for team building, let alone for the issues of professional development.

> *"When people get more dispersed at different sites, which I think is a negative, people get territorial and it becomes their castle. They see less of the regional planning, they are site specific and I think that is a problem for teamwork.*

Those informants who did support the creation of a physical structure commented, however, that location would be a factor. It would be ideal if the Institute was centrally located (downtown) and / or on an LRT route.

c. Collaboration:
The Institute would provide individuals the opportunity to interact and foster cross team - cross sector collaboration, with both an academic/bureaucratic and a patient care delivery focus. One informant suggested that collaboration would be built on clear role definition of the multi disciplinary team and work towards the common goal of providing practical patient care delivery.

> *"All patients are being looked after by various specialists and family physicians, this is not the best way, but is the way it is being done. I see the Institute as trying to improve on what is being done."*

Another informant cautioned there is a need to "*see how our collaboration really makes a difference on individual patient care rather than just coming up with programs and papers and meetings."*

d. Education:

(i.)Health Care Professionals:
One respondent felt strongly that people will gravitate very quickly to the Institute if it makes itself very visible in terms of education venues and knowledge skill sets that are well publicized. *"If we are going to move management and comfort of acute symptom symptoms back into where people live then there has to be a place for people to be educated about how to do this."*

The majority of informants were very enthusiastic about the Institute providing opportunities for education and professional development. Educational initiatives would mentor, guide and provide support resources allowing clinicians to build on their own skill sets. Many of the informants are the only 'EOL leaders' in their specialty with experience in palliative care and associated issues. Often this experience has come by trial and error and has been self taught.

*"There is a lot of interest in EOL care, we are just floundering, we don't know where to go with it"*

Specifically, informants suggested the PEOLCI infrastructure could be accessed in terms of training of nursing staff (Advanced Nurse Practitioner) for pain and symptom management and assessment, social workers to do Advance Care Planning, a place to could go for additional support for difficult cases.

> *"Even though we will be providing clinical care we will need guidance from someone saying ok this what you do, this is how you prescribe, this is what you need to look for."*
> *"We would need some real clear input and help in actually delivering, giving EOL care in a consultative role plus education links – just developing collaboration. It's having all the prongs – education, research, administration, clinical. Right now none of them exist."*

A PEOLCI educational agenda would allow specialties to change their approach with end of life patients and provide resources to initiate clear end of life clinical policy, care pathways, pain and symptoms assessments in their own scope of practice, whether it be nephrology, neurology, cardiology or geriatrics.

The Institute would be *"central repository of expertise and opinions."* One informant stated it would bring her a feeling of relief if there were opportunities to learn from other areas and to bring her experience to those who could disseminate it. The PEOLCI would allow for partnerships in many areas:

- ⇒ A number of illnesses exhibit common symptoms and with agreeable regional ethical standards different specialties can work together to contribute knowledge to central clinical services as opposed to each of discipline "doing [their] own thing to the best of [their] ability. One idea provided was be to have different 'disease per month' and move through different areas so a library of experience and material could be built that could be disseminated which could in turn be turned back into a research project to address gaps. This library of resources (eg. dvd) can be compiled with some permanence versus rounds that cannot be attended by everyone.
- ⇒ Programmatic team learning for things like symptom management and end stage diseases which would be taught by specialists from both palliative care and other diseases would broaden what is currently offered.
- ⇒ Rural providers: Currently a number of the specialties use telehealth and are impressed that a lot of providers are good at getting whole team together for this type of networking.
- ⇒ Rounds: this venue for information dissemination would work if the rounds were telecast or if they could target specialty specific practice rounds already occurring (eg. palliative care physicians continue to participate and expand on presentations at Family Practice Rounds in hospital).
- ⇒ PEOLCI would lend more credibility to needing to incorporate EOL and palliative care into curriculums to medical students and nursing students. At present there is so much information that learners need to be exposed to in such a short period of time. The Institute would lend credibility as to why this needs to be done and also to unite all health care specialties as a group.

As a result of all these initiatives there would be an ongoing and comfortable connection that would be promoted to all the areas to say that people will be dying in your institution and we want to make sure that a good death is available to everyone in Edmonton.

<u>(ii). Patients and their Families:</u>

Many informants felt that their patients and families would access and use educational resources if they were made available and well publicized. One group of informants (community services focus group) felt strongly that the PEOLCI would be of benefit if it provided information and resources to families who many times feel abandoned. The emphasis of these resources should be on preparing the patient and family for end of life and eventually death both emotionally, financially, psychologically and clinically. This information would empower individuals during and after the patients' disease trajectory and also focus on celebrating the life of the patient. All

of these initiatives will facilitate community engagement increasing public awareness and advocacy for palliative and end of life care.

In terms of disseminating of information on end of life care, one informant commented that the communication should be directed to the 'babyboomers', who are a more demanding group, more vocal, better educated, and more technological savvy. The current seniors that we have now, are very trusting and appreciate of service given to them, their children are the ones that are more stressed and in need of the communication and the message properly packaged to them. The informant suggested the PEOLCI have public forums, as a very valuable way of relaying information. Perhaps getting the local television stations involved and having written information in local newspapers as well.

e. Information Management:

A number of informants commented that it would be beneficial if the Institute would be a place that "*manages the information*." Some of the problems many currently face is, not knowing "*who is doing what"*, and where to go with specific questions (pertaining to research methodology, symptom control). The Institute would be responsible for continually updating databases, both research and administrative; standardizing practice, assessments and web based tools; coordinating and disseminating consistent resource material and publications for both health care providers and patients and their families.

May informants also commented that up to date, well publicized website information would be beneficial and useful not only for health care providers, but patients and family members as well. A number of them were unaware of what the current RPCP website offers (www.palliative.org). The present state of the website may not be meeting of the needs of not only those using the site, but others outside of the palliative care arena. Once a website is updated and meeting the needs of its users, medical staff can access information right at the worksite to get the information and apply it to practice which is more practical than getting individuals into a classroom or rounds session.

One informant commented that the key is "*making people aware of things. You can't say enough about communication. You can't publicize enough. The palliative care consultant through services, may want to have a little card on their consult sheet, for every single patient seen for the individuals involved in their care, the card can include info on palliative.org. [We] want empower staff to do problem solving on their own and when they are really stuck, that's when consultants are involved…The message from palliative care should be: we are not going to do it all for you, but we will give you tools and you will become equipped to do it well. That little card for that regular educational update and resource would be helpful."*

f. Research:

The RPCP has tremendous experience in imminently dying, health care professionals in the program have a strong history of research experience and infrastructure support.
There is a dearth of evidence in non-cancer palliative care. Very little of the research that does exist is evidence based. There is a smattering of scattered researchers doing nonmalignant palliative care research. It is believed that these health care professionals can move beyond this

by aligning themselves with "*people who have done research in palliative care, people who have gone through the process of putting a protocol on an end stage population*."

The PEOLCI would provide research education and infrastructure instead of the specialties being off in their silos. *"We can be guided through this very daunting process of doing good studies, providing the evidence when we ourselves don't have the infrastructure.*

Many of the informant responded that they do not have research training, despite having academic track records. Many enthusiastically stated they would attend research methodology courses and in turn increase their skill set and meet people and collaborate.

> "*For some of us to do original research without that background, it's tedious and when you are busy clinically it just doesn't happen, which is not a good thing, but that's just the reality".*

Currently many specialties do not have research infrastructure support. Often times their only exposure to research is providing content and providing patients that may benefit from being involved in that research who may not necessarily be attached to a palliative care service. One informant commented "*if research infrastructure was a component of the PEOLCI I would get more involved… where you team up with an idea, were able to put down a basic draft of a grant proposal and have someone critique it for you, who has the time to do that – that makes a big difference I think in terms of promoting research and good research."*

Research collaborations between palliative care and non malignant health care professional would allow sharing of established links and databases. Moreover, completed studies can be used as a guide and applied to different patient populations or specialists can use previously validated tools in their own populations and complete comparative studies. These research partnerships would be tremendous and ensuing information would then be translated into clinical policy.

Many others commented that their already busy schedules do not afford them time to actively partake in research. They were however willing to offer suggestions on research questions that would be useful to demonstrate through the PEOLCI. One clinician suggested looking at the benefit of provider behavior. One example was a research project looking at the chance of hospitalization or hospice use in different cohort groups, those that have a Primary Care Network, i.e. an engaged primary care doctor versus those that do not. If you could show that there is much decreased use of the secondary and tertiary care system because of that behavior, it would be helpful to show the payers it is worth it to invest in that primary care component. The informant stressed there is need to complete research on the practical aspect of the behavior of providers and not only what it does for the patient, but for the health care system.

## D. LIMITATIONS:

Time and fiscal constraints limited the number of individuals interviewed. These limitations also prevented the project team in engaging in consultation with informal caregivers, patients or the public at this point in time. Consultations are envisaged to take place under an emerging provincial framework.

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## E. CONCLUSION:

The key informant technique and subsequent focus group sessions allowed a rich discussion from various individuals involved in the broader End of Life Care arena. Diversity and depth of perspectives was achieved within the limitations of the project. End of life specialists that were interviewed were very excited and enthusiastic about the concept of a Palliative and End of Life Care Institute. Consultation with these individuals provided further support of the need to strengthen and link palliative care with specialties outside of cancer. The PEOLCI will bring added value if it engages in comprehensive, integrated initiatives that enhance and streamline clinical care as well as provide infrastructure to expand research, education and support not only to formal caregivers, but those patients and families living with and facing a terminal illness.

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