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A Case Study Exploring the Implications of One Alberta Rural Community's Experience with Planning Their Own Hospice Care

Authors: Kyle Yvonne Whitfield

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Kyle Yvonne Whitfield
University of Alberta
Edmonton, Alberta, Canada
kyle.whitfield@ualberta.ca

Abstract

There are major implications for rural health care when citizens are organizing themselves to plan and address their own community health care needs. This article describes how one community in rural Alberta, Canada, worked to plan for their rapidly increasing hospice care needs. Specifically, it explores the factors that both helped and hindered them as they grew from a handful of citizens to a highly organized incorporated organization over a period of several years. The results reinforce that communities are not simply 'engaged' in such work but are actually leading the way in the planning, and delivering of social and health supports and services. Their story emphasizes the significant lack and neglect of needed healthcare in rural communities and shows, once again, how rural communities continue to do more with less by building on their own resources and capacities. This study advances our understanding about how hospice care, a major health care service in high demand, is being provided by community members as a result of governments downloading health service planning onto the shoulders of local communities in the name of 'community engagement'.

Keywords: rural hospice, citizen planners, community development, community engagement

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1.0 Introduction

Members of communities are working in informal groups to plan for hospice care in rural communities in Canada. Hospice is not necessarily—although it can be—a physical place, but essentially is an approach to care that aims to relieve suffering and improve the quality of living and dying for those at the end of life (Canadian Hospice Palliative Care Association, n.d.). As our population ages, the number of people with a life limiting illness increases (Public Health Agency of Canada, 2014) and their families, as the main caregivers, will need support (Carstairs, 2010). Also, rural hospitals are closing (Balasubramanian & Jones, 2016), and population decline is occurring in rural communities (Elsof & Bailey, 2015; Ryser & Halseth, 2014). In addition, we need to consider that palliative care specialists remain a limited resource (Carstairs, 2010; Rural Health Services Review Committee, 2015). And most importantly, people at the end of their life are choosing to live and die in their own homes, neighbourhoods and communities requiring a community response to hospice care needs. But, hospice care in Canada is in a state of crisis (Carstairs, 2010) as is the state of rural Canada (Canadian Rural Revitalization Foundation, 2015). As a result,

significant responsibility is being taken on by rural citizens themselves to plan for and meet the health care needs of their fellow community members. Community level planning for good end of life care is increasingly occurring by communities (Sallnow, Richardson, Murray, & Kellehear, 2016); actually, it is a global phenomenon (Sallnow et al., 2016; Whitfield & LaBrie, 2017). There are a range of factors that are facilitating this direction as well as factors acting as major barriers. But as this trend of communities planning and even implementing hospice care evolves, it is necessary to know more about what is entailed in this community development work such as what sustains communities and what they experience as hindrances. There is very little research to draw on to ground current studies but work in the past five years, from the field of public health and end of life care offers some valuable insights (Sallnow et al., 2016; Stevenson, 2016).

Presented and discussed here are the findings of a case study that examined the experience of Hudson, a middle sized rural community in Alberta, Canada with a population of 8,600. The study occurred when a group of committed citizens from Hudson began to meet informally to talk about how to improve its hospice care in their community. One community member noticed an article about an author–researcher in a University of Alberta Alumnus magazine discussing the future of hospice care being one of a community-based approach. After a meeting between the small community group and the researcher, a request was made to develop a study while they continued through their community development process: the aim became one of exploring the factors that both helped and hindered them in their process of addressing their community's hospice care needs.

This paper first looks at the literature that addresses the current state of knowledge about citizens engaged in leading and planning health and hospice care, specifically. The methodological approaches used in this case study are then described, followed by a report of the findings. This paper concludes with a critical discussion of the implications of community engagement from a health planning perspective focussing on the impacts for rural communities.

2.0 Review of the Literature

Studies detailing the role of the local community in planning for hospice care are sparse in both the academic and grey literature. Recent work, however, highlights the essential need for and value of communities leading the way in addressing end of life care issues at the community level (Abel et al., 2013; Matthiesen, Froggatt, Owen, & Ashton, 2014; Sallnow et. al., 2016; Sallnow, Bunnin, & Richardson, 2016). The active role of the community in planning and sometimes providing end of life care continues to increase yet little is known about factors either facilitating the role of communities in this direction or factors acting as barriers.

Much hospice care planning starts out by the work and efforts of local groups that have a vision to meet the needs of people with a life limiting illness, so their community members can live and die in their own homes, which encompass one's neighbourhood and one's own community (Sallnow, Bunnin, & Richardson, 2016). If such opportunities don't exist, people usually have to leave their communities at the most vulnerable time of their life.

Interestingly, the place of death is changing. Hospital deaths in Canada are declining. For example, it has been recently found that from 1994–2004, the proportion of deaths in hospitals declined significantly from 77.7%, in 1994 to 60.6% in 2004

(Wilson et al., 2009); the place of death is shifting from acute care in hospitals to one's home in one's community (Abel et al., 2013; Skinner & Joseph, 2011). It is clear that when given a choice, people wish to die in their own homes and communities (Horsfall, Noonan, & Leonard, 2012).

Place, therefore, needs further examination as it intersects with the growth of hospice care in rural communities in Canada. An interesting study by Giesbrecht et al. (2016) explored ways that borders and boundaries are perceived to impact access to palliative care in rural Canada; ultimately, they wanted to know how to improve access. After conducting interviews in four communities in Canada with formal and informal care providers of palliative care as well as administrators, they found four key themes that expand further on issues relevant to borders and boundaries that affect access to rural palliative care. Political boundaries impact access to rural palliative care through the existence of challenges around continuity of care and the sharing of information differently between provinces, as well, the existence of political boundaries mean that rural residents often have to travel long distances for specialized services. These same authors found that jurisdictional boundaries created challenges in accessing palliative care because different regions in the same province, for example, used different health systems and therefore services. Geographical boundaries meant that being far away from the centre of the province meant that key palliative care services were less available. Finally, the authors found that there were cultural boundaries when accessing palliative care meaning there were stated differences between urban and rural, non-Aboriginal and Aboriginal, and between doctors and patients where patients said they could not understand their Doctor from Tanzania, for example; the authors named this theme as one that highlighted underlying discrimination against health care providers. In general, their study found that borders and boundaries have the power to divide and also to negotiate people and places and services.

When communities are involved in their own local planning for health care, health outcomes are improved. For example, health equity is elevated (Sallnow, Bunnin, & Richardson, 2016) and positive health behaviours, overall, are enhanced (Sallnow et al., 2016).

Sallnow et al. (2016) conducted a systematic review of impacts of local level planning of end of life care. They found that when communities are engaged in planning hospice care, positive changes at the community level were seen. For example, social capital, that is, strong relationship building increased and people took on more civic roles like lobbying their local government for improved end of life care. A local or community development approach to hospice care planning is still quite recent and a more sophisticated understanding of community development still requires further examination and exploration (Sallnow, Bunnin, & Richardson, 2016).

Community development can promote networks of care (Horsfall, Noonan, & Leonard, 2012) and more sustainable service provision in end of life care (Matthiesen et al., 2014). Such processes of connection occur, says Healey (2015), when communities become active and they have a sense of agency. This occurs when there is a shared belief in building something of value in one's community and people feel a need to do something about the issue. Healey (2015) observes that capacity is generated from learning new skills and new knowledge thus helping to develop confidence.

Although it is significant for communities to lead planning for health care services and supports, caution is also necessary; communities are being given more and more

responsibility by their governments to meet their own health needs (Healey, 2015). While this is often framed as a positive way to engage communities, it is also one of the ways that governments are downloading support onto the shoulders of communities. Isin, Brodie, Juteau and Stasiulis (2008) speaks to this: "increasingly, citizens are expected to shape themselves into self-sufficient market actors who provide for their [own] needs and those of their families...[thus demonstrating that the] responsibility for social crisis…is shifted onto the shoulders of individuals" (Isin, Brodie, Juteau and Stasiulis , 2008) p. 41). Healey (2015) admits that such civil society initiatives fill the service provision gaps left by the state; however, this results in new service delivery models where local needs are met and which enrich democracy. Healy suggests that it is the role of civil society to undertake local development work "…there is both a demand and an opportunity for community initiatives and social enterprises to develop alternative ways of promoting development and delivering services on a significant scale" (2015, p. 2). Healey describes civil society initiatives as being small scale in nature, initiated by citizens and residents of that locale and having an aim to improve day to day life situations where people live. (2015, p. 2)

Skinner and Joseph (2011) also agree that we must be cautious when relying on volunteers; they explored the impact of volunteering in new spaces of care in rural communities. They observe that home and communities are new spaces where care is occurring, whereas care used to be provided by institutional places, that is, hospitals supported by the state. This reliance on volunteers has a transformative impact: "voluntarism is a […] major force in shaping new spaces of care in the community" (Skinner & Joseph, 2011, p. 152). And this new focus on the community and home as a place of care elicits responsibility for the provision of care to the voluntary sector, to communities, to households and onto the shoulders of individuals (Skinner & Joseph, 2011). Such devolution of care by the state to the local community has significant implications on volunteers.

From their analysis of the lived experience of voluntary sector care providers on rural aging related caregiving, Skinner and Joseph (2011) discovered several significant implications: (a) there is an assumption that rural communities are capable of taking on greater responsibilities, (b) volunteers are taking on more complicated and complex caregiving responsibilities, (c) the growing demand for care is beyond the ability of communities, and (d) volunteers are at a high risk of fatigue while at the same time they are being asked to do "more and more [caregiving] with less and less [support]" (Skinner and Joseph, 2011, p. 156)

Rural Canada desperately needs improved health care (Canadian Rural Revitalization Foundation, 2015; Schoo, Lawn, & Carson, 2016) which includes end of life care services (Whitfield & Williams, 2011; DeMiglio, Dykeman, Williams, & Kelley, 2012). The most pressing health care variable is the aging of our population (Williams, Lum, Morton-Chang et al, 2016). As people age, they want to remain in their own homes as they journey toward the end of their lives, however, few community care resources exist to allow this to occur (Williams, Lum, Morton-Chang et al, 2016).

To conclude, communities are leading the way in planning and addressing end of life care, but attention needs to be paid to the vulnerabilities in taking on so much work because in the 21st century there are heavier demands on what is an already stretched health and social services (Sallnow, Bunnin, & Richardson, 2016; Skinner, 2008).

3.0 Methodology

This study used several qualitative methods to understand how a group of citizens in one rural community in Alberta, Canada worked towards meeting their community's hospice care needs. Understanding factors that facilitated their work and also mitigated their efforts required multiple approaches.

3.1 Case Study

This is case study research. First, it explores a particular social phenomenon in a real-world context (Yin, 2014). The phenomenon being examined here is how citizens experience the process of addressing their community hospice care needs, and the context is the geographic community of Hudson and the social community of those who have an interest in planning and implementing hospice care needs. Yin (2014) says that the use of a case study works well when community is the unit of analysis, as it is here. Second, a case study explains a current situation using 'how' or 'why' as their centre of inquisition; again, here we ask 'how' a group of citizens in a rural community in Alberta, Canada worked towards meeting their own community's hospice care needs. In addition, there is a lack of case study based research in the field of end of life care (Chen at al., 2014) emphasizing the important need for this work.

3.2 Interviews

In this study, semi-structured interviews were an essential source of insight into the research question. Three types of interviews were used. First, one focus group interview was conducted with six members (n=6) of the newly established board of the Hudson and District Hospice Society. The aim of this one-time interview with these citizen–community leaders was to get a sense of what had propelled them towards developing hospice care in their community as a collective, the type of activities they had accomplished, and some of the barriers they came up against as well as some of their successes. Essentially, they were asked to share their collective story of their accomplishments. All participants gave informed consent for the interview as is required by the University of Alberta Research Ethics Office. The group interview took place at a local restaurant as was preferred by the group and it lasted approximately ninety minutes. The interview was digitally recorded then transcribed verbatim.

Next, individual interviews were conducted with the same six members (n=6) that participated in the focus group interview. This offered an opportunity to probe queries that arose in the group interview. As well, it allowed a chance for individuals to describe their own personal experience of factors helping and hindering them as they worked to address their community's hospice care needs. Again, all participants consented to the interview as required by the University of Alberta Ethics Office. On average, each interview lasted one hour. All interviews with these individuals were digitally recorded then transcribed verbatim.

Key informant interviews were also conducted. A total of three people (n=3) in professional–health care positions that had some input or influence in the planning work of this community were interviewed. A local physician and two health care administrators representing the provincial government were interviewed. These individuals were identified as key informants by the group of community leaders. Key informant interviews took place over the phone and lasted on average thirty to

forty minutes. Hand written notes were taken for these three interviews. The notes were then typed up immediately following the interview.

3.3 Data Analysis

Data included in the analysis were: (a) the one transcription from the focus group interview of six people, (b) the six transcriptions from the individual members of the focus group, and (c) the notes taken from the three key informant interviews. All data was analyzed together, as one data set to strengthen the rigour of the final themes. Strauss and Corbin (1998) say that in qualitative data analysis there is an interplay between both induction and deduction (p. 137). This interplay occurred through a back and forth reading and note taking of emerging patterns comparing ideas, thoughts and concepts about factors that helped and factors that hindered this community of people in addressing hospice care in their community. Presented below are the major theme areas that arose from this back and forth comparison process.

4.0 Findings

Described here are the major themes that evolved from the one focus group interview with board members of the Hudson and District Hospice Society, the individual interviews, and the key informant interviews. Again, this rural case study asked how a group of citizens in a small town in rural Alberta, Canada experienced planning for the health needs of their community, in particular, their hospice care needs. It probed key factors helping and hindering them and the subsequent impacts of those.

4.1 Accomplishments

This community group came together one person at a time and in a short time became a group highly committed to addressing a major gap in their community. They had a common mission: to improve the end of life care needs in their own community. After a tremendous amount of planning and decision-making, such as conducting a needs assessment, they became an incorporated organization with a name—The Hudson and District Hospice Society. They had a board of directors, committees, by-laws and policies, and a plan to accomplish a range of activities.

Over a two-year time period, their accomplishments were many. They had rented office space, organized several annual 'Hikes for Hospice' and other fundraising events, and were successful in receiving funds from several community grants. When they began their planning process, they were determined to have a hospice building where people at the end of life could be well cared for. But, says one study participant, "we changed our view away from focusing only on the building". Instead they looked to the assets of their community members resulting in the ability to offer a wider range of supports. One study participant explains it like this, "we have so many talented people in our community, and we realized they had to have a role in this too" and, says another, "we wanted to build an empowered community". Hudson had a huge degree of commitment from individuals, and organizations, and a lot of passion and perseverance. As another participant stated: "we had a mass amount of willingness from people who wanted to offer support [as well] as those that needed the support". The need for, and interest in, hospice care grew, resulting in training volunteers to offer care to those with a life limiting illness which also supported family members. Other communities in Alberta came to know about this community because of its successful community development approach. One

study participant affirms this, "we have finally grown in stature to the point that people in multiple communities are recognizing us".

4.2 Responsibility of Government or Community to Meet Local Hospice Care Needs?

A slight variation in perspective was evident from the interviews: there were those who mostly believed it is the role of government to meet hospice care needs, and there was another group who saw the community as being mostly responsible to meet the needs of its own people. Those who believed the government is responsible to provide communities with hospice care services suggested that the government needs to be pushed to ensure end of life care is a priority. As one interviewee says, "I would like to see Alberta Health have a line in their budget for palliative care….there is some commitment…we just have to keep poking at the sleeping giant [the government]".

Those who believed otherwise said it is the role of the community to help its own members and community members should ask one another for help and not wait for the government to help them. Therefore, the role of community is to help one another. As said by one study participant: "There's a responsibility to take care of our own and look after our own. We don't want people to leave". The community needs to be a major part of their own care planning and care provision. As another study participant says: 'it is a must that support at the end of life relies on the extended family and the community'. Here we get a strong sense that at the end of life, people have a right to be cared for by their own family and community. Finally, another participant asks a highly relevant question, "…why should people be abandoned at the end of the hall [e.g., in hospitals] by themselves!" For this group, the community needs to care for their own.

4.3. Factors Facilitating and Hindering the Community's Ability to Plan for Their Hospice Care Needs

4.3.1 Facilitating factors. When asked to describe the factors that helped this group the most through the many processes of planning for developing good hospice care in their community, two main themes were clear: the value of personal stories as a motivator for change and the value of relationships and networks.

Stories kept this citizen group motivated to address the end of life care needs in their community. Some stories were about the difficulties that happened when a loved one died in a hospital in the city several hours away, and some stories were about the benefits they experienced when their family member or friend was cared for in a hospice setting. One study participant describes the power of the stories they were told, "after talking to people some personal experiences of people traveling that journey expressed the need for hospice support". And this kept the group motivated, "everywhere we go we get a heart story…every time we take another step there's people standing there with a heart story that keeps us emotionally connected to this journey".

Networks of important relationships at the end of life are extremely significant. As one study participant says, 'support at the end of life relies on extended family and community, it must'. Another participant affirms that it is relationships that are the glue that keep networks together, and "I learned that being with the dying is about relationship". In fact, a big part of the work of this group of citizens was strengthening several networks in their community because this is where they

observed a huge gap, "mainly the gaps [needing to be strengthened] were the individual connection with the person that is palliative and their family".

4.3.2 Hindering factors. When asked to describe the most significant factors that hindered this group as they made plans to meet their community's hospice care needs, they talked about two main challenges: the lack of direction for rural-focussed, community-based planning for hospice care by government, and the obscurity associated with hospice in general.

There is a significant lack of direction when planning for rural health care in Alberta (Rural Health Services Review Committee, 2015) and even less direction for planning end of life care services. There are no policy documents to draw on, no provincial guidelines, and no dedicated resources for rural communities to plan hospice care. This group of rural citizens of Hudson found no direction available to them and very much felt they were working alone. Cynically, one study participant captures the frustration about the lack of direction, "just get the manual….well…THERE IS NO manual [on how to plan hospice care in the community]!". Another study participant says it this way, "…there isn't a setup anywhere that you can phone and say—how do you set up hospice, this is how you go about it and here are the funds. There's nothing" and "there is nothing, absolutely nothing…that we would've gotten help from…there is nothing set up from the government". Not only is there a lack of direction from the health care system, Hudson's citizen group found tremendous difficulty when they did seek guidance from the government. One study participant expresses her frustration, "[it was a] big challenge engaging with the government [and] we tried multiple ways of engaging them".

There is a great deal of obscurity around hospice; how is it different from palliative care? Is it a place? Is it an approach to care, for example? This lack of clarity associated with hospice care evolved out of the data as a hindrance to planning good end of life care. This theme showed up in a number of ways. In general, the public are unfamiliar with the term 'hospice' or what it means, and people were found to be very uncomfortable speaking openly about issues around death and dying. People are uncertain, a study participant states "[is] hospice a way of caring or [is] hospice a place?". The results of such obscurity impact the person with a life limiting illness, says one study participant, "people are abandoned at the time of death". This may be because, another participant says, "hospice is [still] a new idea" and "we hide death", says another.

To summarize the findings: there were factors that helped and hindered this community as they moved towards the development of hospice care in their community. Those factors that seemed to help them with their planning were hearing personal stories by those with a life limiting illness and their family. Also helping them was said to be strength in the existence of relationships and even networks that exist to promote a good death in that community. What hindered them in planning and providing hospice care were said to be a lack of direction by government about how to plan local-level hospice care, and the high level of obscurity around what hospice care is. Also hindering them are competing community values about who should plan and implement hospice care, that is, should it be the community members themselves or should planning and hospice care be planned and provided by the provincial government.

5.0 Discussion and Conclusion

This very committed group of citizens became aware of a major health service gap in their rural community: a lack of hospice care. They came together as citizen planners to find ways to address this need. As a result, they organized themselves to become an incorporated organization—the Hudson and District Hospice Society. They raised money through fundraising activities and were successful at receiving several community grants. The personal stories of members of their community related to end of life issues motivated them forward as did a need to foster and bridge relationships and strengthen social networks so that people with a life limiting illness and their families were connected to other people and to resources in their community. This group of citizens were significantly challenged by (a) a lack of direction by the government about how to meet their community's hospice care needs, (b) a lack of engagement on the part of the provincial government to collaborate with them, and (c) by the obscurity that surrounds hospice and hospice care in general.

From this case study, a good picture is generated of the many factors associated with citizens planning and providing hospice care in a rural community context. When strengthening social networks, it is useful to draw on the work of Pancer (2015) who explores citizenship and civic engagement. As affirmed by authors that study similar concepts (see Sallnow & Paul, 2015; Horsfall, Noonan & Leonard, 2012) such as community engagement, it is an important requirement in planning for marginalized communities because social networks foster belonging and make a positive difference in the civic life of a community: strong relationships and feeling connected improve the health of a community (Pancer, 2015; Horsfall, Noonan & Leonard, 2012). When Horsfall, Noonan and Leonard (2012) asked if caring networks increase and benefit those at the end of life, they found that it takes a community of people to work together to allow someone that is dying, and their family, to experience a positive death. It takes significant levels of social capital for there to be strong networks and many interconnections between and amongst people, resources and other organizations.

What does this important need for social connection mean for the health of rural communities? The Canadian Rural Revitalization Foundation (2015), critically examined the state of rural Canada and found that community development has been eroding, "[there is a] diminishing of the social safety net as a result of the decline of the Canadian welfare state" (p.3). On the other hand, after reviewing rural health services in Alberta, the Rural Health Services Review Committee (2015) found that rural people in Alberta band together when resources are scarce as a way to provide needed services because they want to live their lives in their communities, especially at the time of death (p. 3). Therefore, strong relationships and networks need to be sustained and continually built.

An interesting conflict arises in the findings. Although people in our study banded together as a response to scarce resources in their rural community, this is both a benefit but also a challenge. Such resources generated by the community help to address and meet important hospice care needs, but it begs the question of the larger role and status of the community; does their charitable status enable them to be the sole provider of a service or does government play that role at either the municipal or the provincial level? Integrated with this is the question of funding: are funds for services—for a hospice building and staff, and so forth—to be raised at the community level or, again, does government play that role? This conflicting role was clear in the findings. A combination of funding sources is one model being used

in Ontario, Canada, for example. For many years, one rural community had a hospice supported by local donors and local volunteers until recently the provincial government joined the partnership; funding is going to go towards existing hospice beds in addition to six more beds (Ministry of Health and Long-Term Care, 2016). This type of approach is likely how community-based hospice care will develop, through partnerships between and among local donors, community and the provincial government.

What we have learned from Hudson is that communities are often leading in the planning of health care in their communities (Skinner & Joseph, 2011). This is an interesting dilemma, one where restraint and attention is needed. Governments partnering with communities to plan hospice care services still ask community members to be involved, but on a voluntary basis. This is why community members' roles as leaders in planning their own community's end of life care may not be sustainable over time. Therefore, governments may need to play a stronger role in the planning process. And although Volunteer Canada encourages Canadians to be involved in their communities—as it is vital to a healthy and democratic society (2012, p. 1–2)—this sector is under increasing stress (Volunteer Canada, 2012; Ryser & Halseth, 2014; Skinner & Joseph, 2011).

To our existing knowledge of how rural communities plan for health services, it can be concluded from the story of Hudson, that there are facilitators and hindrances when a community leads the way in addressing its hospice care needs. There are many stressors on rural communities, such as: population decline, an aging population, and a lack of specialized services in palliative care—and communities must not be put in an even more precarious position. But, it seems that communities are awakening to these challenges by taking the lead in planning such services. If the future is to be one that is sustainable, caution is required as these community groups are working voluntarily, often in addition to their own paid jobs and family responsibilities. From rural communities like Hudson, it can be learned that there are still those that believe it to be their responsibility to care for their own—and caretaking is a major characteristic of building a healthy and democratic society—a right that must not be taken away, but supported.

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