

# A SNAPSHOT OF HOSPICE VOLUNTEERS IN ALBERTA AS COMMUNITY CAPACITY BUILDERS:

## RESULTS OF FOCUS GROUP AND INDIVIDUAL INTERVIEWS

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Communities are working hard to respond to their hospice care needs. Much of this is occurring not at a government service level but at the local level. It is here where citizens in many communities are taking it upon themselves to plan, implement and evaluate ways to ensure individuals with a life-limiting illness are able to remain in their own homes on their end-of-life journeys. A necessary part of this is to foster and support volunteers who offer care.

Our study sought to explore community capacity development as one way to enhance hospice care in three Alberta communities. We wanted to determine what type of evidence exists to demonstrate the value of a community engaged model for hospice care. Our data indicated that the work of volunteers in these communities showed tremendous value for a community capacity approach to hospice care.

Insight was generated by holding focus group interviews with volunteers in two communities and an interview with one individual in another community. One focus group was held with seven (n=7)

volunteers that were associated with their local Hospice Society in a community with a total population of approximately 8, 235. This community is located roughly 1.5 hours from a large urban centre in Alberta. Another focus group was held with three volunteers (n=3) also who were associated with their local Hospice Society. These volunteers were from a community that is very close to a large urban centre



(i.e. under 15 minutes) where the total population is 54, 891. Finally an interview took place with one individual (n=1) that is also affiliated with her local Hospice Society. She lives in a small rural community of 995 people and her community is just under one hour to a small urban centre that has a population of 55, 032.

Of the combined three Hospice Societies, 11 (N=11) volunteers

agreed to be interviewed. The researcher (K. Whitfield) requested each of the three Hospice Societies choose volunteers they thought would be keen to participate in such an interview and who was an active volunteer. The focus group interviews were conducted in person and the individual interview took place over the telephone. All interviews lasted about 1 hour. The focus group interviews were digitally recorded then transcribed

for analysis purposes while hand written notes were taken during the telephone interview which was analyzed along with the focus group interviews.

All data was qualitatively analyzed. Transcripts and notes from the one individual interview were read once and general notes were taken. A second reading allowed me to begin coding the interviews looking for patterns between and

amongst statements, terms, concepts and general ideas in the three interviews. Presented below are the major themes that arose from this back and forth comparison.

Before we could determine if the work of volunteers is valuable evidence towards benefitting a community capacity model, it was important to know what volunteers do and why they choose this work.

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Although a small overall sample group, these volunteers mainly provide direct care and support to individuals with a terminal illness and they also help out with organized events of their local Hospice Society. Statements such as “I just go and sit with them” was a statement used by most of the volunteers to sum up the care they offer which helps those with a life-limiting illness and

*Interviewees say the most significant impact of their work as volunteers is that now people with a life-limiting illness can remain in their own homes and community throughout their journey and for one community; this was not possible before they had volunteers.*

their family. Helping at events such as the annual Hike for Hospice and attending trade shows to promote their local Hospice Society were also mentioned as things volunteers do.

By responding to a “personal calling” to care for people while they are dying, their statements clearly describe their work as being a relationship builder in their community. For example: “it’s not just give, give, give, it’s a back and forth which is a really good relationship”, and “when the community benefits [this] intermingling with the community... she is still connected with us”. The work of volunteers: “it’s a connection with everybody, it’s a real thing”, says one volunteer.

Engaging in one’s community through participating in health issues, for example, says Isin, Brodie, Juteau and Stasiulis (2008) they are investing in their community fostering a sense of citizenship which these authors describe as: “...the art of being with others, negotiating different situations and identities, and articulating...[themselves] as distinct yet similar to others

in our everyday lives and [this] asks questions of justice” (ibid, p. 7). This sense of justice related to end-of-life care is discussed by Reimer-Kirkham, Stajduhar, Pauly et al (2016). They say death needs to be viewed through a social justice lens not only because palliative care is a human right but also because there is tremendous differentiation in society and great disparities in

accessing meaningful palliative care.

These volunteers talked about the impact of their work as volunteers. It has helped them be better citizens in their community because it has helped foster their own learning. For example “[volunteering] affirms my own faith [and] the most important things in life” and for another volunteer it helped her with the loss of her own daughter making her feel she wanted to give back. Isin et al. (2008) talks about negotiating different identities of the self. As one volunteer describes it “it keeps unfolding...the profoundness of each journey, each life...every one of them touches you”. The work of volunteers has also helped

to foster awareness about hospice in the community. A major impact of the work of volunteers has triggered opportunities for dialogue between and amongst the community and the Hospice Society. It has also helped raise awareness about hospice care and activities. One woman described talking about hospice care in her community on an informal basis, such as when she meets people in the grocery store.

Interviewees say the most significant impact of their work as volunteers is that now people with a life-limiting illness can remain in their own homes and community throughout their journey and for one community; this was not possible before they had volunteers.

Two major challenges the volunteers expressed are burnout and a lack of government support at the provincial level. For one community, burnout of Hospice Society board members was very real. As stated by one volunteer, “we have a Hospice Society that is all volunteers...all volunteer committees, all volunteer everything, they’ve been going from 5-10 years...they are burning out. If we lose our Board we lose the Hospice Society. So we need people willing to volunteer to be on the board”. Finally, the volunteers called for guidelines for where to go for, “a recipe....hospices we talked to, they had to support themselves independently...we need some dollars to provide support”.

The analysis of the conversations with hospice volunteers made it very clear that hospice volunteers are essential to caring for people with a life-limiting illness at the community level. It is apparent that they foster and maintain existing relationships in the community but also, importantly, they build new relationships. There is no doubt they are strong builders of community.

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