Palliative Care Society of the Bow Valley

UNIVERSITY OF CALGARY
CUMMING SCHOOL OF MEDICINE

Alberta Health Services

Bow Valley Palliative & End of Life Care Community Engagement Report

In Association with: ***The Cochrane Hospice Society***

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Project Overview

The aim of this project was to establish a partnership between the Palliative Care Society of the Bow Valley (PCSBV), the Cumming School of Medicine (CSM) and Alberta Health Services (AHS) – Calgary Zone Palliative and End of Life Care Services, in order to identify community members' perceptions surrounding palliative and end of life care (PEOLC). This knowledge will help communities to learn how to better support further community development surrounding PEOLC. Parallel to this project, PCSBV and CSM are working with Stoney Nakoda First Nations of the Morley area to identify needs and solutions specific to their community.

Banff, Cochrane and Canmore were selected to each host two community conversations. The conversations in Cochrane were hosted by the Cochrane Hospice Society. All residents of the Bow Valley were invited to participate in all the conversations. The focus of these events was to learn from community members' experiences and knowledge.   Collectively, between the six events, there were 90 participants. Figure 1. summarizes the percentage of participants from each community.

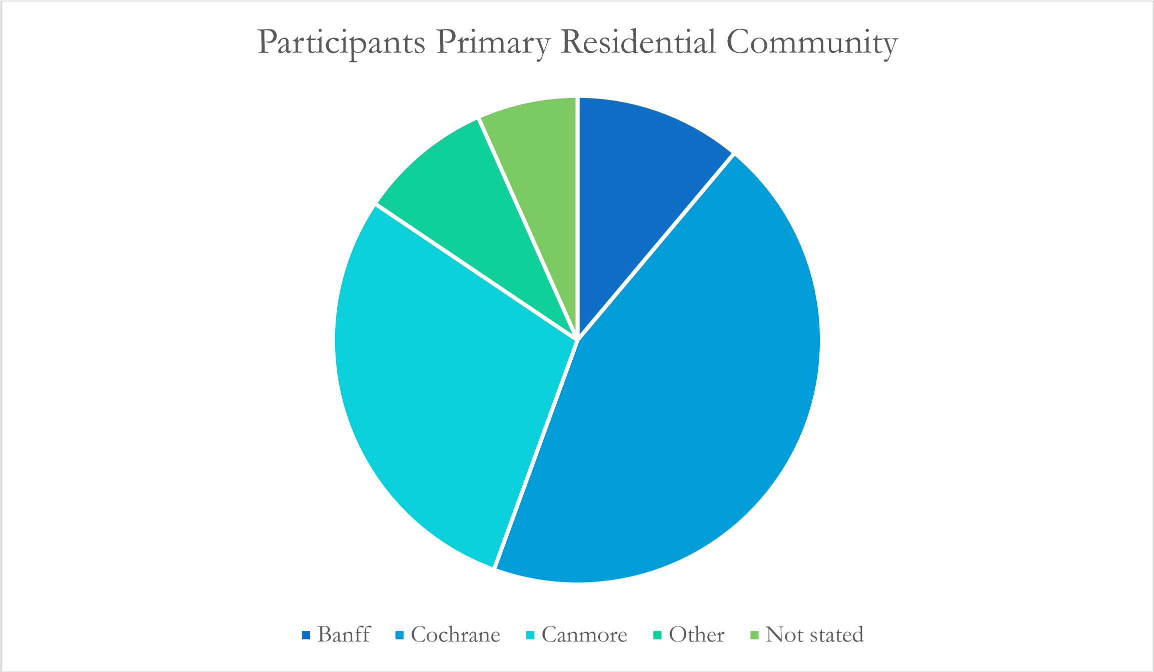

Figure 1. Reported primary residential community of participants

The “other” category was comprised of individuals from Lac Des Arcs, Exshaw, Calgary and Rocky View County. Four participants listed secondary communities of residences of Canmore, Banff and Saskatoon. Overall, most participants attended an event located within their community. Table 1. outlines attendance numbers for all six events and identifies how many participants resided in a different community.

Community event	Number of participants	Number of individuals from other primary communities
Banff 1	11	6
Cochrane 1	30	2
Canmore 1	19	1
Banff 2	4	0
Cochrane 2	16	4
Canmore 2	10	2

Table 1. Attendance of each community event, identifying individuals from other primary communities.

Demographics

Banff

Banff's population has remained stable between 2011-2016, experiencing a population increase of 3.5% (Statistics Canada, 2016 Census). In 2016, the total population of Banff was 7, 851. The average age of the population is 38, the same age as the provincial average, with 80.7% of the distribution between 15 to 64 years of age.

The age range of Banff residents who attended a community conversation was 33 to 78 years of age, with an average age of 55. A significant majority of participants from the Banff community were female (87%). Table 2 compares the average of participants from Banff to the community and provincial average.

Cochrane

Cochrane's population has increased by 45% between 2011 and 2016, this is 35% more than the provincial growth average (Statistics Canada, 2016 Census). In 2016, the total population of Cochrane was 25,289. The average age of the population is 37, with 67% of the distribution between 15 to 64 years of age.

The age range of Cochrane residents who attended a community conversation was between 42 and 89 years of age, with an average age of 64. A significant majority of participants from the Cochrane community were female (75%). Table 2. compares the average age of participants from Cochrane to the community and provincial average.

Canmore

Canmore's population increased by 12% between 2011 and 2016, this is the same as the provincial average growth rate (Statistics Canada, 2016 Census). In 2016, the total population of Canmore was 11,764. The average age of the population was 41 - three years older than the provincial average.

The age range of Canmore residents who attended a community conversation was 30 to 88, with an average age of 67. A significant majority of participants from the Canmore community were female (81%). Table 2. compares the average of participants from Canmore to the community and provincial average.

Community	Participant average	Statistics Canada average
Banff	55	38
Cochrane	64	37
Canmore	67	41
Other	59	N/A
Provincial	N/A	38

Table 2. Average age of participants compared to the average age of the population reported by Statistics Canada. Data taken from the 2016 census.

Other communities

Ten participants listed their primary community as an area other than Banff, Cochrane or Canmore, and two participants did not list a community. The age range in this group was 42 to 82, with an average age of 59. A significant majority of participants in this group were female (92%).

Participant Experiences

In the community conversations that occurred across the Bow Valley, there was a wide diversity of experience with PEOLC. Forty-seven participants identified as having a career in a health related field. A majority of participants who did not work in a health related field said they had no experience with PEOLC, even if they had supported and cared for someone as they approached end of life (EOL). Despite this, 86% of participants indicated providing some form of support for individuals or their families near the EOL. All participants were interested in learning more about palliative and EOLC for their community and increasing the supports available. There were no significant differences between the roles and experiences of participants in the communities.

Services

Services were a predominant theme in all six of the conversations. Members of the Banff, Cochrane and Canmore communities felt that the currently available PEOL services were inadequate. Communities feel that care should focus on the specific and unique needs of families and individuals as they approach end of life. Many individuals stated that they were unaware of range of services that were available and felt a need for increased communication from health care providers.

> **"It is crucial that the bad days are as a result of the illness, not the facility"**

Financial Barriers

Members of the Bow Valley community felt that financial barriers to care and supports play a large role in determining the likelihood of an individual being able to remain in their community. Because of limited access to services, additional support for caregivers is often required to assist an individual approaching end of life (EOL) to remain at home. The cost of respite care was often cited as major burden for families. Community members suggested the development of a fund to provide financial support for members of their community who could not otherwise overcome financial barriers. Additionally, participants in all communities of the Bow Valley strongly supported the enhancement of Home Care services in order to better support lower income individuals and families.

Delivery of Care

In response to the lack of services available in their community, many individuals suggested repurposing existing programs. The most common suggestions were providing accessible palliative training to existing nurses in all three communities and increasing Emergency Medical Services' (EMS) abilities beyond patient transport to providing home services. These suggestions would help address current gaps in services.

Community members felt strongly that there needed to be an increase in continuity of care and communication between care providers. One community member said *"the Rural Palliative Care team has been amazing… they have been the best addition to connect people"*.

Home Care

The community identified AHS Home Care Service as the major source of support for members of the community who were living with life-limiting illness. Many community members found that Home Care was not available enough and advocated for expanding their services. The relationship built between families and the home care team was crucial for increasing the dignity of

"Home Care is a wonderful support that keeps people in their community, but they are very understaffed."

individual's in care. Consistently having the same care team made families more comfortable and enhanced continuity of care.

Residential Hospice Care

"A hospice is not just bricks and mortar. There's a lot more to it"

Community members spoke very highly of all the experiences they had with a variety of hospices. Many individuals contrasted the environment to experiences they had with hospitals, and felt much more comfortable and better cared for. The community expressed that being in an environment that felt like home made a big difference, as opposed to the sterile environment of the hospital. They felt that hospice provided the patient with a stronger voice in their care. The privacy provided in hospice was very important to community members as it allowed families to be together as their loved one approached end of life. Concern was expressed as to whether the current provision of hospice met the diverse cultural needs of individuals and families who reside in Bow Valley communities. In any future residential hospice planning, the community felt that the facility should be as inclusive as possible. While community members had very positive experiences with residential hospice care, they felt that the current distance between their community and existing hospices was very difficult, especially for individuals who did not drive. Community members in Cochrane felt that having a residential hospice built in Canmore would not meet their needs, due to the distance between the two communities.

"The focus of [hospice] is on quality of life to the end of life… It's an environment where you can be the child, the spouse, where you're not the caregiver"

Access

The availability of services and supports in communities was identified as very important to participants. *"When people are sent to Calgary they lose their community"*. This was a significant concern to community members - when an individual has to leave their community to access services, they often feel very isolated. Furthermore, travel to another community is not only a financial burden to individuals, but also an additional stress to community members.

"When you're talking about rural palliative care, everyone is different… one size does not fit all"

Personalized Care

In regards to the delivery of PEOLC supports and services, personalized care was considered very important in all the communities. Many individuals felt this was more likely to be available if care was provided outside of hospitals. Poor communication between individuals and professional care providers was identified as a barrier to the provision of personalized care. One participant said that "doctors need to communicate with more openness and honesty to families… this provides the opportunity of choice to the patient". "It's very important to encourage people to have ideas or goals of how they would like to LIVE until the end of their life".

"We are all different… this needs to be the focus of all supportive services in the community"

Advocacy

“It’s the small things you need and it’s different for every person”

The need for community based advocacy surrounding end of life came up in all six community conversations. Individuals who had experienced a loved one dying described the experience as overwhelming and exhausting. Community members said that they learned a lot about the available supports and resources through their personal experiences, and from other people who had already gone through the process of losing someone. Individuals suggested sharing this type of knowledge could be accomplished with community networks supported by a core team of navigators. Some community members suggested that the fear and logistics of being an advocate prevented people from stepping into these roles. However, another community member said, *“whoever can advocate for palliative care patients and their families should”*. Support from local PEOLC focused groups and boards could take a leadership role in organizing advocates and navigators. Community members suggested this type of resource should be available from the time of diagnosis. Often beneficial resources exist and individuals do not know how to access them. The community felt that the role of an advocate should go beyond system navigation to encompass volunteer coordination in the community.

Supports

Community members often stated that when a loved one is approaching end of life, they are often too overwhelmed to know what they need or how to access support. Building on existing community networks as a means of support could help increase the capacity for community members to care for each other at end of life. Community members felt that this could be facilitated by volunteers who could provide mentorship for individuals and families regarding access to supports within the community. This type of resource could also potentially improve communication between the individual and professional health care providers.

> **“Support groups are so important… I wish we had talked more about it – it would have made it easier to accept and prepare for [my loved ones] death”**

Volunteers

Discussions occurred surrounding what role volunteers might have within the community. Community members suggested reaching out to other boards and engaged community groups for direction and support on how a volunteer program should look. A barrier for some potential volunteers was the fact that volunteer training occurs in Calgary. Many community members expressed a desire to have training programs for volunteers in their communities that took place over a longer period of time than current courses. Adjusting the training to better meet communities’ needs could greatly increase the PEOL supports available in local communities.

Caregivers

“Sometimes you’re so busy caring, that you don’t have time to grieve”

While the experience of caring for someone as they approach end of life is very rewarding, it can also be very stressful. Having more accessible respite care options would provide needed help for caregivers. Many community members also suggested that having supports provided, like meals, mowing the lawn and doing errands, would make a big difference. Supports like these take some of the stress off caregivers and allow them to be with family members while also giving them time to grieve. Community members from Cochrane found the program that Family and Community Support Services (FCSS) runs for caregivers very valuable. This course focuses not only on how to care for someone as they approach end of life, but also on the mental and emotional aspects of being a caregiver. One community member said *“we need someone with the knowledge and experience to show us the tricks and supports to make life easier*”. Caregiver courses, such as the one provided in Cochrane would help achieve this while also building peer support networks within the community.

Community

Participants felt that community resources need to be well established and readily available. Many people felt lost and overwhelmed when their loved one was confronted with a life-limiting illness, and they did not know where to find guidance. They felt uncomfortable asking for help because they did not know what they needed and/or did not want to be a burden on their community. Conversation participants felt that it was important to grow existing networks in order to help support each other in the community. Creating a community network of care would recognize the knowledge and experience of locals

“Palliative care is not about building a house, it’s about caring for each other” and enhance the community’s capacity. Many participants felt that “this should largely be an informal network, so that the care is strongly based in love and compassion”.

Culture

While communities want to grow their “compassionate community”, many were concerned about barriers such as language and isolation. When working towards building a network of volunteers and increasing the networks between community members, inclusivity should be held core to the planning and outreach. Many community members suggested this could be encouraged by having a diverse group of people on boards and committees including an array of cultural groups. Not only would this make PEOLC supports more holistic, it would also provide the opportunity to learn from different cultures and groups within the community.

Grief and Bereavement

Grief and Bereavement was an important theme that came up in all of the community conversations. Currently, available services are often not convenient to access and are primarily advertised solely to the individual’s close family. Community members suggested having open peer support groups in the community would help them work through their grief, and help them to feel more connected to the community. The communities felt it would be valuable if these support networks existed before the death of their loved one. This would provide access to established relationships leading to less isolation. Many community members felt that religious groups were the strongest form of support within the community and felt it was important that people who did not belong to a specific religious community received the same level of support. Participants felt that the community needed to

> **“We shouldn’t be waiting until death to talk about grief. We should start talking about it in the context of all losses so that there is less fear surrounding it”**

come together to respond to the need for grief and bereavement support to foster more culturally appropriate supports for all members of the community. One suggestion to increase community resources was to host public talks on PEOLC to support discussions and awareness on the topic.

Education

Throughout all three communities, many people felt that an important role of boards and other PEOLC groups was to increase awareness and supports through education. Special attention was noted to increasing attention in all demographic groups and not just individuals actively involved in some way with PEOLC.

> **"Palliative care isn't about sadness, it's about living. We need more education & should talk more with friends & family. Death & dying can and should be positive"**

Stigma

> **"Palliative care is not about sadness, it's about living"**

Community members felt it was essential for PEOLC groups to foster discussion and awareness surrounding PEOLC. Many community members were confused by what palliative care was until they heard stories and examples. It was suggested that having individual's share their stories could be a powerful tool in educating the community. The community felt there was a strong stigma surrounding death and because of this, no one wants to talk about it. Community members also often felt this stigma from doctors. Throughout the community conversations, community members stated that, *"the culture surrounding death* *needs to change… we need to become more comfortable talking about death and dying"*. Death *"is a very intimate experience… childbirth is talked about in a positive way, but we don't talk about death or dying in the same way, even though it is often an honour to be a part of someone's experience"*. Community members felt it was important to celebrate someone's life when they die in the community in a similar way that we celebrate bringing a new life into a community. *"We live in a death denial culture…. We need to normalize death through discussion"*. The stigma surrounding death and dying could be addressed through educational nights surrounding death and dying, as well as other awareness campaigns.

Awareness

"A big part of education is getting the information out"

There is often a lot of confusion between the different services available and the terms used surrounding PEOLC. Many community members suggested that family doctors would be a great resource to increase awareness and help navigate end of life as they hold a respected role in the community and have an established relationship with individuals. Community members felt that, overall, family doctors are lacking an awareness of services. Doctors should be provided accessible training so that they can be an even more valuable resource for their communities. Participants mentioned increasing awareness around death and dying by creating an online library with e-books, resources and podcasts. The community hoped that creating awareness surrounding PEOLC in the community would foster conversation. Addressing the taboo surrounding death and dying makes advanced care planning easier and increases the supports available to individuals approaching EOL and their families. Often, we neglect to include children in these discussions and recognize how decisions affect them - the community felt this culture needed to change. Specialized support and education for children is critical and further discussion should occur

"By the time someone is palliative, it's not a good place to make decisions. [These decisions] need to be made proactively"

within and between communities to address awareness of death and dying. Being inclusive with education and awareness strategies has the potential to strengthen communities to come together and own PEOLC in their communities.

Community Differences

"Palliative & end of life care affects everyone. We need to come together"

Overall, the priorities and recommendations from all three communities were very similar. This is especially true of Canmore and Banff - this could however be in part due to the small number of participants from Banff. Two significant discussion points unique to the conversations in Cochrane came up. Firstly, the services that FCSS provides are very valuable to the community. This extends to PEOLC because FCSS acts as a network for support and resources. Second, community members in Cochrane felt that while increased resources for PEOLC were needed in the Bow Valley, having a hospice in Canmore would not serve them any better than the existing hospices in the Calgary area. Participants in Cochrane expressed desire for a hospice facility in Cochrane. While all the communities that make up the Bow Valley are distinctly unique, the commonality of response represents the importance of coming together to collectively advocate for increased PEOLC resources.

Conclusions

"It's about celebrating people's lives"

All three communities across the Bow Valley felt that they needed increased supports surrounding PEOLC. Often the conversation began with discussion surrounding the need for services, but always shifted to the importance of coming together as a community to support each other.

The development of educational activities for community members and professional caregivers was identified as an important need for the communities. Improving awareness in these areas would work towards addressing the stigmatization of those who are approaching the end of living and was seen as action areas that community organizations could address.

Bereavement support was identified as a critical need for communities. The isolation experienced by bereaved loved ones is a major source of suffering, and should be a priority issue.

Community members would like to see boards and groups related to PEOLC create volunteer programs and navigational tools to enhance community based support. This would not only increase the community's capacity for its members to care for each other, but would also increase awareness surrounding death and dying. The community believes these supports should be in place from the point of diagnosis to after death, to foster improved grief and bereavement resources. Hosting community events would help increase awareness of PEOLC issues in the community. Community members felt strongly that educational programs should be accessible and relevant to all demographic groups of the community. The community hoped that by working to achieve these desires, the community could come together and recognize that PEOLC is *"about celebrating people's lives".*

While the communities of the Bow Valley share common needs and goals for addressing PEOLC, there are also significant differences among communities regarding local knowledge and culture. In addition to the differences in local cultures of communities, there are significant variations in health services resources between communities. Community palliative care leaders will have to continue to develop collaborative relationships with other stakeholders (local physicians and health providers, AHS, educational institutions, government ministries, etc.) and among the communities of the Bow Valley. Developing and nurturing these relationships will promote the identification of the health services that would be required as well as the issues that only communities themselves can address. This will ensure that community members are able to remain not just in their homes, but also as part of their community for as long as possible as they approach the end of living. Achieving this goal, will enhance the lives of all members of Bow Valley communities.