



Hospice Palliative Care Community Consultations Report January- March 2015

Thank you to Our Cowichan Health Network, for small project funding which when paired with some support from Shared Care allowed Hospice to facilitate 5 community meetings in Lake Cowichan, Ladysmith, Shawnigan Lake and two meetings in Duncan. About 100 people participated at these sessions to talk about hospice palliative care. A subsequent on-line survey received responses from 78 people, including 23 who had had direct experiences of palliative care of a relative in our community. Detailed records of responses are at the end of this report.

Both workshops and surveys were great opportunities for thought and conversation about end of life and bereavement care, which we defined as whole person care that attends to the physical, social, emotional and spiritual needs of the dying and their families. We shared information about the services that currently exist that many were not aware of: including home care, the Palliative Benefits program, EI Compassionate Leave, the new pain and symptom consultation team, and the 3 existing end of life beds at Chemainus and Ladysmith. Then we asked people about their experiences caring for a dying relative into bereavement and we asked what they saw as needed improvements to our system of care.

Some themes arose, including much positive feedback on the care that individuals in the system were able to provide, as well as many suggestions for improvement. We learned:

- It is important for **the needs of the whole family** to be considered as they take care of a dying person, so that family members can continue to care and to regain equilibrium and their own health after a death
- A **plan for care** is often lacking, and often family members feel that they must manage all aspects of their loved one's care

Cowichan Valley Hospice
Caring for families through advancing illness and grief
Since 1981



- **Management of pain and symptoms was not consistent** and often hampered by an apparent lack of knowledge of palliative care or misunderstandings about the use of opioids.
- It is vital that physicians and nurses and care aides receive **palliative care training** and that patients have access to specialist care when needed
- Care in the hospital is hampered by **overcrowding**, resulting in people dying in four bed wards without privacy or dignity
- **Palliative care must respond to the cultural and spiritual needs of the dying** and their families. **Only 21 percent of those who responded in the on-line survey said that these needs were attended to: all, most or even half the time.**
- There must be **respite for those caring at home** in order to avoid burnout
- **Advance care planning conversations** are very important both to families and to medical practitioners, to avoid unnecessary and invasive procedures
- The need for **timely clear information** for patient and family about the likely progression of the disease, the care and other resources available, planning and legal tools etc.
- And a resource that would support better care in many of the areas described: the need for a dedicated hospice facility with specialized staffing and room for family and for life to happen even through the final hours

The information gathered will serve as a guide the growth and development of hospice palliative care for our whole community through end of life and bereavement, including the development of Cowichan's hospice house.

Respectfully submitted,
Gretchen Hartley, MSW
Cowichan Valley Hospice
September 10, 2015



END-OF-LIFE CARE IN THE COWICHAN VALLEY: FINDINGS FROM THE COMMUNITY CONSULTATIONS

Prepared by:

Gretchen Hartley

Executive Director
Cowichan Valley Hospice Society

Lori Wagar

Project Manager
Shared Care, Cowichan Valley

Karen McDougall

Office Support/ Reception
Cowichan Valley Hospice Society

June 23, 2015

METHOD

Between February 10th and February 17th, 2015, Cowichan Valley Hospice Society led five community consultations in the Cowichan Valley. Meetings were held throughout the Cowichan region with one session in each community including Lake Cowichan, Ladysmith, Shawnigan Lake, and two sessions held in Duncan. Themes for discussion were identified through initial conversation with family caregivers and a focus group of caregivers known to Cowichan Valley Hospice Society was held, on February 6th. During the consultation participants were organized with 5-8 people per table. Participants were each asked a set of predefined questions by a table facilitator and responses were recorded by a note taker at each table. Cowichan Valley Hospice Society took a lead role in initiating, planning and leading the community consultations with funding assistance was providing by Shared Care, Cowichan Valley and Our Cowichan Community Health Network.

FINDINGS

A total of 98 community members attended the community consultations and 8 attended the initial caregivers' focus group. The attendees at the community meetings represented a diverse group of stakeholders including:

- Caregivers and family members,
- Health professionals, physicians, and other clinicians,
- Volunteers involved in end-of life care, and
- Community members with an interest in end of life care.

Of the caregivers present, many had experienced the provision of end of life care within Cowichan Valley. Other care caregivers reflected on end of life care they experienced outside Cowichan Valley including experiences within other health jurisdictions in British Columbia, health jurisdictions across Canada and even experience internationally. Furthermore, caregivers had participated in end of life care to a loved one within different health settings: at home, in acute care in hospital, in extended/residential care and within a palliative care unit.

EXPERIENCES REPORTED BY SETTING

Participants reported a variety of experiences with end of life care within Cowichan Valley and elsewhere. The experiences are sorted by setting and by whether they are seen as positive or negative.

SETTING	POSITIVE	NEGATIVE
Community/Home	<p>Nice to be within own culture (i.e. First Nations) surrounded with family</p> <p>If symptoms can be managed at home its done well</p> <p>Good management of medication to balance pain & lucidity, nurses stayed when patient passed into a coma</p>	<p>Not enough home care available</p> <p>Difficulty with pain/symptom control</p> <p>Pain/symptom control changed personality of patient</p> <p>Hard on caregiver, stressed and not supported</p> <p>Private care is costly</p> <p>Pain/symptom control difficult at night</p> <p>Need a revamp of community services to provide: consistency of care, more complete full care, support for family members, appropriate care for young people</p>
Acute Care	<p>Was good 15 years ago in Duncan</p> <p>Received excellent care in PCU in St Paul's in Saskatchewan:</p> <p>Great model for care with big rooms that accommodated family with washrooms</p> <p>Family encouraged to attend weekly care planning meetings, there was a kitchenette available for family so they can eat together and are encouraged to stay overnight</p>	<p>Lack of privacy and dignity</p> <p>Lacks the comfort of home</p> <p>Overcapacity in hospital</p> <p>Chronic care focus</p> <p>Lack of dedicated beds</p> <p>Lack of training,</p> <p>No time to do palliative care</p> <p>Family required 24/7 to monitor care</p>
End of Life beds in Residential Care/Residential Care beds	<p>If not complex, care is good</p> <p>Impressed with (EOL) bed in Chemainus</p> <p>Lodge on 4th went well for patient referred by Mental Health: rapid placement & helpful coordination, needs were not complex or could not</p>	<p>Far away for some seniors to drive</p> <p>End of life beds are available but no complex care</p> <p>Poor monitoring and staffing levels</p>

	<p>have stayed Caregiver comforted to know there was a nurse to monitor 24/7 Good management of pain & agitation Every LTC facility provides end of life care, this is not recognized</p>	
Residential Hospice	Good experience in Victoria Hospice	

The remaining findings are sorted into the themes identified within the questions asked of participants.

PAIN & SYMPTOM CONTROL
<p>Palliative physician & palliative nurse provided good pain control Palliative physician helped with pain control so that patient could go home Caregivers should not have to advocate for pain control It is hard for the family to know if a patient is in pain Family doctors were reluctant to provide pain control in frequent & large enough doses Told morphine would speed death Every LTC facility needs education for staff on palliative symptom management Need ongoing pain & symptom management education for home care givers and health care staff Physician would not give codeine or Demerol and said that double doses would not help Wife had to use porta-cath for pain as HC nurse was not familiar with its use Had to drive repeatedly from Lake Cowichan to the Cancer Clinic as pain was not controlled Sometimes patients appeared overmedicated, patients' personality was masked Patients' individual needs not considered Lasting memory of poor pain control had a devastating impact on family</p>
COORDINATION OF CARE
<p>Family physician coordinated Family physician was too busy Nurses in residential care facilities Family and friends Private home support Palliative Response Team at Hospice Mental Health coordinators for transfer to residential care Coordination of care was non-existent Need to for care 'team' leader or navigator Caregivers may not even know the questions to ask, they are in trauma It is not clear whose responsibility it is to educate the client Need for caregiver respite is not considered</p>

COMMUNICATION WITHIN CARE TEAM

Communication between shifts and between doctors and nurses is disconnected
Family and friends were not involved in communication
Absence of team meetings
Discharge planning is not communicated and continuity of care suffers Patient moving setting of care may lose contact with GP
Communication was not consistent or non-existent
Without communication care cannot be coordinated
Family told to dial 911 when care could no longer be managed at home
Communication book worked well, it was kept at home and used by family and care navigator
GPs may not know about hospice services or discourage their use

INFORMATION NEEDS

Information needs to be simplified and occur right before it is needed
Lack of information on services available, end of life beds, lack of hospice beds (assumed they existed) what to expect through illness, what to do at time of death, connection with funeral resources, hospice for palliative support
Cultural spiritual and linguistic needs and barriers should be considered
Community education and awareness about end of life care and services should take place
Advance care planning education needed, My Voice documents are not simple
Family doctors and other clinicians need a better understanding of hospice and hospice services
Need support for patient at the time of prognosis, referral back to GP
When staff are rushed they do not have time to support provide caring & compassion for family

WHAT WAS MISSING FROM CARE

ASPECTS OF CARE

End of life care for dementia
Space for culturally appropriate death with dignity
Holistic care for a diverse population
Spiritual support
Advance Care Planning
Information about Hospice palliative support
Palliative care coordinator or navigator
Options to avoid many trips to hospital by ambulance/ care in emergency
Good personal care: put in hearing aid, wash face, treat with respect, dignity
Continuity with home care aides
Too much intervention in final stages of dying
GPs not using palliative specialist unless requested by HC nurse
More complete & consistent care, without having to hire private care
Services for dying and for grieving children
Humour
Music

FACILITIES

Care facility with a palliative room set up for patient and family's needs
Hospice facility/ that services all ages
Dignity and respect missing from 4 bed ward in hospital
Residential hospice, designated palliative beds outside hospital
In CDH and residential care: a place for family to stay overnight, 24/7 food and coffee

SUPPORT FOR CAREGIVERS

Information about Hospice grief care
Financial support for caregivers
Emotional support for family esp. caregivers
Support to care at home
Who helps the helpers in care homes where 10 people may die in a week?

WHAT WORKED WELL

EXCELLENT PATIENT EXPERIENCE:

Palliative approach to medication

Excellent nurses and care aides

ACP in place

Choice in care

Positive attitude on the part of patient

Privacy for individual family members to spend time with patient

Hospice Vigil team with dying person when family could not be there

Red Cross was helpful and proactive (equipment for home care)

BC Cancer Agency programs for patient and family

Opportunity to be human to the last day: visits with grandchildren, pets, finding 50's music, finishing unfinished business

Family took patient to see palliative care unit so that she could see how it would be better for her children in their young 20's: cozy, pets allowed, food for children

Home support

Wonderful death in emergency where senior was offered the choice to extend his life by three weeks, family encouraged him to let go, it fit his religious faith, oxygen was removed and he passed peacefully with family there

LOCATION OF CARE:

Good experiences in: PCU, residential care facility, hospice residence

NRGH PCU provided good care, however lost support of gp, who did not have privileges in Nanaimo

Compassionate staff

Chemainus facility provided good communication between staff & family, a great room with a private bathroom, great community support

Cairnsmore provided beautiful care and tremendous support

Sunridge is homey, relationship with staff, even though they change often

SUPPORT FOR CAREGIVERS:

Good communication and information for family

Space for and participation of families in care

Family carers with the confidence to direct care can do an excellent job

Family Caregivers' Society

On-line Caregivers' support

Encouraged to have family conversation with dying person: "It's okay to die"

Hospice bereavement group

One on one grief counselling with Hospice

ADDITIONAL RECOMMENDATIONS

Throughout the community consultations, participants made a variety of recommendations on how to improve end of life care in the Cowichan Valley, those not mentioned above include:

SETTING	RECOMMENDATION
All settings	<p>Create a package of info with forms about services, benefits; what to expect with death at home, services available</p> <p>Improve community education through: newsletters, brochures in physicians' offices, seniors centre, elder college, library, churches, column in newspaper, ACP training, web, addressing death denial</p> <p>Identify a designated person to navigate and coordinate care/ patient navigator/case manager across settings</p> <p>Develop political understanding and advocacy: better care at a better price is possible</p> <p>Improve the frequency and consistency of communication between care team members</p> <p>Coordinated care team using a daily goals of care approach</p> <p>Develop leadership for end of life care and related services in Cowichan</p> <p>Offer ongoing physical, financial and emotional and spiritual support for caregivers</p> <p>Education of employers: re: return to work after a death</p> <p>Develop age-appropriate services for younger populations</p> <p>Provide more ongoing palliative training for home care, physicians, hospital staff and caregivers, "confidence to give that higher dose"</p> <p>Earlier conversations with patients about prognosis, likely disease progression, potential for palliative approach</p> <p>Reduce unnecessary procedures performed on palliative patients & medicalization of dying</p> <p>Support dignity, respect and health of whole family including elderly caregivers</p> <p>24 hour crisis information line for caregivers (exists)</p> <p>Training for first responders</p> <p>Registration of ACP</p> <p>Awareness that an older generation may not self-advocate</p> <p>Right to die in dignity in a location of one's choosing</p> <p>Support for caregiver and all family as needed after a death</p> <p>Focus on care needs of those who live alone and have no family nearby</p> <p>Need to understand the billing process to develop advocacy for palliative care</p>

Community/Home	<p>Provide comfort care for patients in their home</p> <p>Expand pain and symptom management consult service available 24/7</p> <p>RN phone check -in</p> <p>Respite for caregivers, in and out of home</p> <p>Offer alternative health resources to patients and their caregivers (i.e. TT; Reiki)</p> <p>Emotional support for caregivers before and after a death (hospice)</p> <p>Support for care at home that paralleled level of care in hospital</p> <p>Alternatives needed if family is too tired, caregiver is aged or there is no one else in home</p>
Acute Care	<p>Create dedicated palliative care space including space for family and friends when patient is in hospital</p> <p>Currently acute palliative care beyond scope of home care may be better provided by Victoria Hospice than at CDH</p>
End of Life beds in Residential Care/Residential Care beds	<p>Educate clinicians so pain and symptom management can occur in residential care facilities</p> <p>Need hospice beds</p> <p>Dream facility would have 24/7 beds, care up to 20 beds, suction, O₂, C pap, space for belongings, sacred space/cultural room, wifi/speaker system, counsellors, pharmacist, education and practical approach</p>

CONCLUSIONS

The community consultations provided an opportunity for the members of the communities within Cowichan Valley to express their experiences, concerns and ideas about end of life care. A significant amount of valuable information was collected and will be used to inform the planning of palliative care services moving forward.



Community Consultation on Hospice Palliative Care 2015: Table Facilitator Information

Please introduce yourself and the recorder

Introductory comments:

We have about an hour and a half to talk, and we will take a 15 minute break in the middle.

We want to hear from everyone, and we trust that people will share the floor and be respectful of other's point of view.

We do know that discussing these topics may bring up strong emotions for some. If the conversation becomes too uncomfortable for you please feel free to take a little break or take some time out to talk to a hospice person.

We will be recording details without any identifying information about the person or individual care providers involved. We ask you to please respect the confidentiality of any personal stories that you hear here today.

We want to understand more about the care that people receive here in the Cowichan region, but we also want to hear of things that worked **well** in other settings.

Questions:

1. Please introduce yourself by first name, and let us know whether you were involved with the care of someone dying, in which community (cvrd or not?) and in what capacity? (family member, professional, volunteer) (*If not they may want to share their reason for an interest in hospice palliative care.*)
2. Where did the person die? (at home? In hospital ? etc) Was this where they wanted to be? What determined this location?

3. Were their pain and other symptoms managed well for the most part?
4. Who coordinated the care that they received?
5. How was communication between members of the care team (family, physician, pharmacist, nurses, care aid etc.) ?
6. Did the patient and family get the information they needed at the right time?
7. What was missing from the care that people received?
8. What worked well?
9. What do you think can be done to improve care for the dying and their loved ones in the Cowichan region?
10. Any last comments or thoughts? (*do a round of closing comments*) (*one word about what is most important for care in our region in the future works well*)

We will gather together after and thank people from the front and invite them to stay to complete the community survey if they wish.

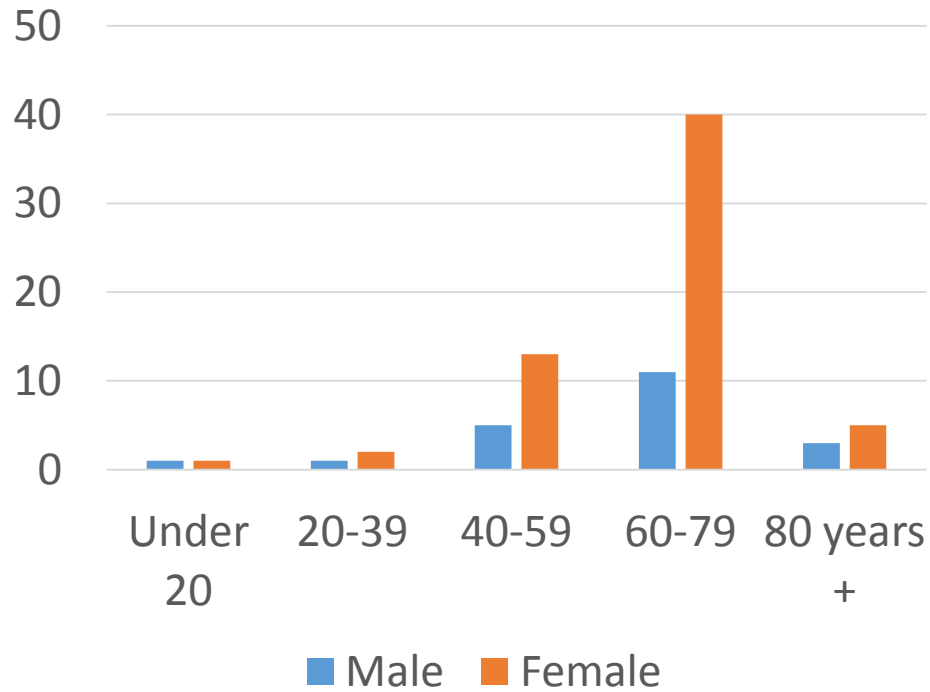
After the group ends, please take the time to review the notes together with the recorder to ensure that they are accurate and legible too!



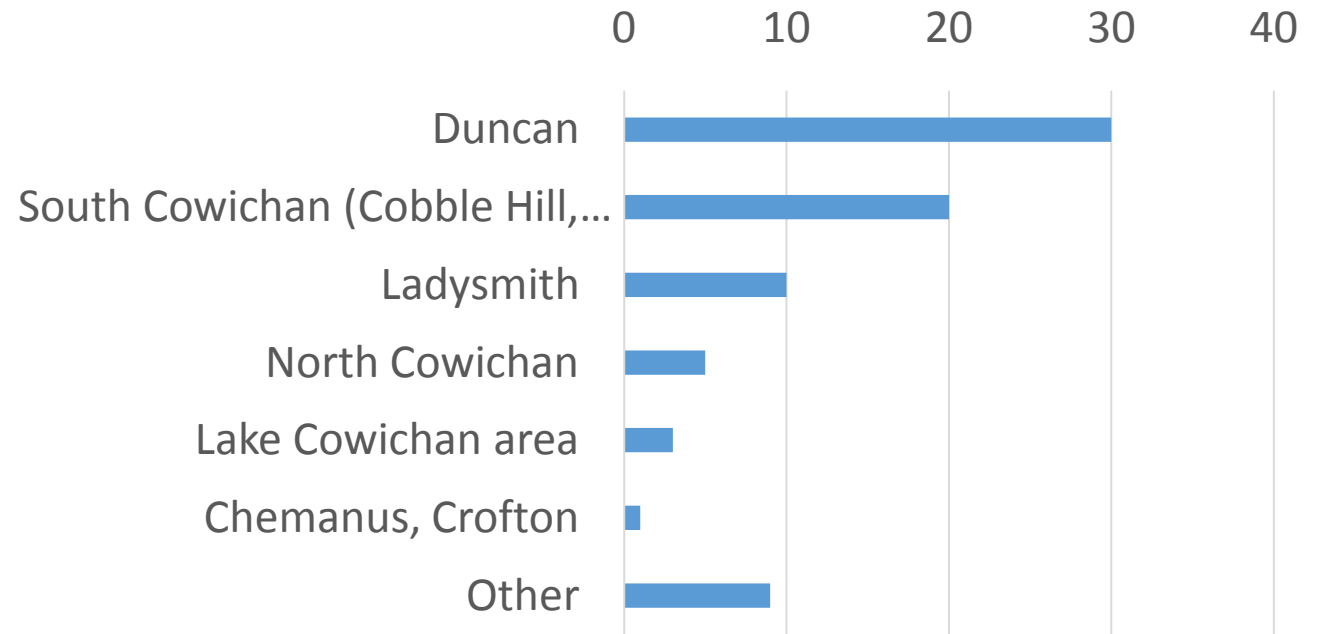
Cowichan Valley Hospice Palliative Care Survey



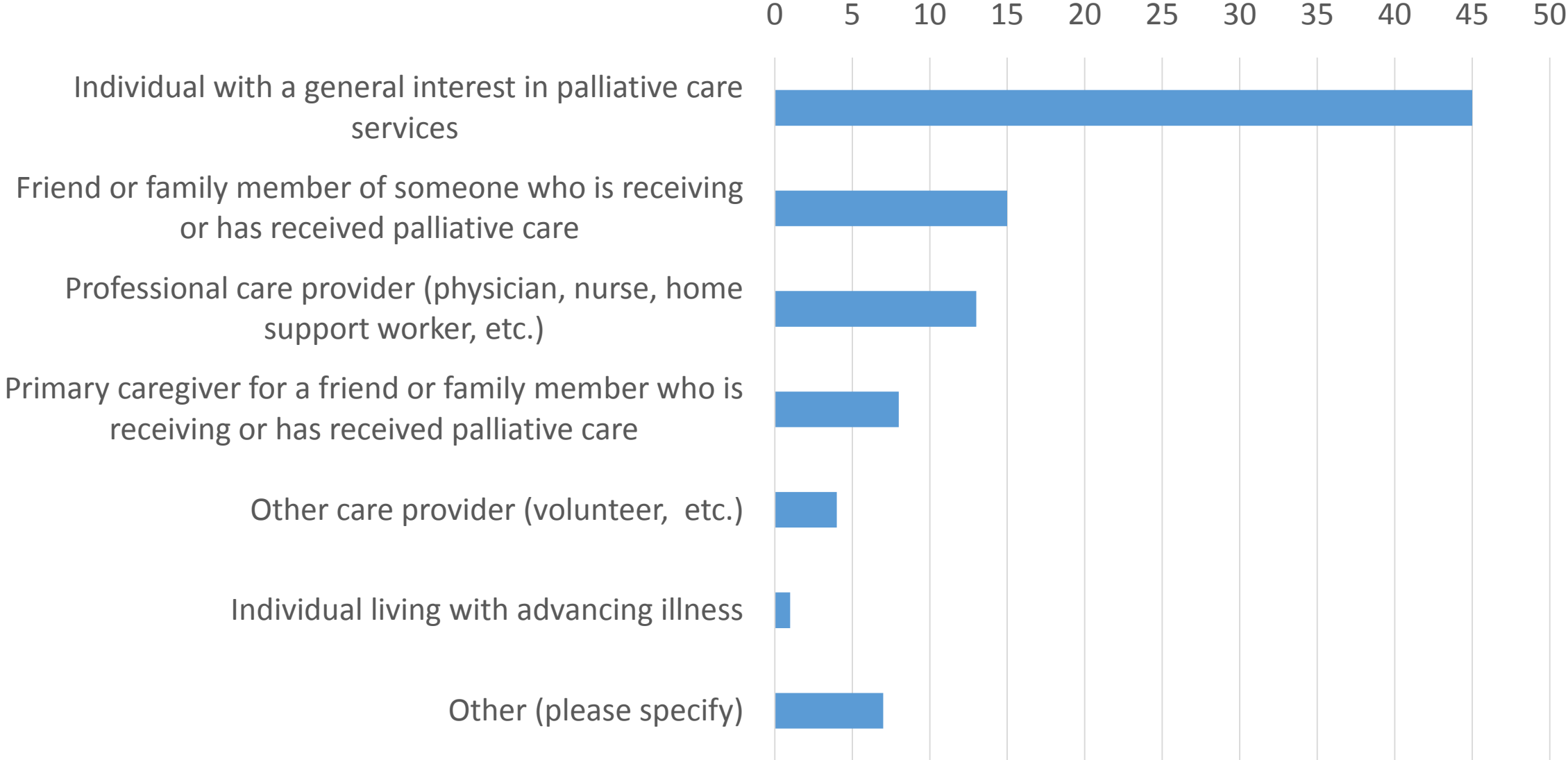
Respondent Age and Gender



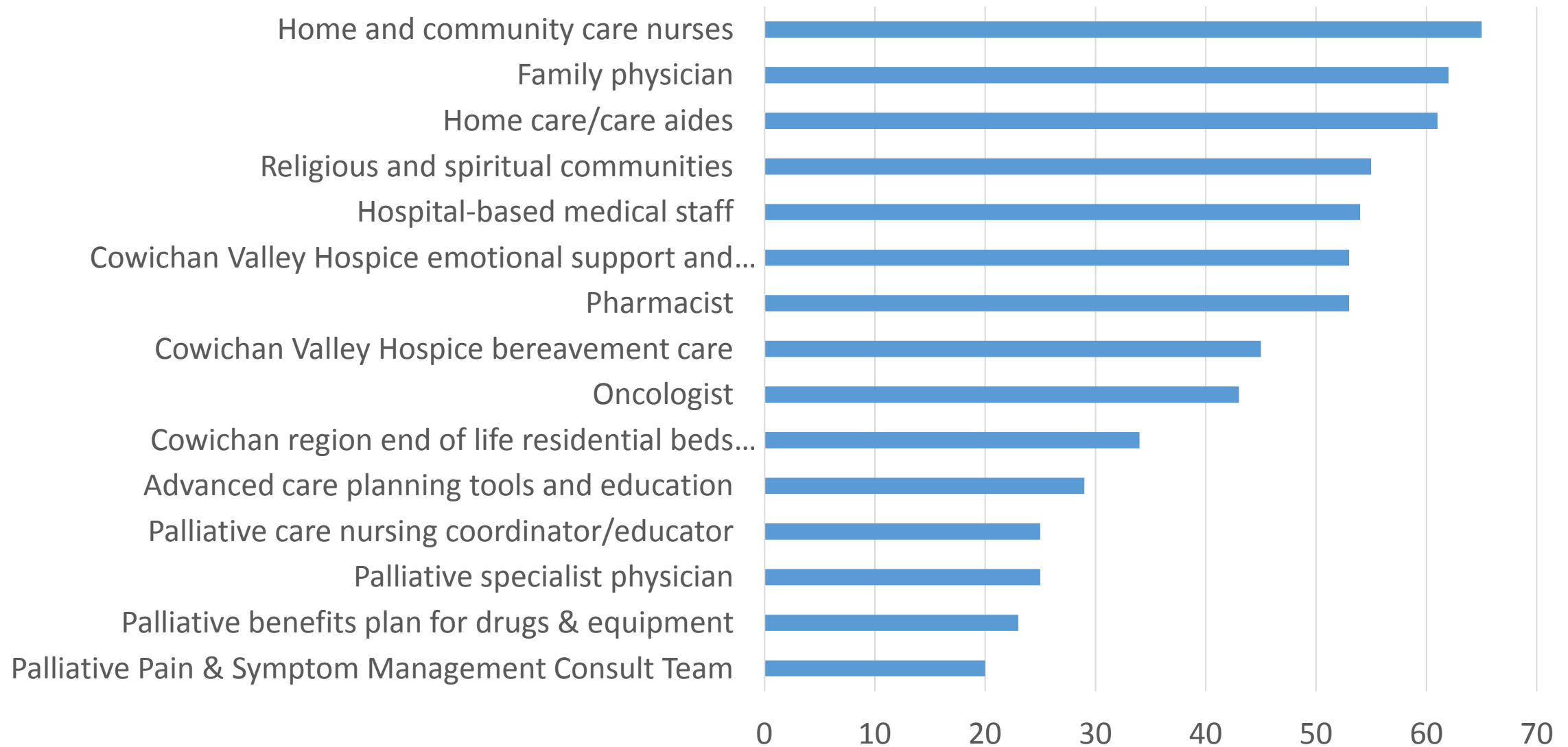
Respondent Location



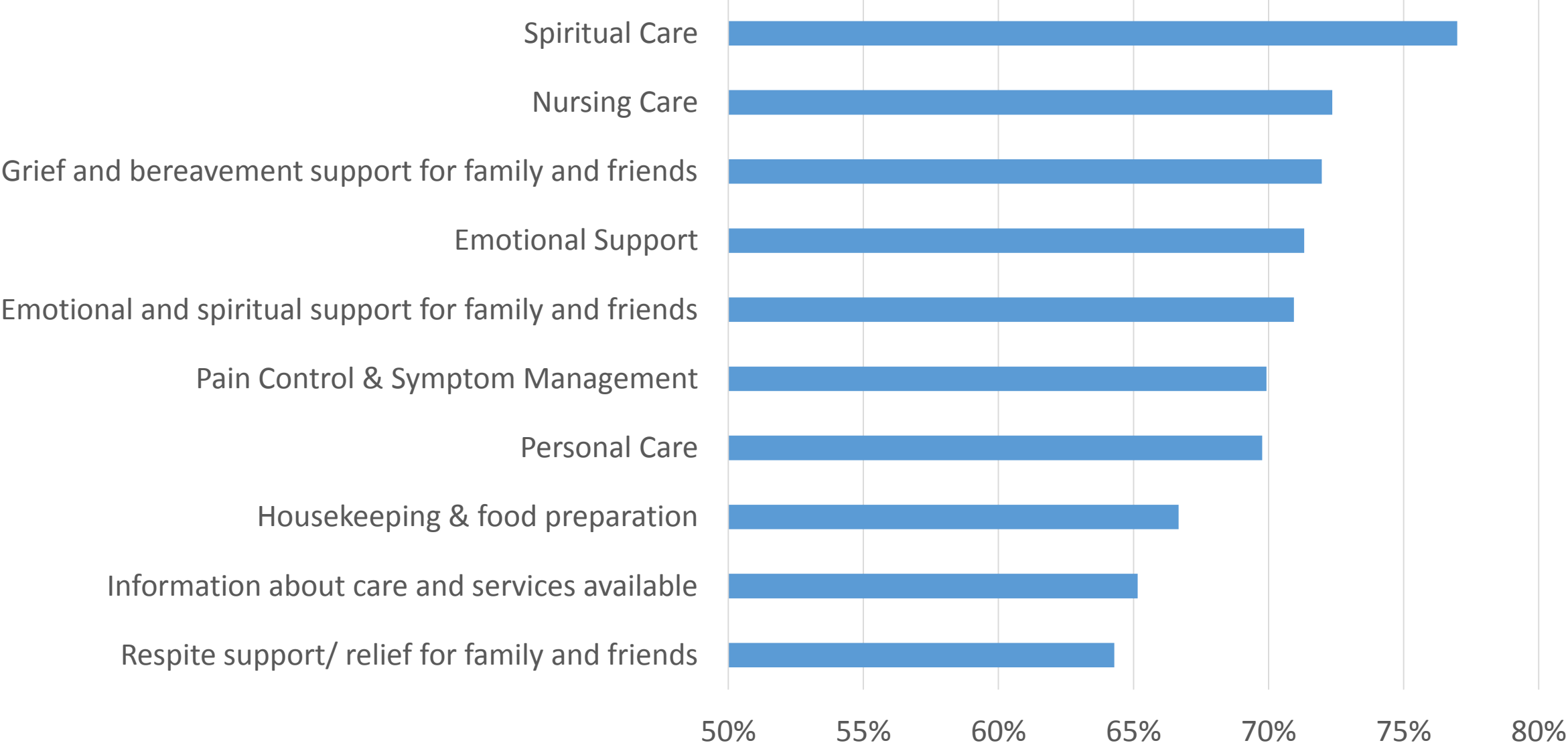
Which of the following best describes your circumstances?



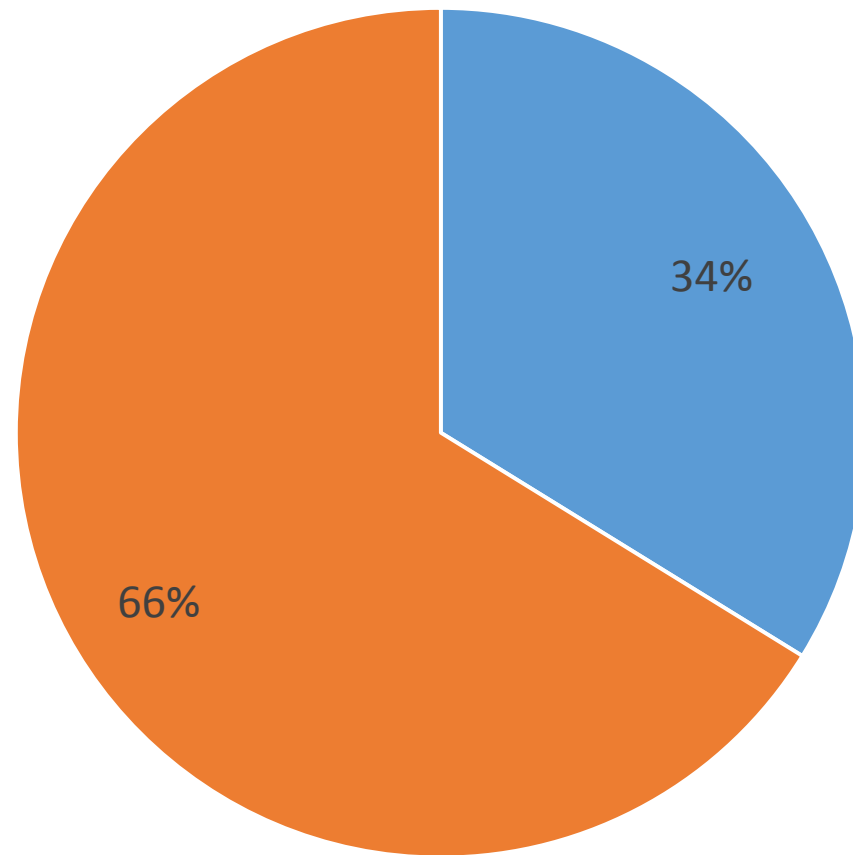
Which of the following hospice palliative care providers/services are you aware of in the Cowichan region?



In your opinion, how well are the following needs of people living with advancing illness currently and their families being met in the Cowichan region?

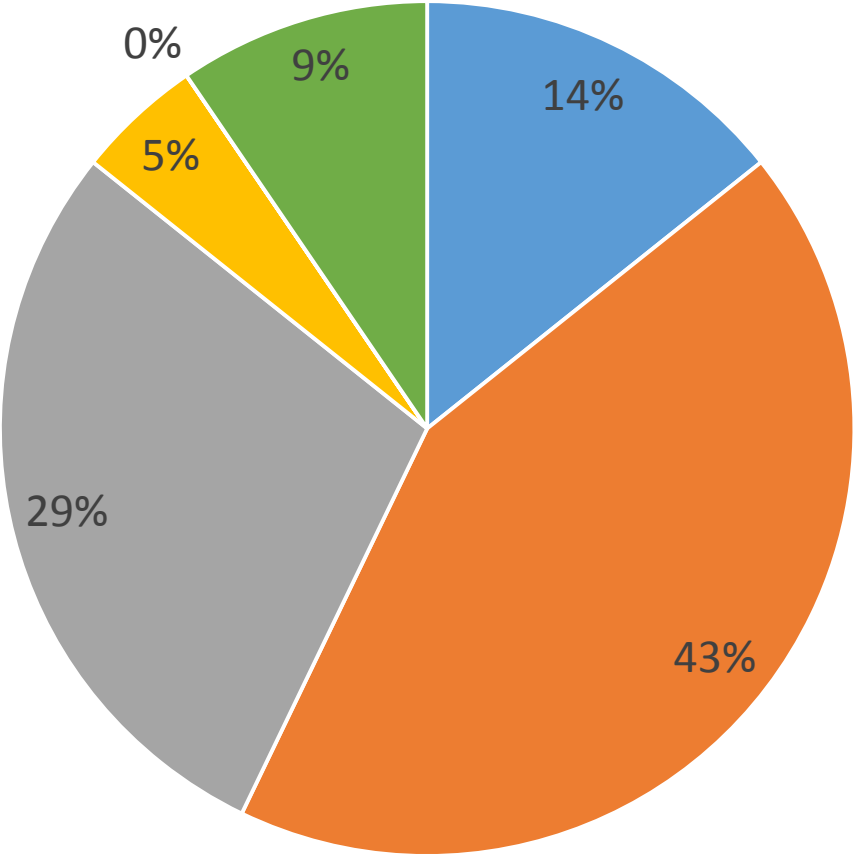


Have you experienced aspects of Hospice Palliative care in the Cowichan region as someone with an advancing illness or as a care-giver for someone you know or family ?



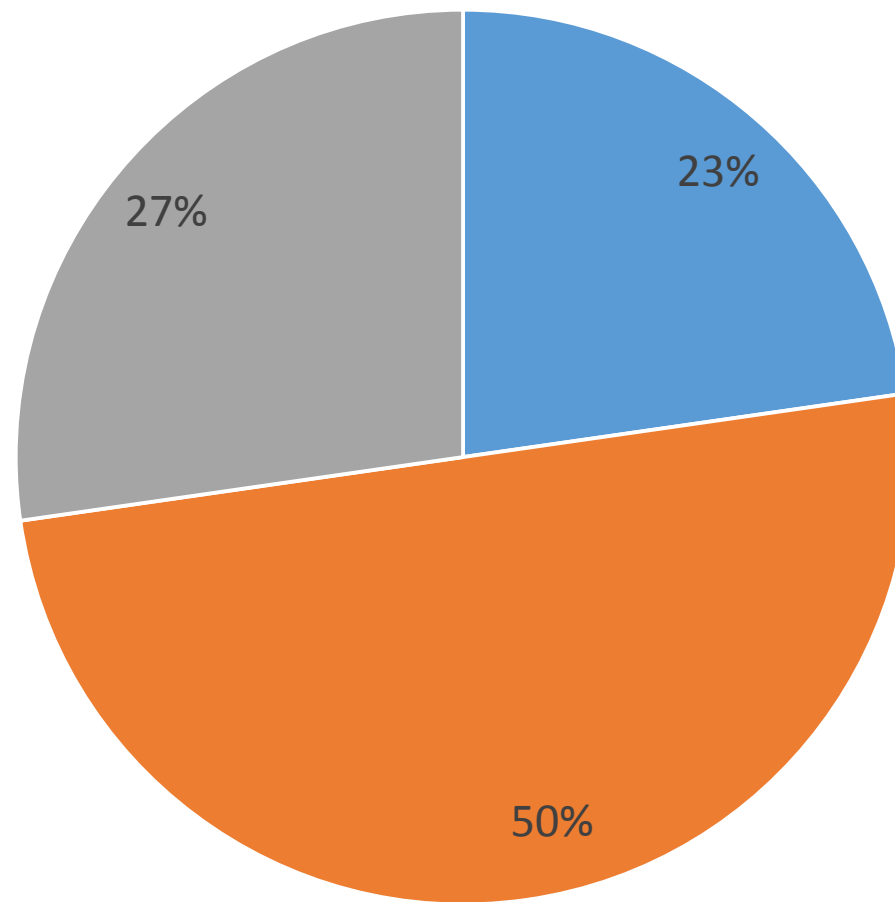
■ Yes ■ No

Were pain and other symptoms controlled to the satisfaction of the person receiving care?



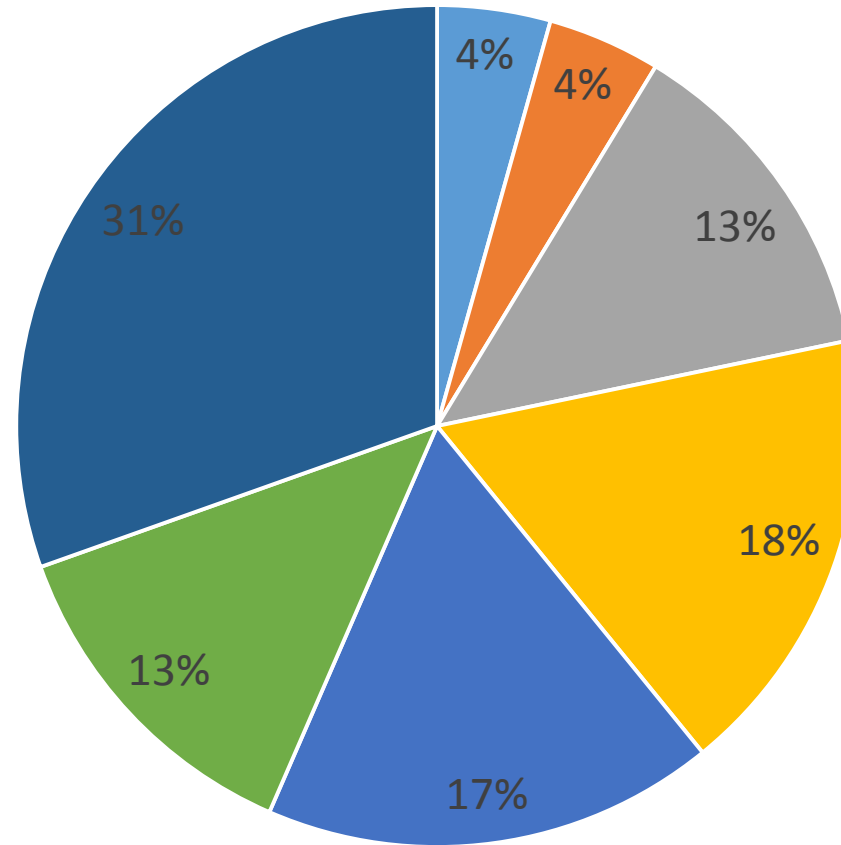
■ Always ■ Most of the time ■ Half the time ■ Rarely ■ Never ■ Other

Was a plan for care developed, based on the needs identified by the person living with advancing illness?



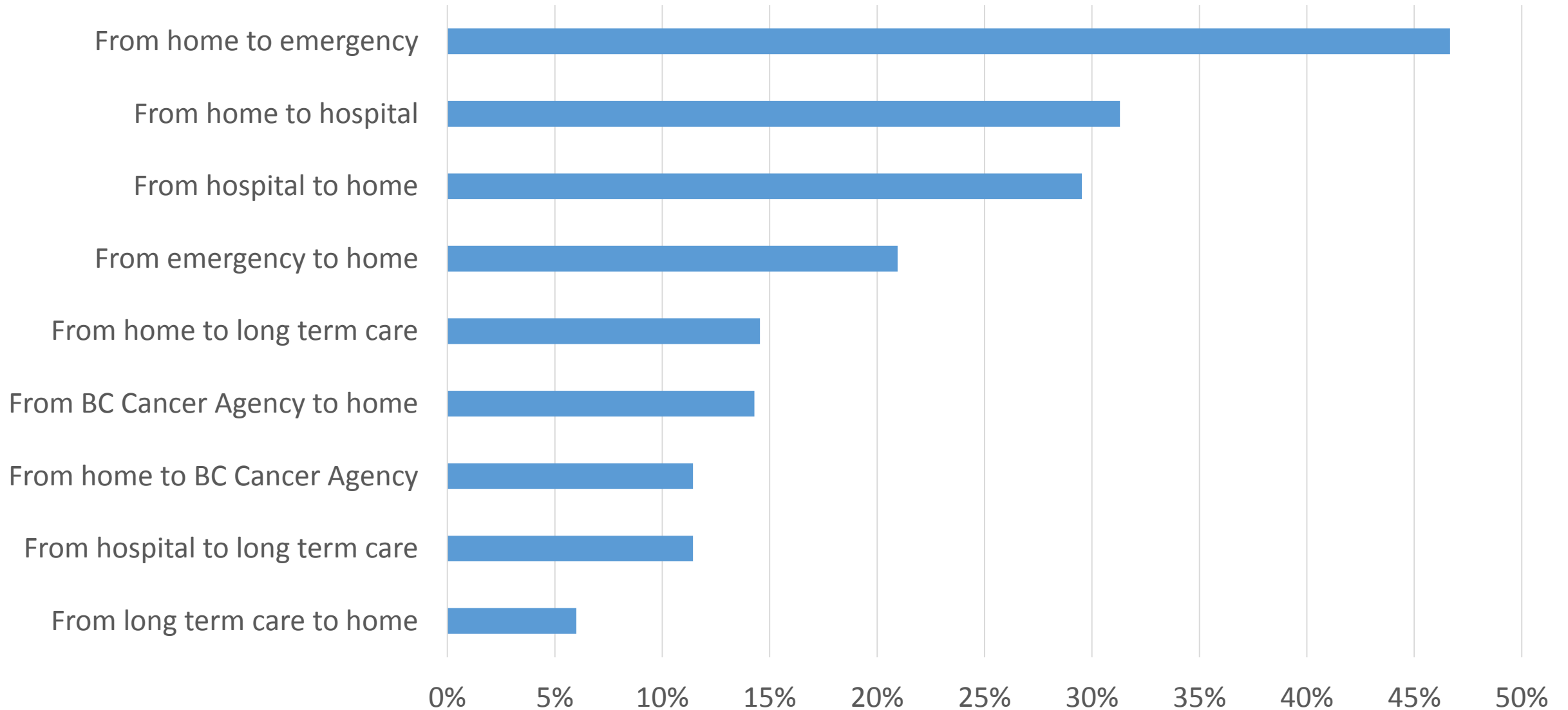
■ Yes ■ No ■ Don't know

Was there consideration for the cultural and spiritual needs of the patient and family?

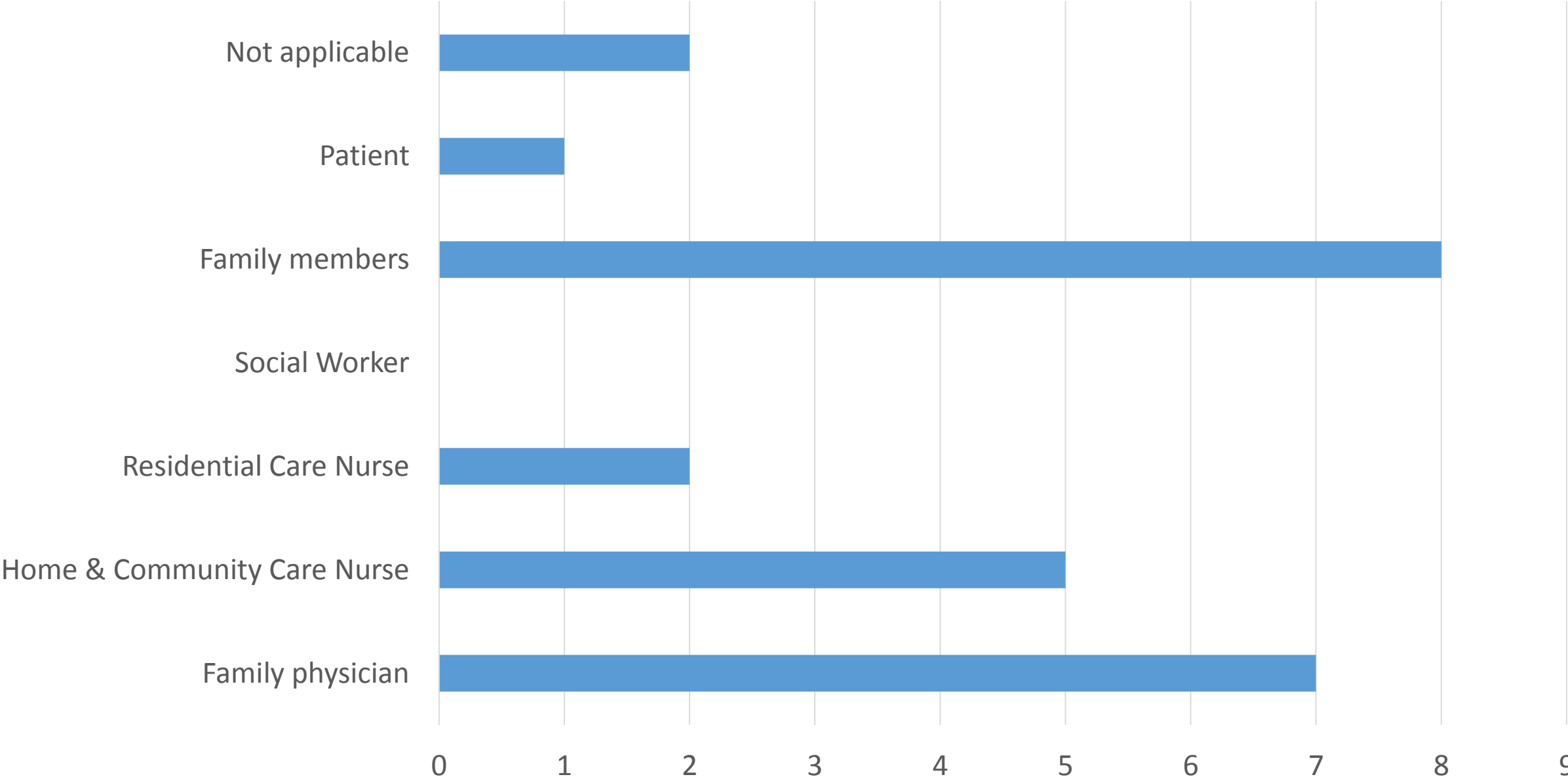


■ Always ■ Most of the time ■ Half the time ■ Rarely ■ Never ■ Other ■ Don't Know

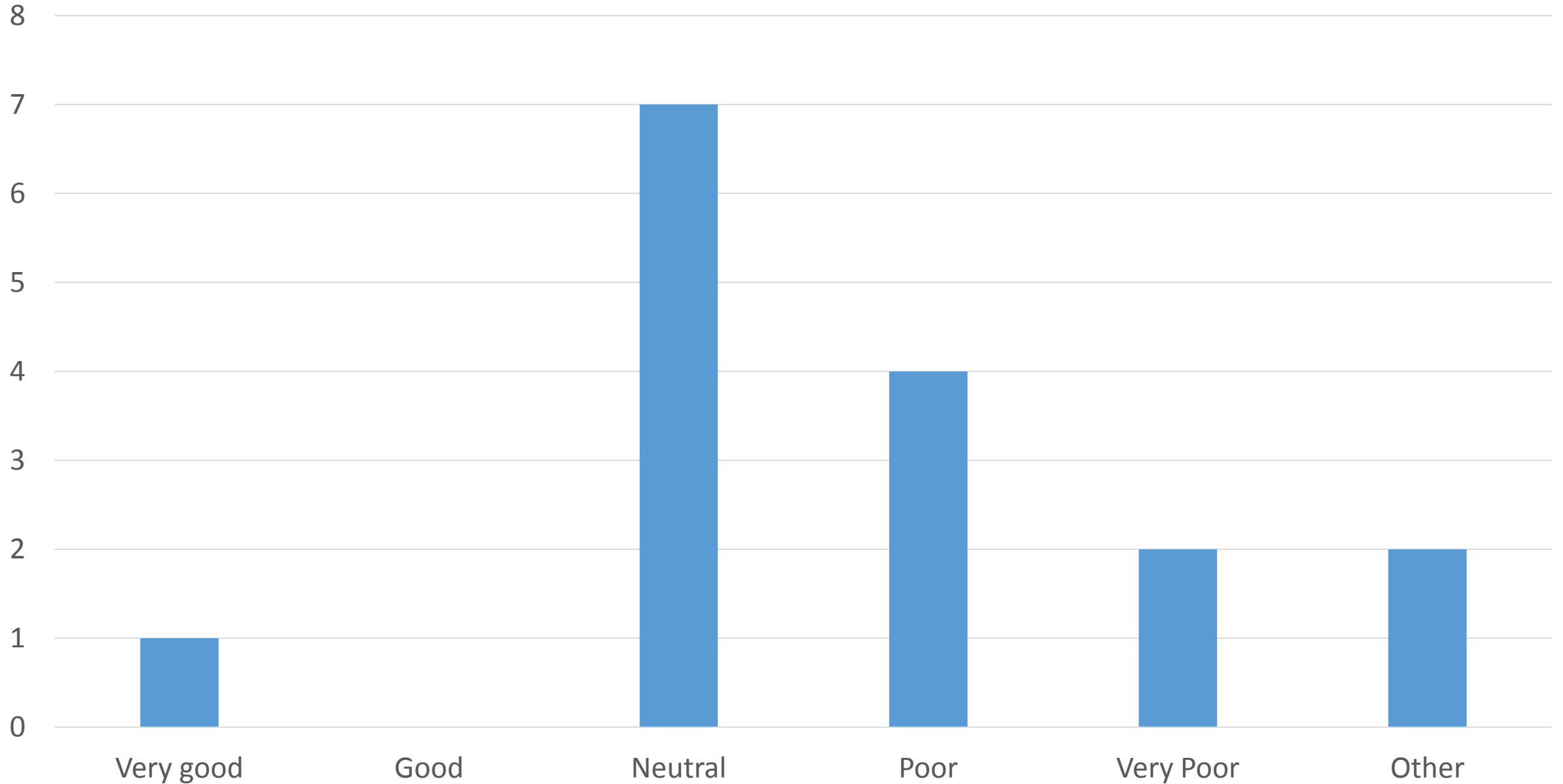
How satisfied are you with the consistency of care received as the person receiving care transferred from one care location to another as described below



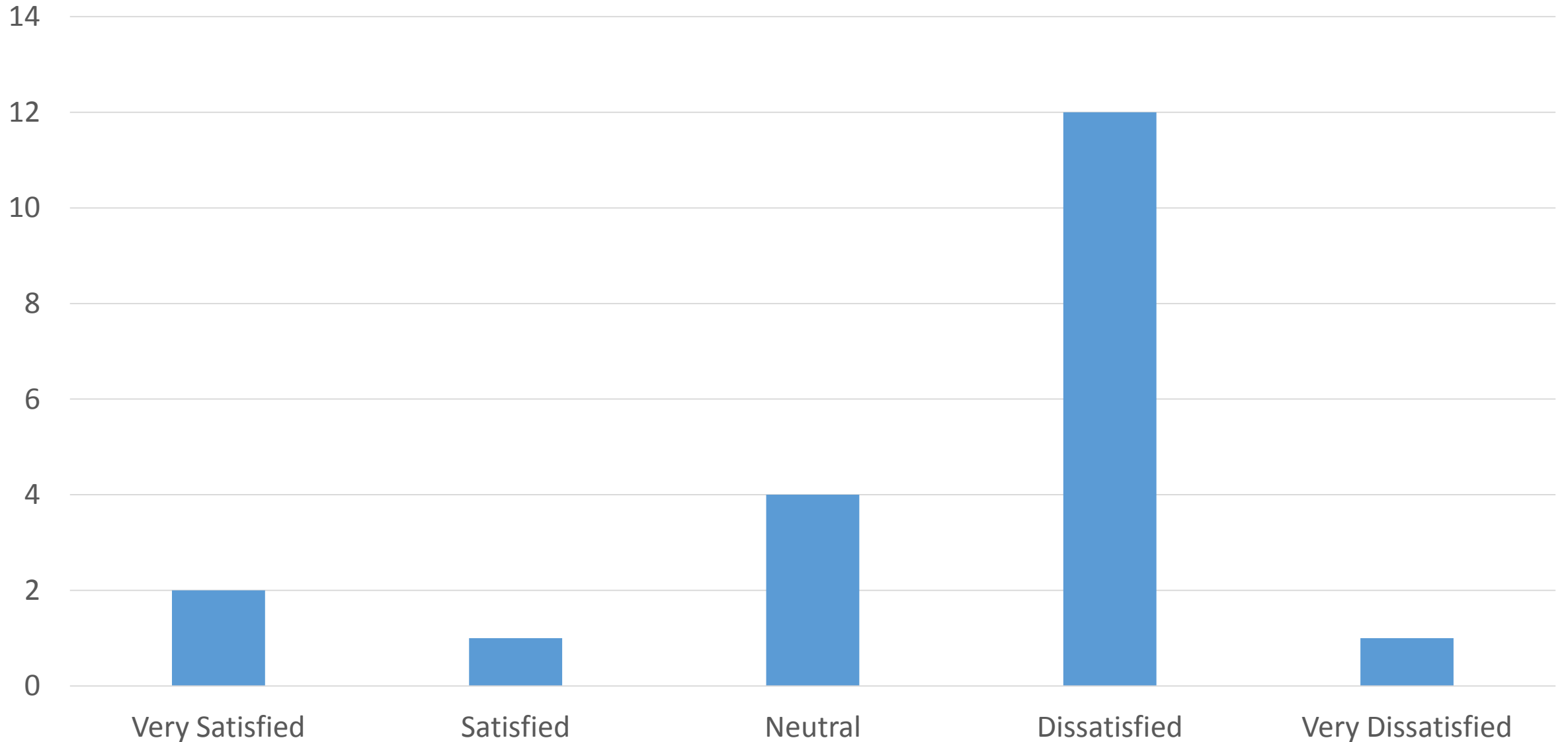
Who coordinated patient care?



Overall, how was communication between care providers?



Overall, how satisfied are you with the current hospice palliative care services in the Cowichan Valley?



Do you have any other comments or ideas about how best to meet the needs of people living with an advancing illness and their families in the Cowichan region ?

Income		*Volunteer	
CVRD Our Cowichan			\$1,000
CVHospice In Kind	volunteer facilitation, recording 30 hrs @\$20.	\$600	\$600
Shared Care			\$3,000
Income total			\$4,600

Expenses

Focus Group development, facilitation, recording hrs @\$50	8	8	\$280
Out of meeting preparation 3 days (7.5 hrs) @\$50			\$1,125
Media & promotion			\$180
Community meeting facilitation, recording hrs @ \$50.00			
Lake Cowichan	4	3	\$150
Ladysmith	4	4	\$200
Duncan x2	10	14	\$700
Shawnigan Lake	4	4	\$200
Total	22	25	\$1,250
Food, Ladysmith			\$54
Facility rental, 4 locations/5 meetings			\$361
Data compilation, reporting 15 hrs @ \$25			\$375
7.5 hrs @ \$50			\$375
subtotal			\$4,000
subtotal vols 30 hrs @ \$20/hr	\$600		\$600
Total expense			\$4,600

*Volunteer expense and contribution valued at \$20/hr



Community Consultation on End of Life Care

How would you like you and your loved ones to be cared for at the end of life?

Join us for conversation about how to make our community the best possible place to live when our families are challenged with advancing illness or bereavement

Tuesday, February 10th (2:00 – 4:30pm) Lake Cowichan Upper Hall Community Centre

Wednesday, February 11th (6:30 – 9:00 pm) Ladysmith Eagles Hall

Monday, February 16th (1:00 – 3:30pm & 6:00 – 8:30pm) St. John's Anglican Church, Duncan

Tuesday, February 17th (1:00 to 3:30 pm) Shawnigan Lake Community Centre



Unable to attend? You can participate in an online survey
contact events.cvhs@shaw.ca



Thanks to *Shared Care* and *Our Cowichan Community Health Network* for funding assistance



3122 Gibbins Road Duncan, BC V9L 1G2 Email: cvhospice@shaw.ca www.cowichanvalleyhospice.org
Phone: 250-701-4242 Fax: 250-701-4243 In Ladysmith: 1-888-701-4242

FOR IMMEDIATE RELEASE

January 22, 2015 Duncan BC: How would you like you and your loved ones to be cared for at the end of life? How do we make our community the best possible place to live when our families are challenged with advancing illness or bereavement?

Cowichan Valley Hospice is leading a community consultation on end of life care, through a series of public meetings and a survey that will be available on-line and distributed in public locations. You are invited to participate in a conversation about end of life care experiences and a vision for the future of hospice palliative care in Cowichan.

A definition: Good hospice palliative care is whole person care. It is based on a plan for care defined by the dying person in the context of their whole life, including physical comfort, relations with family and friends, concerns about meaning and existence. The care team may include family and friends, family and palliative physician, nurses, home care workers and counsellors and volunteers who offer emotional and spiritual support. Hospice palliative care includes care for the family before and after a death.

Hospice palliative care is an approach to care, not a place. And we know that we need choices for where people will be cared for at the end of their lives, choices that are very limited in the Cowichan region.

Cowichan Valley Hospice Board Chair MaryAnn Deacon makes an invitation:

“ I hope that as many residents as possible will participate in these discussions and survey opportunities so that all of us together are able to develop the end of life care that our community needs now and into the future. Mark your calendars. Please join us.”

Dates for community meetings:

Tuesday, February 10 at Lake Cowichan Upper Hall Community Centre 2:00 to 4:30 pm

Wednesday, February 11 at Ladysmith Eagles Hall 6:30 to 9 pm

Monday, February 16 at St. John’s Anglican Church, Duncan 1:00 to 3:30pm and 6:00 to 8:30pm

Tuesday, February 17 at Shawnigan Lake Community Centre 1:00 to 3:30 pm

Thanks to *Shared Care* and *Our Cowichan Community Health Network* for funding assistance.

Unable to join us but still want to participate? The online survey will be available soon. Contact us at events.cvhs@shaw.ca.

-30 -

Cowichan Valley Hospice
Caring for Cowichan families through advancing illness and grief since 1981
Thanks to the generosity of people like you and the United Way – Cowichan!





Contact for More information:

Gretchen Hartley
Executive Director
Cowichan Valley Hospice
gh.cvhs@shaw.ca

Jennifer Yee Fairweather
Client and Donor Relations
Cowichan Valley Hospice
jennifer.cvhs@shaw.ca

ABOUT COWICHAN VALLEY HOSPICE

At Cowichan Valley Hospice, we're here to help. Cowichan Valley Hospice provides emotional one-to-one or group support, resource materials and caring services to those diagnosed with an advancing illness, their families, and anyone experiencing the loss of a loved one. Hospice services are provided by skilled and trained staff and volunteers throughout the Cowichan region from the Malahat to Ladysmith and communities around Lake Cowichan.

Cowichan Valley Hospice services are confidential and offered free of charge. With the generous support of donors, sponsors, United Way of Cowichan and events like Hike for Hospice, Cowichan Valley Hospice supports 600 - 800 Cowichan residents each year.