

Introduction

Burlington, Ontario, Canada, is working towards being designated a Compassionate City, under the charter designed by Prof. Allan Kellehear^{1,2}. Burlington (see Figure 1) is a mid-sized city with a growing population of older adults (65+), who make up 22.5% of the city's population; of these, approximately 16% are people over the age of 85³.

Citizens of a Compassionate Community understand that death, dying, loss, and bereavement are a natural part of life. The aims of Compassionate City Burlington are to normalize discussions of death, dying, loss and bereavement, and to improve the palliative care experience for Burlington residents (Figure 2), by mobilizing the community to help each other, and increasing education and awareness of palliative care resources in the community, using a public health approach.

The Compassionate City Burlington project is driven by Carpenter Hospice, under the leadership of Executive Director Karen Candy, and with the support and/or partnership of the City of Burlington, Burlington Public Library, Art Gallery of Burlington, Cogeco, and others. Much work has also been done with the local faith communities, which will be the focus of this poster, and directly addresses two of the Charter's areas for social change: churches and temples, and hospices and nursing homes.

Burlington's Faith Community

Many faith groups are already actively engaged in the wider community and are inherently service-oriented, making them excellent candidates for engaging as partners in addressing end-of-life care (EOL) care in the community as volunteers – for friendly visits, bringing or organizing meals, cutting lawns, dog-walking, etc. Here in Burlington, we started by communicating with the many local faith groups, and organizing focus groups to see how we might engage the faith community in EOL care of fellow community members, and what support they would need in order to undertake such work.

Faith Community Focus Groups

In July 2016, three focus groups were conducted with 18 different faith groups (17 Christian denominations, 1 Buddhist group), after initial contact with over 60 faith groups.

Evidence from the focus groups suggests that many faith groups in Burlington are willing to support those who need care (whether the person is a member of their faith group or not) but feel unequipped and need training to help people who require palliative care and/or are at EOL.

Our Response: Faith Community Training Sessions

As a result of the findings from the July 2016 focus groups, two training sessions were offered in July 2017. The sessions consisted of a presentation by Carpenter Hospice staff, and a demonstration of hipinfo.ca, an online community resource managed by the region's public libraries, and presented by a Burlington Public Library staff member.

We asked each faith community to identify a 'point person' to attend the training session, and in future act as the main contact between their community and the hospice. Then, if faith group members are visiting people at EOL in the community and questions or the need for further services arise, the point person could funnel questions through to the hospice.

The hour-long training session, entitled 'Supporting End-of-Life Care in the Community', included information on disease trajectories, conversational do's and don'ts, some tips on how to sit with someone who is dying, and community resources, alongside more detailed handouts. Also included was a participant survey to gauge the utility and practicality of the training session.

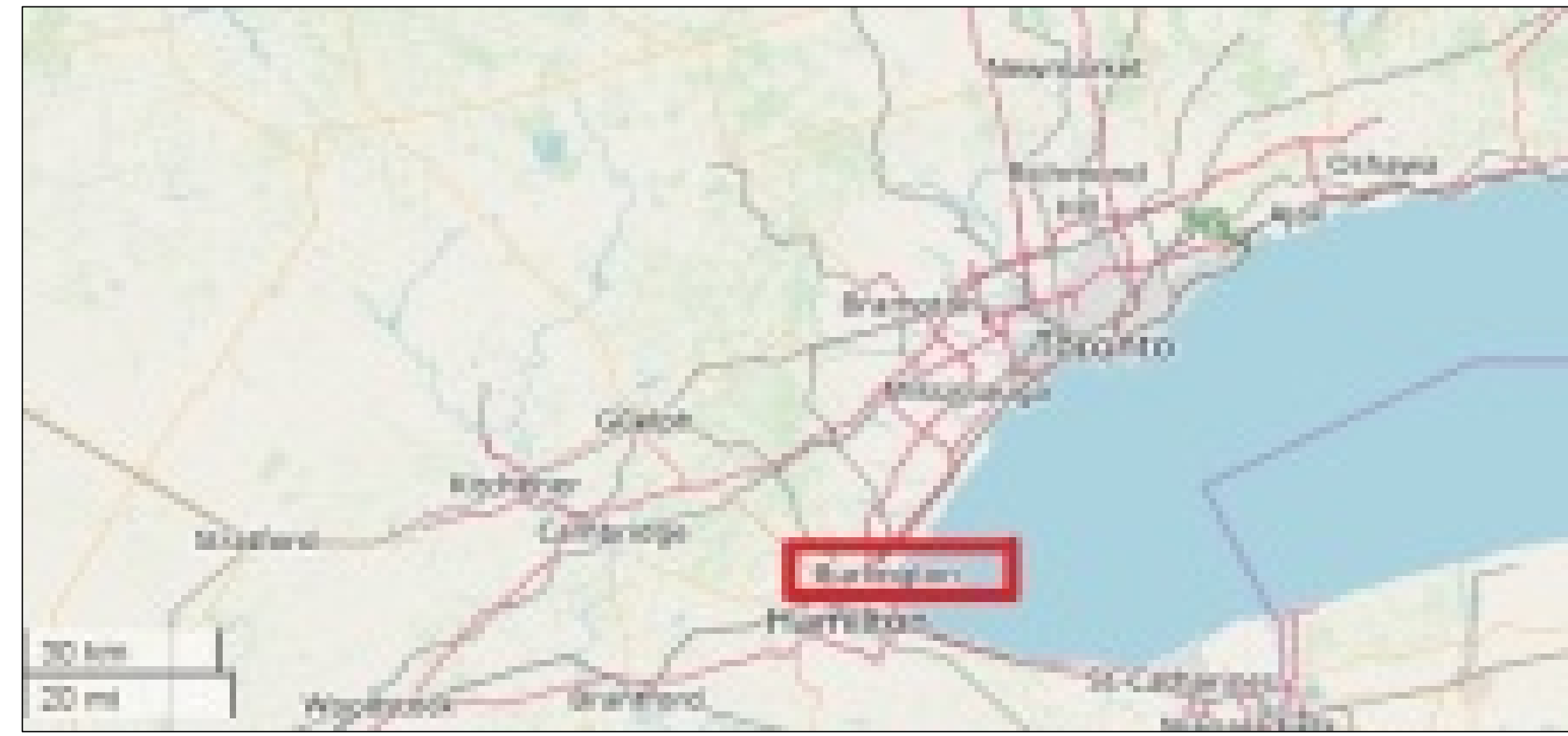


Figure 1: Location of Burlington on northwestern shore of Lake Ontario.

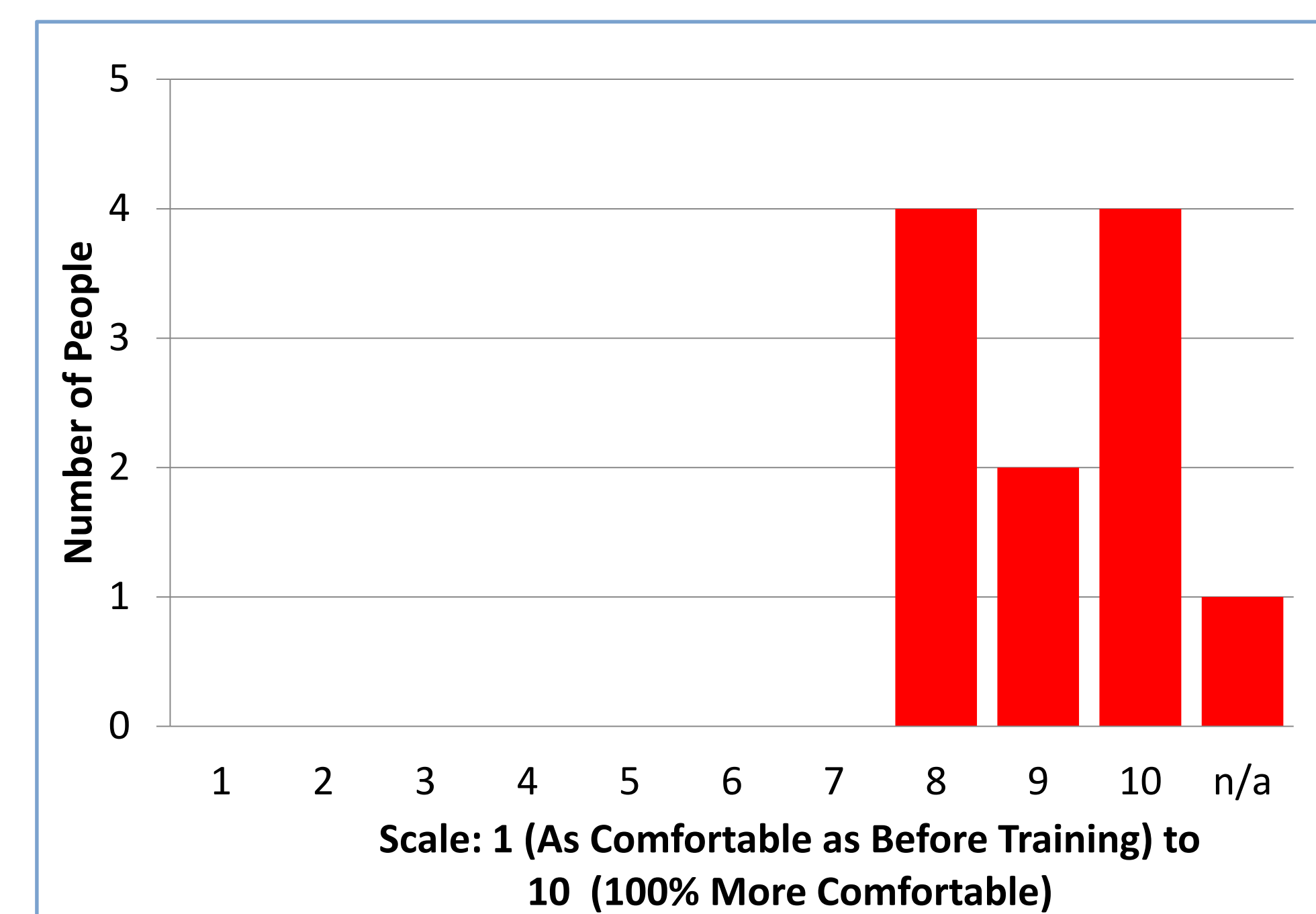


Figure 3: Participants' Post-Training Levels of Comfort Discussing Death, Dying, and Bereavement

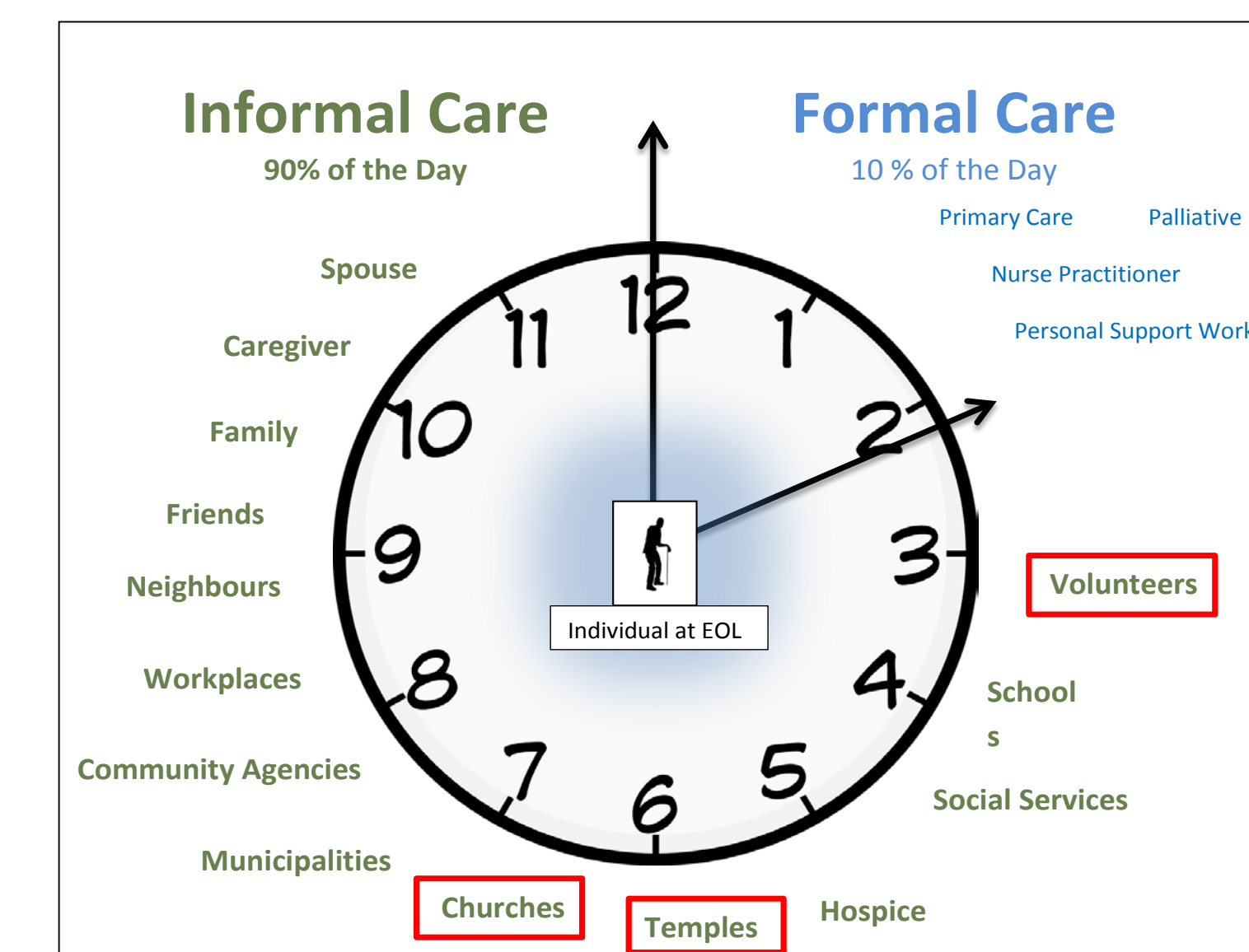


Figure 2: Adapted from Windsor Essex Compassion Care Community. Formal services take up only 10% of the day for an individual at EOL. With this work, we aim to help fill the other 90%.

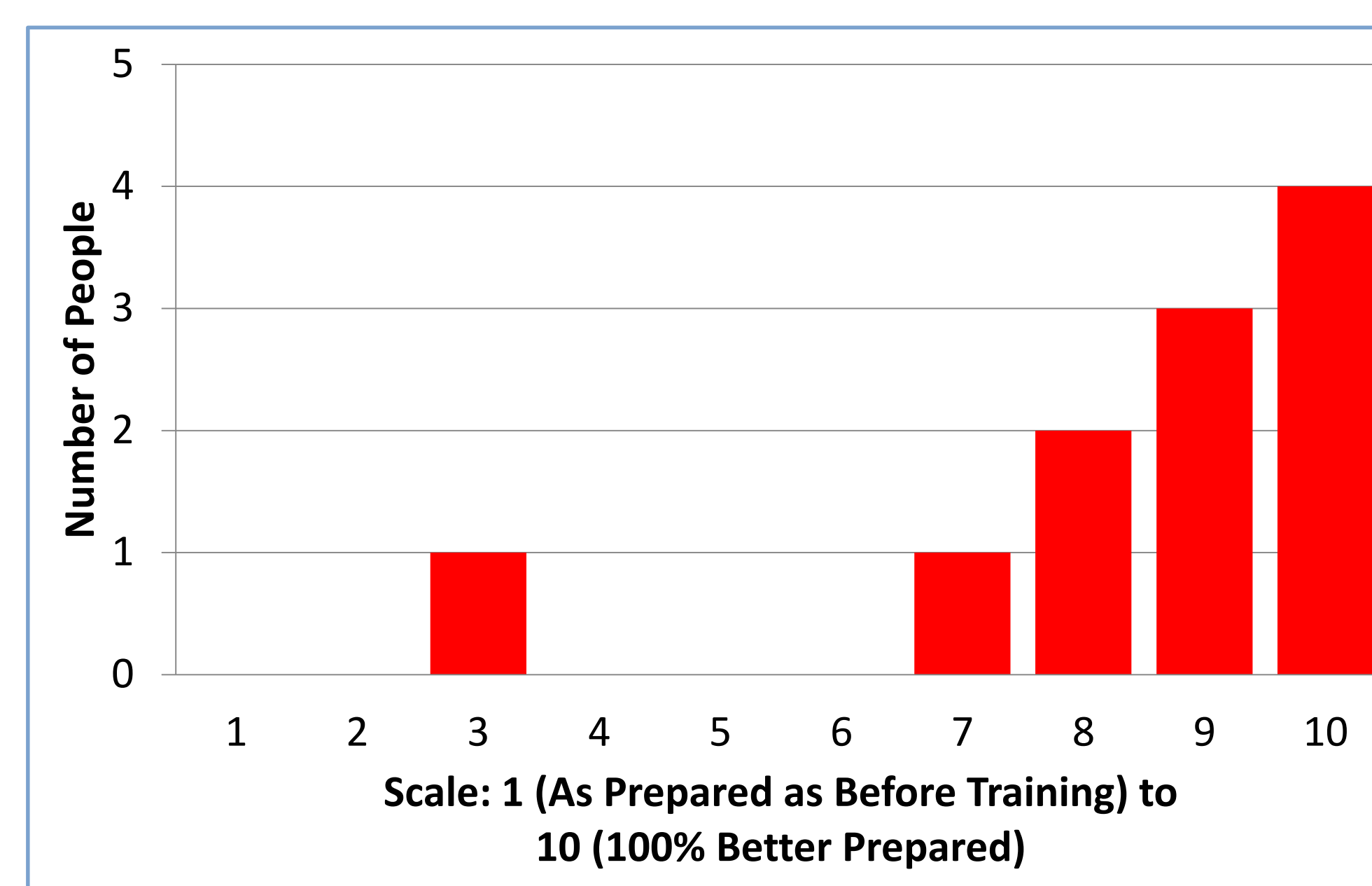


Figure 4: Participants' Post-Training Preparedness in Finding Community Resources Related to Death, Dying, and Bereavement

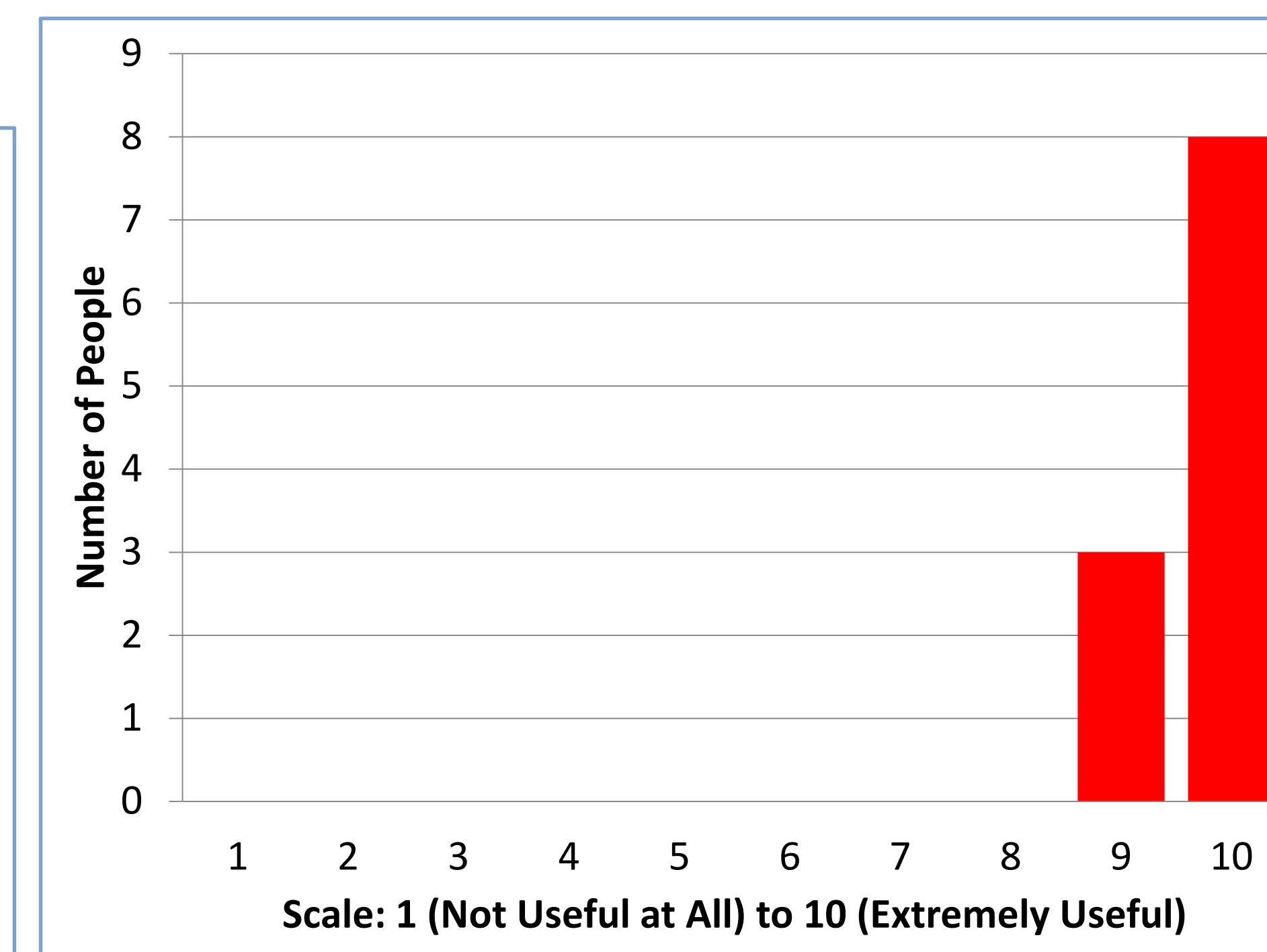


Figure 5: Participants' Rating of Utility of Training Session

Participation and Challenges

Despite 18 faith groups participating in the July 2016 focus groups with professed interest in having training to better help those at EOL, only 11 participants from four different faith groups attended the training sessions in July 2017.

Possible reasons for the low training session attendance include:

- Too much time between expressing interest and the actual training sessions (1 year gap)
- People may have been unavailable due to summer holidays
- People were not as interested in having the training as they indicated initially

Post-Training Survey Results

The sessions were well received. Compared to before the session, participants felt more comfortable, and better prepared (see Figures 3, 4, and 5). The information on community resources (hipinfo.ca, 211) was deemed the most useful part of the presentation.

Navigation Partnerships: Connecting, Accessing, Resourcing and Engaging (N-CARE) Older Persons, Families and Communities

N-CARE is a volunteer-led navigational program, based at the University of British Columbia and led by Dr. Barb Pesut, which improves the quality of life for those in the community dealing with a life-limiting illness and living at home. Carpenter Hospice is currently piloting this program in Burlington. Trained N-CARE volunteers are paired with participants for bi-weekly visits to:

- Establish a trusting relationship
- Facilitate community connections
- Navigate access to community services and resources
- Advance community engagement

The Burlington pilot project started with the identification of five highly-experienced, motivated and compassionate hospice volunteers, who then undertook the N-CARE training in June 2017. Currently, there are five participants enrolled in the program.

One of our N-CARE volunteers, said this after the initial meeting with his first participant:

'There seems to be a real need in the community, and I think we can really make a difference. I'm excited about this opportunity [to help people]...I just met with [the participant] yesterday, and the two hours just flew by...I asked him what he most needed help with, and he responded, "Just help make my life easier."

During the conversation, the volunteer learned that the participant had difficulty cooking due to the symptoms of his condition: "I asked him if he had considered using a Crockpot instead. Now my wife is helping as well by putting together Crockpot recipes that he could use.'

Building a Bridge

While N-CARE is still in its infancy in Burlington, we aim to connect N-CARE volunteers and identified 'point people' from the faith communities when clients need support with things like food, dog walking or driving to appointments so they can help to make arrangements.

In future, we aim to make the referral system mutual, so that a point person from the faith community can refer individuals to the N-CARE program.

Conclusion

Burlington is an engaged, caring community, and we aim to make the most of the compassion that is already present by making connections between people in the community who have life-limiting diagnoses and people who can help make their lives a bit easier. Between the faith communities and our N-CARE pilot, we are beginning to improve quality of life for people with life-limiting diagnoses who are still living at home, working to fulfill the goal of Compassionate City Burlington.

Acknowledgements

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References

- ¹ Kellehear, A. 2005. *Compassionate Cities. Public Health and End-of-Life Care*. New York: Routledge.
- ² Karapliagkou, A., and Kellehear, A. *Public Health Approaches to End of Life Care: A Toolkit*. Public Health England, The National Council for Palliative Care. Accessed online 28/08/2017 at: http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf
- ³ Statistics Canada. 2017. *Burlington [Federal electoral district], Ontario and Ontario [Province] (table). Census Profile*. 2016 Census. Statistics Canada Catalogue no. 98-316-X2016001. Ottawa. Released August 2, 2017. <http://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E> (accessed September 8, 2017).