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Title

Building community capacity for end of life: an investigation of community capacity and its implications for health promoting palliative care in the Australian Capital Territory.

Authors

Mr Jason Mills, School of Nursing, Midwifery and Paramedicine,
Australian Catholic University, 223 Antill Street, Watson ACT 2602.

Dr John P. Rosenberg, formerly Foundation Director, Calvary Centre for Palliative Care
Research, Australian Catholic University, 223 Antill Street, Watson ACT 2602.

Prof. Fran McInerney, Professor of Aged Care, School of Nursing, Midwifery and
Paramedicine, Australian Catholic University/Mercy Health,
115 Victoria Parade, Fitzroy, VICTORIA 3065.

Corresponding Author

Prof. Fran McInerney, Professor of Aged Care, School of Nursing, Midwifery and
Paramedicine, Australian Catholic University/Mercy Health, 115 Victoria Parade, Fitzroy,
VICTORIA 3065; T: +61 3 9261 2066; E: fran.jmcinerney@acu.edu.au

Abstract

This study identified and examined community-based activities around death, dying, and end-of-life care, which might reflect a health promoting palliative care [HPPC] philosophy. This approach is argued to restore community ownership of, and agency in, dying and death through the building of community capacity. However, the enactment of the HPPC approach has not been extensively examined in Australia. Current understandings of community capacity-building relating to end-of-life are orientated toward service provision.

A qualitative interpretive approach was used to engage with local community groups in the Australian Capital Territory (ACT) with an interest in death, dying and end-of-life care. Data were collected from ten in-depth, semi-structured interviews and thematically analysed. The themes of *Practical Support, Respect and Responsiveness* and *Connection and Empowerment* were identified, reflecting community activities initiated in response to the experience of life-limiting illness.

Building community capacity offers to restore community agency in end-of-life concerns, while potentially enhancing health service provision through collaborative partnerships. This study indicates an existing community capacity, demonstrated by activities that promote socialisation, peer support and normalisation of death and dying. However, as these activities occur primarily in response to illness, proactive and preparatory interventions in HPPC are a priority.

Key words: palliative care; health promotion; community; dying.

Introduction

The once communal experiences of death and dying have become highly medicalised under institutional service provision models. Communities have become reliant on professional expertise to care for the dying. Yet professional workforce capacity is increasingly limited, while care demand continues to rise. End-of-life care represents a major public health concern; there is a heightened recognition of the need for consideration of alternative approaches to be used in conjunction with more conventional responses. In restoring community ownership and agency, the public health approach of health promoting palliative care [HPPC] may contribute to change through the building of community capacity. However, current understandings of such capacity-building for end-of-life care are both limited and service-provision oriented.

This research was conducted as part of a broader mixed-methods study aiming to identify and examine both organisational and community-based activities focused on building community capacity around death, dying, and end-of-life care. This paper considers activities solely occurring within the community—as represented by non-professional community groups—rather than clinical activities delivered by professional service organisations.

Literature Review

In Australia the interface between professional and non-professional groups is of increasing interest in palliative care. A growing number of Australian projects have highlighted partnerships for community capacity-building in the areas of death, dying and end-of-life (Kellehear and O'Connor 2008; Kellehear and Young 2012; Salau, Rumbold and Young 2007). Byock and colleagues (2001, 760) articulated an appreciation of the remit of the community:

The experiences of serious illness, dying, caregiving, grieving and death cannot be completely understood within a medical framework alone. These

events are personal, but also fundamentally communal. Medical care and health services constitute essential components of a community's response, but not its entirety.

The social cohesion of communities and their activities are essential to responses to death and warrant attention. How do communities respond to death? How do they build capacity to do so?

Current understandings of community capacity-building are limited and service-provision oriented. For the purposes of this study, *community capacity* refers to the awareness and understanding of death within communities as a significant yet normal life experience, represented by an ability to demonstrate attitudes and practices consistent with this understanding (Palliative Care Australia (PCA) 2005) along what has been called a spectrum of engagement activities (Sallnow and Paul 2014). While definitions of "community" are complex and contested (Zhang and Jacob 2012), in this context communities are represented by existing or potential networks of individuals and groups that either share or have the potential to share common concerns and goals.

Care for the dying has become professionalised by institutions within a medical service model (Conway 2007). The current provision of palliative care in Australia is organised around care needs classified into five distinct phases: 'stable', 'unstable', 'deteriorating', 'terminal' and 'bereavement' are used by services to inform outcome measures (Eagar et al. 2010). Contemporary palliative care represents a shift from the socially informed modern hospice movement which sought to humanise care for the dying, towards a more medicalised and regulated provision of expert services by health care institutions for those with incurable illness (Lewis 2007).

Rosenberg's (2011, 27) question 'Whose business is dying?' explores the "tension between the paternalism of mainstream palliative care and a social understanding of end-of-

life care”. While connotations of commerce and profession are inherent to this question, Rosenberg (2011) concludes that its answer extends beyond the clinical gaze of the healthcare professions. Underpinning the tension between community ownership and service provision is a sociological discourse that informs the development of HPPC. Central to this discourse is the sequestering of death and dying which has proven problematic for communities (Green 2008) and which persists in the developed world despite the emergence of so-called death revival practices, particularly around bereavement (Walter 1994).

Despite the many advances made in medical science including increased life expectancy, shortfalls remain for the dying who now live longer with chronic illness and poorer quality of life (Howarth 2011). Their families and communities who engage with death and dying must cope with the physical, psychological, spiritual and social impacts of life-limiting illness, carrying an unfamiliar burden of care (Currow et al. 2011; Hudson et al. 2012). According to Kellehear (2005), this has been influenced by the loss of community capacity to live with and respond to death, accentuated by a gradual reliance on service provision by expert professions. This progression can be traced alongside the evolution of care for the dying – from the original socially-embedded hospice movement towards contemporary professionalised palliative care (Lewis 2007). As professional expertise has developed, community awareness of, and capacity to respond to, death and dying has arguably regressed via a growing dependence on professional knowledge and service provision.

In Australian healthcare reform, institutions and service providers are increasingly under workforce pressure, with supply struggling to meet demand. Health Workforce Australia (HWA) in a recent report projected this problem to worsen by 2025 to a shortage of 2,700 doctors and 109,000 nurses in Australia (HWA 2012). The increasing constraints on professional service provision are cause for concern, as is the health system’s acute-

treatment-centric model which is inappropriate for the holistic needs of people experiencing life-limiting illness (Conway 2007). Mowbray (2005) rightly warns against an uncritical embracing of community empowerment discourse, identifying its potential to obfuscate or justify cynical attempts to reduce State support of health and social services. We do not argue for simplistic partnerships between community and professional groups, but for recognition of community activities that show potential to support both the dying and their loved ones as they care, live and die in both social and institutional contexts. Consideration of alternative models of support for the dying such as HPPC is therefore warranted.

The seminal work of Kellehear (1999) introduced HPPC as a public health approach to end-of-life care. Further HPPC literature followed (Gardner, Rumbold, and Salau 2009; Salau, Rumbold, and Young 2007; Street 2007), however, it was largely representative of implementation projects. While a perceived conceptual dissonance between palliative care and health promotion remained a challenge to the uptake of HPPC (Rosenberg 2012), the work of Street (2007) was effective in articulating HPPC in its up-stream (macro), mid-stream (meso), and downstream (micro) approaches to end-of-life concerns.

HPPC aims to promote community ownership of death, dying, and end-of-life care by fostering community participation and agency (Kellehear 2005). Acknowledging the significant contributions made by informal carers, the social model of HPPC promotes a more balanced relationship between health professionals and the communities within which they practice (Rumbold 2012). A core HPPC message is that as communal care of the dying *preceded* institutional, professionalised care, restoring community ownership and social participation in relation to death, dying, grief and bereavement as a normal part of life is desirable (Kellehear 2005). A primary initiative to achieve this outcome is death education, which seeks to normalise death and equip communities to better prepare for it (Kellehear and O'Connor 2008) – not to be confused with the clinical education routinely provided to carers

by health services (Rosenberg 2012). This is recognised in PCA's stated priority area that: *All Australians must have access to education about dying and death* (2011, 3). Kellehear and Fook (2010, 25) further articulate this priority:

Workplaces, schools, churches and temples, clubs, pubs, art galleries and museums and shopping malls are among the many places where people can and are able to learn about health, well-being and ultimately – mortality.

In their HPPC implementation projects, Salau, Rumbold and Young (2007) elucidated the mutual benefits of community capacity-building for *all* parties. However, community capacity must first be determined for partnering with professionals to be meaningful and sustainable in response to death, dying and end-of-life care. Such a determination is critical if the building of community capacity is not to be rendered merely another service to be provided, nor community engagement used to replace palliative care or reduce associated costs.

The significance of community capacity-building is made explicit in PCA's (2005) *Standards for Providing Quality Palliative Care for All Australians*. However, the title is suggestive that community capacity-building must be provided by clinical services, rather than communities themselves possessing ownership of their development. For community development to enhance community capacity in this way, "the needs, wants and problems identified are [to be] articulated by a cross-section of the community affected by those needs or problems" (Kellehear 2005, 118). Thus, community participation must be present in developing the social resources of the community to build capacity, thereby enhancing quality of life *and* death in communities.

What can be gleaned from community narratives around death and dying? The community voice adds value to discussion of community capacity, and there are many biographical and autobiographical narratives to be found within local community libraries:

From the moment some people found out I had cancer, they started looking at me as a man who was dying. But we will all die. So why think of cancer as dying? Why not think of it as living? (Stynes 2012, 308-309)

The narratives of those including Australian sportsman Jim Stynes (2012) who died from cancer; historian Donald Horne (Horne and Horne 2007) who died from pulmonary fibrosis; author David MacKenzie (2002) who died from motor neurone disease; and former Australian Prime Minister's wife Hazel Hawke, who died of dementia (Pieters-Hawke 2004) can all be seen as testaments to the existence of community capacity in the journeys of affected individuals.

Stynes (2012), Mackenzie (2002) and Pieters-Hawke (2004) all described the valuable support they received from community groups throughout their journeys. Horne and Horne (2007) articulated the importance of partnership between informal carers and health professionals, echoing a similar message in the professional literature (McCreddie 2011). Others have published books as a way of grieving for their spouse (Hayes-Smart 2002), consistent with the emerging trends of online bereavement communities (Lynn and Rath 2012).

Other examples of Australian community responses to death and dying include the development of communal memorial spaces for the dead, such as the 'Place of Reflection' in Western Australia, or public awareness campaigns such as 'Dying to Know' (Pilotlight 2007), that combat the stigma of dying and promote open awareness of death as a normal part of life. Internationally, best-selling books such as 'Tuesdays with Morrie' (Albom 1997) and 'The Last Lecture' (Pausch 2008) engage the global community by sharing the human experience of dying. These activities highlight ways that communities can respond to death and dying; their existence indicates community capacity around end-of-life.

The need for community capacity-building is evident however, within a context of burden on informal caregivers who provide the majority of care towards end-of-life (Currow et al. 2011; Kovacs and Fauri 2003). Currow *et al.* (2011) identified a burdened population of caregivers who would *not* take on that role again with relatives at end-of-life. Others have highlighted financial burdens of care (Crooks et al. 2012). In response to such burden, Hudson *et al.* (2012) developed guidelines for professional psychosocial and bereavement support of informal caregivers. While citing sub-optimal professional care and unmet needs of families who require better preparation for the caregiver role, this work focuses solely on health service providers, who are already struggling to meet those needs. Furthermore, this kind of intervention is contingent on the existence of a *palliative care patient*; assistance in preparing for death can only commence post-diagnosis. As a social model of care, HPPC acknowledges that responsibility for the support of people with life-limiting illness rests with entire communities, not just individuals or palliative care service providers (Earle, Komaromy, and Bartholomew 2009; Rosenberg and Yates 2011). This appreciation in turn calls not for the *provision* of, but for the collective *building* of community capacity in a way that normalises death and prepares communities for end-of-life, in a manner that is not contingent on diagnosed disease.

There is however, a notable absence of substantive guidelines in the HPPC discourse for the building of community capacity, perhaps hindering the uptake of HPPC. While there is some early evidence to suggest that the public health approach of HPPC is gaining momentum in the Australian setting, its uptake and utility in this country has not been formally examined. Notwithstanding the work of Pegg and Tan (2002) and Rosenberg (2007), there have been to date few empirical HPPC studies. This paper addresses this gap by identifying and exploring community-based practices focused on community capacity-building around dying and death in the ACT.

Methods

Following ethical approval from the Australian Catholic University Human Research Ethics Committee, a qualitative interpretive approach was used to engage with eight local community groups identified as having an interest in issues of death, dying and end-of-life care. Ten representatives from these groups were recruited through purposive sampling, having identified that both the objectives of each community group and the roles of participants were of direct relevance to the aim of the study. In the case of larger community groups where multiple support roles existed, two representatives were recruited.

Data were collected via ten in-depth, semi-structured, digitally-recorded interviews augmented by field notes. Verbatim transcripts were manually coded and analysed thematically. Methodological rigour was addressed primarily through an audit trail and the documented reflexivity of the researchers.

Findings

Sample

Nine of the ten participants were women, reflecting women's predominance in informal community caring roles (Rice, Walker, and Main 2008). All participants engaged with local community members by providing direct support following a medical diagnosis. With one exception, the participants interviewed represented a community group engaging with community members – either on the basis of being a disease-specific or carer-specific community group. The remaining group engaged with any person who had been referred to them, primarily through palliative care services. While some of the community groups represented a territory chapter of a national parent body, other groups were formed in a backyard or family room. Their roles varied from providing information help lines and day

respite care, to financial assistance, to coordination of peer support and social activities. Although a disease-specific context was not an inclusion criteria, the life-limiting diseases represented within the community group sample included motor neurone disease, dementia, muscular dystrophy, and cancer. Table 1 provides an overview of the community groups and the number of participants interviewed.

INSERT TABLE 1

Each community group supported people of various ages; collectively there was full coverage across the lifespan. While their activities did not include any formal provision of palliative care, the focus of groups' engagement was holistic and not limited to individuals living with a life-limiting illness, but extending to families and social networks. Pseudonyms are used for interview participants.

Emergent Themes

Three themes emerged from the data and are reported here. *Practical Support, Respect and Responsiveness*, and *Connection and Empowerment* corresponded to the community activities initiated in response to terminal illness.

Practical support

Many examples of practical support were offered by and in the community. These included financial assistance to accommodate treatment or medication expenses and the provision of food and fuel vouchers. Free financial planning services were available for debt management and accessing superannuation. Legal services were offered for will preparation:

We provide financial assistance by paying for...their medication. We pay for their chemotherapy bills. We pay for nutritional drinks...and we give food and fuel vouchers...to help put food on the table and the fuel to get to their appointments.

(Tania)

The financial planning and legal services might be looking at accessing superannuation earlier; getting affairs in order – writing up wills and other things.

(Odette)

Practical support was offered in navigating health care, through the provision of information and by way of referrals. This was seen as highly important in addressing the frustration of community members who felt they were alone, as Tania observes:

Nine times out of ten, I hear from people, “Well we got the diagnosis and we were just sent off, and that was it”. So then they start...the journey of the maze, of trying to sort what to do next.

Respect and responsiveness

Responsiveness to the individual’s journey and experience was considered vital, in recognition that people cope or express themselves in different ways at different times. Here Herbert, while using the ubiquitous concept of ‘denial’, nonetheless does so in a respectful and non-pathologising manner:

...the denial; and that’s how some people cope, you know? And that’s not necessarily a bad thing; it’s where they’re at, at the time. It’s not up to me to force people to understand where they’re at.

Respect and discernment was required when encouraging people to attend activities. While encouragement was given, it was seen as important to not be coercive:

...it’s very important to be respectful of that because you don’t want to push them away; they are already going through a hard time; you don’t want to make them feel even more pressured to come on something [activity]. (Odette)

Normalisation activities were used strategically to counter the adverse effects of stigma and resistance to social participation or to aid open discussion about death and dying:

We go to the beach, we go to the snow next week, so just kind of purely respite and recreation activities that people are allowed to come along to, and that one's all about just meeting new people and connecting with others, and just that knowledge or normalising it a bit that there's other people in a similar situation. (Jennifer)

Information was provided to clarify the concept of palliative care. The way this was communicated was seen as influencing how well the information was received. Resistance around barriers of stigma and terminology was addressed by a reframing of 'dying' to 'living':

Often I need to explain exactly what palliative care is. You just say "look, palliative care isn't just the last six weeks – end of life; it's your journey with cancer from the very beginning, and it's to make your life – give you more quality of life, and to enjoy family time, and things you still want to do". (Odette)

Connection and empowerment

Peer support strategies provided social community interaction to balance the frequent medical interactions associated with treatment and professional care. Empowering opportunities for social reconnection offered the potential for meaning-making:

Trying to get these people to reconnect socially and also to give them that confidence that they do make a difference in society, they do make a difference in everyone's life by being here and sharing their life with us or sharing their life with the other clients. (Tania)

Tania's use of 'clients' above demonstrates a curious tension within the de-professionalised discourse promoted by HPPC. Jennifer below similarly uses language more commonly associated with the professions, saying: "It's all about independence and enabling, and empowerment." Notwithstanding this linguistic tension, community participants showed sophistication in their understanding of the need to frame dying as a normal part of life.

Central to the promotion of connection and empowerment, normalisation was a common guiding principle for planning and organising activities:

A lot of our programs, especially the recreational-based ones, are everyone coming together and just, meeting with people and normalising experiences. (Jennifer)

The principles of peer support and normalising everyday experiences encouraged active participation and fostering of new social networks. Activities included arts, exercise and social outings in the local community:

...it's the social group; it's really about the socialisation and you know, getting out and about in the local community. (Stephanie)

...the sorts of things we offer are the art groups; exercise groups; the gallery visit groups; the walking groups...they're just normal activities. (Herbert)

Many forms of support for grief and bereavement were also offered, and these began with conversations before death, consistent with the concept of anticipatory grieving:

We talk about trying to use it as an opportunity to sort of set the record straight...if there's any unspoken things [sic] that they need to deal with now; rather than waiting for the person to pass away, and then regret that they haven't said anything. (Herbert)

There was a perception that for the bereaved, there is an aversion towards contact with health professionals after death:

When someone loses someone, the last thing they want to do is have something to do with the medical [sic]. (Stephanie)

Forms of communal memorial activities were used to actively promote collective grieving.

These included the use of a remembrance tree in the foyer of a community group's centre:

...they can put their picture up there when they pass – like, the families do, and that's our tree of life. Everyone loves the tree. I suppose it's just a remembrance tree. (Maryanne)

Discussion

So, whose business is HPPC? The above findings indicate that care of the dying occurs in an environment that is occupied by both community groups and health care service providers. Within this space there is an ‘opportunity to reconceptualise dying as the business of individuals, communities and societies, including, but not constrained to, the provision of palliative care’ (Rosenberg 2011, 27).

From this understanding of dying it follows that a whole-of-community response to end-of-life care matters incorporates both social and professional discourses. The concerns of community ownership and agency are fundamental to the business of HPPC. Questions arise from this study however, regarding the accessibility of HPPC for communities. Is community ownership included in the building of community capacity? Is community capacity in end-of-life care seen as more than reactive and ad hoc provision of services not readily accessible elsewhere in the ‘system’? Is community agency adequately recognised through the HPPC lens? Such questions may inform future studies into HPPC and community capacity.

The processes of connection and empowerment, respect and responsiveness, and practical support were identified as communal responses to the experience of death and dying. These were reflected in the health-promoting activities of community groups in this study that fostered socialisation, peer support and normalisation of death and dying. Such processes have been identified as assisting communities to build capacity to demonstrate healthy attitudes and practices regarding death, dying and end-of-life care (Kellehear and Young 2012; Street 2007).

Community responses to burdens of care

Despite the development of palliative care into a mainstream specialty area of professional practice, this study’s findings suggest that many burdens of informal care outlined in the literature (Kovacs and Fauri 2003) continue under a service provision-oriented model. Carer

burden, stigma and loss continue to be challenges for communities, compounded by the limited response capacity of professional service providers (Chiarella and Duffield 2007).

The informal care and support provided by the community groups in this study were aligned to increasing community capacity through the redress of loss, isolation, and practical hardships faced by both those living with dying and those around them. While community groups' activities did not constitute formal provision of palliative care, the content and focus of their activities were both holistic and extending toward families and social networks. This resonates with the philosophy of palliative care espoused by formal service providers (Lewis 2007).

Identification of HPPC practices within the community

In seeking to build professional capacity through HPPC, Kellehear (1999, 33) observed that 'the practice of health promotion does exist in palliative care today, although its existence is not common'. In respect of community-driven practices, this study identified existing HPPC activities suggestive of a self-determined community capacity. This finding is important, in that consideration of *pre-existing* community capacity has been largely absent from previous HPPC projects (Kellehear and O'Connor 2008; Kellehear and Young 2012; Salau et al. 2007). For example, Kellehear and Sallnow (2012, 10) critique the service provision approach of 'things to be done TO communities – rather than things to be done WITH communities'. However, the above criticism could be made of previous HPPC interventions themselves, in addition to the service provision approach of PCA's (2005) national standards, where the building of community capacity is principally rendered as another service provided by palliative care professionals.

Context of HPPC activities in response to disease

The health-promoting activities identified in this study were initiated by community groups in response to particular disease entities. Across the eight participating groups, six disease-

specific groups were represented, accommodating the needs of communities arising from specific diagnoses. This raises implications for those living and dying with other health conditions, regarding what comparable social supports are available to these community-dwellers. Preparatory processes, that is, community activities around dying and death not linked to known life-limiting illness, would be of yet further assistance (Kellehear and Fook 2010).

As outlined in the literature, HPPC activities are not contingent on a medical diagnosis, but based upon fundamental appreciation of a shared mortality; that death is a normal life event, and not a medical failure (Kellehear 2005). A core principle of HPPC is that community capacity-building takes place outside the context of medical diagnoses, through death education and in recognition of death as a normal part of everyday life (Kellehear and Fook 2010). The absence of health-promoting community activities found outside of a medical context in this study highlight an area ripe for investigation in future community capacity-building initiatives.

To this end, the development of guidelines that include preparatory processes for communities might better assist the building of community capacity for end-of-life. While HPPC practice guidelines were developed by Kellehear *et al.* (2003), these too were service provision-oriented. PCA's national palliative care quality standards (2005) explicitly cite the importance of community capacity-building, however, implicitly deny community agency and ownership of the process via a focus on service provision. A need for community-based guidelines around building community capacity for end-of-life is evident; they could be developed in collaborative partnerships between community groups and health service providers. The guidelines could also encompass preparatory death education (Kellehear and O'Connor 2008) to address related difficulties for the entire community, not only those who are dying. This approach might articulate with the professionally established phases of

palliative care (Eagar et al. 2010) as a 'preparation' phase; thereby contributing to the reorientation of health services from their preoccupation with disease to a more authentic public health response.

Limitations

This study's scope is limited in respect of addressing community capacity in eight identified support groups in one Australian city. The results are not intended to be generalisable however, but rather to extend understandings of existing community capacity as evidenced by activities initiated in response to the experience of life-limiting illness. Activities supporting those without known medical conditions were not identified; exploring such practices would provide further understanding of existing community capacity.

An Indigenous community group was a potential participant, however was unable to be recruited due to the lengthy consultation processes required with a Secretariat and Elders' Council. Future work might usefully explore the practices of more socially diverse groups, particularly in the light of observations around community bereavement groups for example being primarily attractive to the middle class (Allen 2007).

Conclusion

This paper has highlighted the processes of connection and empowerment, respect and responsiveness, and practical support that currently enable and reflect community capacity to demonstrate healthy attitudes and practices regarding issues of death, dying and end-of-life. These processes were demonstrated within community group activities that promoted socialisation, peer support and normalisation.

In this study, community-based activities were initiated in response to specific illnesses. Thus, the support provided to community members was contingent on those members being a 'patient' or 'carer' of someone diagnosed with those diseases. Future work might profitably consider what community supports exist for those with *other* diagnoses, and

redress the apparent lack of pre-emptive activities that support the community *prior* to illness—on the basis of a universal mortality rather than diagnosed disease.

Rumbold (2012) notes the importance of partnership in community capacity-building for end-of-life. Community groups and health service providers are currently both limited by resource availability and funding capacity. Effective partnerships that acknowledge mutual ownership and barriers, and collaborate towards the achievement of shared goals, offer real possibilities for the building of community capacity for end-of-life. In this way, the whole-of-community may benefit.

This study has presented new considerations of processes and partnerships that assist the building of community capacity for end-of-life. Perhaps of greater significance is that the community's *ownership* in end-of-life concerns is evident, which has not been apparent in previous work. The development of guidelines to inform the building of community capacity for end-of-life could assist in increasing the scope of community activities to encompass death education and the needs of people not yet diagnosed with life-limiting illness. It is consistent, therefore, that such guidelines would be developed in partnerships between community groups, health services and public health workers. In addition to developing community agency and ownership of activities around the universal experience of mortality, following Labonte and Laverack (2001, 124), such engagement may further assist communities to “mobilize needed resources and negotiate more effectively with those agencies and institutions that often gate-keep access to them”, and thereby enhance the operation of HPPC.

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Table 1. Community Group Sample

Groups	Focus of community support	Number of interviewees
A	Dementia	Two
B, C, D	Cancer	Three
E	Carers of people with life-limiting illness	One
F	Respite care for patients with any life-limiting illness	Two
G	Motor Neurone Disease	One
H	Muscular Dystrophy	One