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Informal caring networks for people at end of life: building social capital in Australian communities.

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Abstract

The care of a person living at home near the end of their life is predominantly provided by family carers with the support of health services such as palliative care. In addition, informal caring networks also contribute at times to the support to the dying person and their carer. In this way, these networks can promote social capital in the communities from which they are drawn. This social approach to end of life care enhances community capacity to provide support to those dying at home and their carers. This article examines relevant published literature to explore the conceptual foundations of informal caring networks, examining the place of social capital and community development in the provision of end of life care at home, particularly in the Australian context.

Key words community; health promotion informal networks; palliative care; social capital; sociology.

Introduction

In Australia, around 75% of all deaths follow a course of illness reasonably expected to end with death (Palliative Care Australia, 2005). Up to 90% of people with a terminal illness spend most of the final year of life at home (Palliative Care Australia, 2005) and most therefore will need some form of end of life care (EoLC). Family caregivers are essential to this EoLC and when supported by specialist palliative care, report better health outcomes (McNamara & Rosenwax, 2010; Palliative Care Australia, 2010; Thomas, Hudson, Oldham, Kelly, & Trauer, 2010). Further, most Australians indicate a preference to die at home if they have an incurable, progressive illness, however, most will not (Palliative Care Australia, 2011).

The predictors of successful home care at the end of life [EoL] indicate that the presence of a carer from within the dying person's family or circle of close friends increases the likelihood of a home death occurring (Masucci, Guerriere, Cheng, & Coyte, 2010). Yet in turn, these informal carers themselves identify complex support needs in order to succeed at this undertaking (Funk, Stajduhar, Auon, Grande, & Todd, 2010; Stajduhar et al., 2010). Though a substantial proportion of the published literature expresses these needs within the dominant health services paradigm, the role of informal networks in supporting the home-dwelling dying person and their carer is less well understood; moreover, the contribution informal caring networks make to building community social capital is under-attended in the published literature in EoLC. In our examination of the place of social capital and community development in the provision of end of life care at home, we considered the conceptual foundations evident in the health services dominance of EoLC and the emerging narrative regarding health promoting palliative care in the Australian context.

The nature of caring

Over the past ten years, a wide range of research has described the individual experiences and needs of carers and caring at home at the end of life (Donnelly, Michael, & Donnelly, 2006; Weibull, Olsen, & Neergaard, 2008; O'Brien & Jack, 2010; Thomas, Hudson, Oldham, Kelly, & Trauer, 2010). There is now a large body of evidence documenting the burden on family members providing EoLC at home. The average length of community based palliative care is 119 days, of which 117 days of care are typically provided by family, friends, neighbours and community members (Rumbold, 2010). The financial and human costs of such care are well documented (Australian Bureau of Statistics, 2012; Access Economics, 2005). Research describes both carers' and patients' risk-factors and the 'optimal' kind of services required to support caregivers and people with terminal illnesses when they are cared for at home (Foreman, Hunt, Luke & Roder, 2006; Hudson, 2003; Palliative Care Australia, 2005; Tang, 2003; Zapart, Kenny, Hall, Servis & Wiley, 2007). The consequences for carers of providing EoLC include adverse physical, social and psychological effects with stress, poor mental health, sleep disruption, fatigue, family and social isolation all noted as significant burdens (Grande et al., 2009; Zapart, Kenny, Hall, Servic, & Wiley, 2007). The physical and psychological demands of the caring role itself can lead to adverse health and social outcomes for carers; the Australian Institute of Health and Welfare (2008) reported that older carers were more likely than their non-carer peers to have a disability (61% to 51%) and although a third felt satisfied with their caring role, a similar proportion frequently felt fatigue and weariness.

However, it is also recognised that caring provides personal rewards as well as burdens (Zapart et al., 2007). Carers report considerable satisfaction and benefits from caring for terminally ill people (Zapart et al, 2007; Hudson 2003; Grande et al, 2009). Currow et al (2011) found that 75% of people who have cared for someone who is dying would indeed do it again – this finding was stable across all age groups. Positive aspects of caring at EOL include an increase in personal satisfaction and commitment (Donnelly, Michael & Donnelly, 2006), and caring as an expression of love and increased intimacy (Aranda & Hayman-White, 2001; PCA, 2004; Horsfall et.al. 2013). In a comprehensive, two-part review of both quantitative (Funk et al., 2010) and qualitative (Stajduhar et al., 2010) research literature into home-based family caregiving (1998-2008), loneliness, social isolation and dysfunction were identified as prevalent burdens amongst carers, whilst the essential role of the family caregiver was strongly acknowledged. Notably, however, the place of social networks is not clearly identified in these reports. Given the universal nature of the experience of dying, why are informal social networks not noticeably evident in the literature?

The professionalisation of EoLC

Dying was once considered a social and community event, however, over the last 50 years or so, dying and death have become medicalised life events, especially in developed countries (Howarth, 2007; Kellehear, 2007). This change to the social positioning of death and dying has profoundly altered people's experiences of death, and greatly influenced societal attitudes about death, dying, and the provision of EoLC. Dying has become firmly located within the remit of health care systems and its perceived experts, with the result that for most people, the process of dying is both medicalised and institutionalised (Howarth, 2007).

Although significant and effective advances have been made in the clinical care of people receiving EoLC, the published discourse and models of palliative care provision are dominated by health services approaches. It has been suggested that community knowledge of EoLC has waned as a result of this dominance of EoLC by health systems, wherein the navigation of EoLC has become the remit of the 'expert' in a paternalistic dyad with the dying person and their carer (Gomes & Higginson, 2006; Kellehear, 1999). Over the past 15 years or so, however, there has been an increasing acknowledgement that highly medicalised health care for people nearing the EoL is an *incomplete* response to dying. Byock and colleagues articulated this point clearly:

> 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. (Byock, Norris, Curtis, & Patrick, 2001, p.760)

Further, Conway (2008) sounded a warning to the health care professions and the community itself, suggesting:

> …death and loss are increasingly being seen and misunderstood as a private matter, rather than the most 'universal and routine human experience of all.' The 'professionalisation' of death and loss carries with it the dangers of a continuing exclusion of communities and the consequences of this are likely to be profound. (p.411)

The place of the whole community in supporting its dying members is gradually being reconsidered as an integral component of a more complete response to EoLC, particularly as health care services are increasingly less able to respond to the clinical demands of palliative care service provision. At a global level, community engagement is understood to be an essential component of the response to the support of dying people (Stjernsward, 2007). In widely varying contexts, communities are being challenged to respond to a complex, yet universal, experience. The need for community involvement has been articulated in the emergence of Health Promoting Palliative Care (HPPC).

Health Promoting Palliative Care

In response to a growing concern with the consequences of the professionalisation of palliative care practice in the broader setting of health care, the concept of HPPC emerged in the late 1990s. Australian sociologist, Allan Kellehear (1999, 2005) proposed the application of the core principles of health promotion to the practice of palliative care. HPCC is defined as a social approach to care that promotes optimal health in individuals, their carers, and communities, even in the presence of incurable disease (Rosenberg & Yates, 2010). HPCC strategies include:

- Provide education and information for health, death and dying.
- Provide social support at both personal and community levels.
- Encourage interpersonal reorientation.
- Encourage reorientation of palliative care services.
- Combat death-denying health policies and attitudes (Kellehear 1999, pp. 19–20).

Rather than primarily focussing upon the provision of health services, HPPC advocates a wider focus on social change for palliative care services and other groups concerned with EoLC and related issues (Rosenberg, 2011). As a national peak body representing services supporting people nearing EoL, Palliative Care Australia (PCA) has articulated the health promoting component of palliative care in its *National Standards for Providing Quality Palliative Care for All Australians*, stating that community capacity is created through partnerships between services and the dying person, their carers and family (Palliative Care Australia, 2005). This is evident elsewhere, including the UK where the principles of HPPC are incorporated into an aim to effect social change:

> A commitment to support changing knowledge, attitudes and behaviours around death and dying, and aim to encourage a greater

willingness to engage on death and bereavement issues. (http://www.dyingmatters.org/)

Moreover, as palliative care services demonstrate proximity to, and familiarity with, the issues of dying and death, this approach has found its way into the national agenda for health and wellbeing in the *Australian Government National Strategic Plan for Palliative Care* (Commonwealth of Australia, 2010):

- Goal #1: to significantly improve the appreciation of dying and death as a normal part of the life continuum.
- Goal #2: to enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services.

Whereas there is evidence that goal #2 is addressed routinely in Australia (see www.palliativecare.org.au), it is less clear how goal #1 is attended to. There is emerging evidence that the Australian government policy on community capacity building (Commonwealth of Australia, 2010) and the HPPC approach to EoLC (Kellehear, 2005) has not been widely translated to practice in the field. Examples can be found in Australia (Kellehear & O'Connor, 2008; Mills, Rosenberg & McInerney, 2014; Rumbold, 2010) and internationally (Sallnow, Kumar, & Kellehear, 2012) including developing countries (Kumar, 2007; Salau, Rumbold, & Young, 2007), however for the most part these approaches are unheard of or have yet to be utilised by the majority of formal service providers (Horsfall, Leonard, Noonan & Rosenberg, 2013). Nevertheless, social approaches to the support of people requiring EoLC returns responsibility for that care to whole communities, rather than solely clinical services or, indeed, dying persons and their carers in isolation from the communities in which they live.

The gap between the rhetoric of HPPC and the reality of the experiences of many carers is quite stark. It is not immediately obvious how to move from the current situation to empowered, capable and supported communities working alongside health services to enhance EoLC. However, we argue that informal caring networks have an important role in that change.

The key role of informal caring networks for carers and communities

Although it has been noted that support networks for carers can have a crucial role in effecting positive outcomes for carers (Greene et.al. 2011; Hudson, 2003), there are few examples where research identifies carer support needs that include the provision of informal support. One example is an Australian study of a metropolitan community (Zapart et al., 2007), in which social networks are mentioned in passing as a possible source of emotional support. Another study mentions the social impacts on family caregivers although this is not elaborated upon (Thomas et al., 2010). One review noted that the network of carers around a dying person can be the source of some complexity (for the health services involved) given current changing social demographics (Grande et al., 2009).

Perhaps less evident, but equally important, is that informal caring networks may also have a positive effect *for communities*. It has been argued that community capacity building at the end of life can contribute to approaches to EoLC that provide greater community self-sufficiency and sustainability within the context of our rapidly ageing society and highly medicalised dying (Kellehear, 2005; Leonard, Horsfall, & Noonan, 2010; Rosenberg & Yates, 2010; Street, 2007). This has been found in related fields of care, for example, frail elders (Keating & Dosman, 2009), chronic and eventually-fatal Alzheimer's disease (Carpentier & Greiner, 2012) and motor neurone disease (Ray & Street, 2005). Further, Horsfall, Leonard and Noonan (2011), in partnership with Cancer Council NSW (CNNSW), recently conducted a research project that sought to understand how being involved in caring for someone dying at home positively affected family, friends and the wider community. Focus groups with primary carers and members of carers’ informal support networks found that these networks comprised informal support from family, neighbours, friends, workmates, volunteers and community members. Using photo-voice methods and participatory network mapping this project found that all but one of the networks were extended and strengthened by the caring experience, with networks growing in terms of the number of people involved and the intensity of relationships. In this study, people often maintained the connections after EoLC activities had ceased, with caring networks not only supporting the principal carer but contributing to building a community that is knowledgeable about EoLC (Horsfall, Noonan, & Leonard, 2012; Leonard, Horsfall, & Noonan, 2013; Noonan, Leonard, & Horsfall, 2011).

A number of other authors emphasise the importance of a refocus from individual to community capacity building and community development for EoLC, in particular Donnelly et al (2006), Kellehear (2005) and Thomas et al (2010). Current Australian policy asks palliative care services to move towards implementing the *National Strategic Plan* that foregrounds health promoting approach to palliative care (Palliative Care Australia, 2010), and takes up the concepts of community capacity building and community development. This approach is well described by Kellehear (2005), Rumbold (2010), and Rosenberg (2011). In an Australian example, Thomas et al (2010) argue that there is a disparity between the current practice and the Australian standards in palliative care which promotes the provision of support to the primary caregiver and family. Their findings describe a tendency for palliative care services to focus on individual caregivers, and we argue that there is significant value in further understanding the input and caring of the sometimes extensive network of people supporting the primary family carer. However, it is important to avoid a simplistic notion of ‘community’ as a universal panacea, and carefully analyse the contribution that informal caring networks contribute to building social capital and community development.

Social capital and community development

Social capital and community development are two theoretical frameworks which provide a conceptual link between the networks around an individual carer and the building and strengthening of the community. Although social capital is a contested concept, there is evidence that it is capable of producing a variety of positive outcomes beyond economic advantages, such as improved health and wellbeing (Halpern, 2005; Putnam, 2000). The term ‘social capital’ has been used widely and rather loosely, but we use Putnam’s 1993 definition which states social capital comprises:

> …those features of social organisation, such as trust, norms and networks that can improve the efficiency of society by facilitating coordinated actions. (Putnam 1993, p.167)

When caring is linked to social capital, it is generally assumed that social capital is a resource that can be used for care work (Johansson, Leonard, & Noonan, 2012); however, this does not have to be the case. EoLC can contribute to social capital when deliberate efforts are made to build formal or informal relationships to connect carers with the wider community. Recently there has been a growing interest in examining social capital in palliative care conceptually. Lewis and colleagues (2013) have provided a summary detailing how they see a social capital framework as it applies to the social networks and relationships in the palliative care setting. They argue that at the micro-level of analysis, bonding networks provide not only resources and help with daily functions but also build trust and a sense of belonging. At the meso-level, bridging networks can enable access to information and local services and create a sense of community inclusion and cohesion. At the macro-level, linking networks provide access to government to obtain resources for the lower levels, increase civic trust and social cohesion, and influence policy.

However, a barrier to bridging social capital is that the relationship between EoLC service providers and communities largely remains a paternalistic one, with the expert-recipient dyad predominant in Australia and elsewhere. There are a number of key activities defined as community participation, including fundraising, open days, public forums and volunteer programs, although these are arguably not community development activities. Community participation in service governance is less evident, despite the assertion that ‘a key way for any healthcare practice to claim social acceptability is to consult about its appropriateness through the participation of the community’ (Conway, 2008, p.407). Similarly, Zapart et al., (2007) note that it is a challenge for health professionals to identify the support needs of carers without replacing the carer’s role. Even when formal service providers have a positive regard for informal caring networks, they typically keep their distance and play a minimal role in mobilising, supporting and maintaining these networks (Horsfall, et. al. 2012).

People vary in their ability to access the various types of social capital depending on their social and cultural context. For example, previous research on social capital suggests that rural and regional communities find it easier to mobilise around areas of perceived need (Leonard & Onyx, 2010). Further, people from rural communities need to travel further to access services (AIHW, 2008), and have reported unmet needs for support during dying, including inadequate provision of information, fewer options for transport, and greater need for practical care and support (White, 2007). Although this suggests heightened needs may be appropriately addressed by rural communities’ responses, the experiences of CCNSW over the past 20 years suggest that issues of privacy in rural and regional areas work against mobilising informal care networks (CCNSW, 2012). These observations indicate not only the need for further investigation into the particular needs of rural and regional communities and strategies for managing privacy concerns when they arise, but also the need to recognise the diversity of Australian society more generally.

Social capital, however, is not sufficient to guarantee community development (Mayer & Rankin, 2002). The Community Development Foundation defines community development as “any practice which results in the development of communities or community activity… the purpose of community development is to help groups and networks of people to take joint action on matters that concern them for the public good.” (www.cdf.org.uk) Community development approaches build stronger and more resilient local communities, by empowering individuals and groups of people, providing them with the skills they need to affect change in their own communities. If a community is to develop its capacity to both make decisions about the type of support they require, when and where, in addition to providing informal support for those at EoL it will need knowledge and experience, a sense of empowerment and supportive social structures (Gilchrist, 2000; Kenny, 1994), and as noted above, these elements have been diminished due to the medicalisation and institutionalisation of death. Kellehear (2005) noted that genuine community development provides opportunities for experiential, practical knowledge to be developed and stay present within the community, because people have had the chance to become aware of their own abilities, knowledge and skills. He argued that this process allows communities to utilize available support systems, problem solve, make decisions, and communicate and act more effectively. Involvement in broad social networks around EoLC provides opportunities for many people to learn about caring and the provision of support for carers without being the principal carer.

Conclusion

There is a major gap between the ideals of Health Promoting Palliative Care and the reality of many carers' experiences of isolation and overwork. We argue that an essential step in closing that gap is by understanding and strengthening the social networks surrounding carers. Previous research (Horsfall, Noonan, & Leonard, 2012) has found that people can and do die well at home providing they are supported by a complex network of community carers. It also found that in order to make sure that community caring networks are sustainable and people who provide unpaid caring are not exploited and isolated, carers and networks need support. It is suggested here that organisations that provide care at EoL could take an active role in facilitating and supporting informal caring networks and further develop the community's capacity to provide care at EoL. This investment in community networks is then part of a positive cycle. Using Lewis et al's (2013) typology, these networks create more bonding social capital among community members, and bridging social capital between the community and service providers. In turn, this may assist in the development of linked social capital, as community and service providers work together engage government and promote informal caring networks for EoLC.

Furthermore it is clear that a research focus on informal networks is long overdue. If palliative care services are to reorient themselves to actualize Health Promoting Palliative Care, then a deeper understanding of the role of carers and informal caring networks from community development and social capital perspectives could indicate the path to that goal.

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References

Access Economics Pty Ltd. (2005) *The economic value of informal care*. Report prepared for Carers Australia. Canberra: Carers Australia.

Aranda, S. K., & Hayman-White, K. (2001). Home caregivers of the person with advanced cancer. *Cancer Nursing, 24*(4), 300-307.

Australian Bureau of Statistics (2012). Caring in the community: Australia (Cat no. 4436.0). Canberra: ABS.

Australian Institute of Health and Welfare. (2008). *Australia's Health 2008.* Canberra: AIHW.

Byock, I., Norris, K., Curtis, J. R., & Patrick, D. L. (2001). Improving end-of-life experience and care in the community: a conceptual framework. *Journal of Pain and Symptom Management*, *22*(3), 759-772.

Cancer Council New South Wales & LifeCircle. (2012). Submission in response to "Palliative Care NSW policy statement discussion paper". Available from http://www.cancercouncil.com.au/wp-content/uploads/2012/02/Submission_Palliative-Care_Jan-2012.pdf

Carpentier, N., & Greiner, A. (2012). Successful linkage between formal and informal care systems: the mobilization of outside help by caregivers of persons with Alzheimer's Disease. *Qualitative Health Research, 22*(10), 1330-1344.

Commonwealth of Australia (2010). *Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy 2010*. Canberra: Commonwealth of Australia.

Conway, S. (2008). Public health and palliative care: principles into practice? *Critical Public Health, 18*(3), 405-415.

Currow, D. C., Burns, C., Agar, M., Phillips, J., McCaffrey, N., & Abernethy, A. P. (2011). Palliative caregivers who would not take on the caring role again. *Journal of Pain and Symptom Management, 41*(4), 661–72.

Donnelly, S., Michael, N., & Donnelly C. (2006). Experience of the moment of death at home. *Mortality, 11*(4), 352-367.

Foreman, L., Hunt, R., Luke, C., & Roder, D. (2006) Factors predictive of preferred place of death in the general population of South Australia. *Palliative Medicine, 20,* 447-453.

Funk L. Stajduhar K. Toye C. Aoun S. Grande G., & Todd C. (2010). Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research 1998-2008. *Palliative Medicine, 24*(6), 594-607.

Gilchrist, A. (2000). The well-connected community: networking to the “edge of chaos”. *Community Development Journal, 35,* 264–75.

Gomes, B., & Higginson, I. J. (2006). Factors influencing death at home in terminally ill patients with cancer: a systematic review. *BMJ Clinical Research, 332*(7540), 515-518.

Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., Payne S. & Todd, C. (2009). Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine, 23,* 339-344.

Greene, A., Aranda, S., Tieman, J., Fazekas, B., & Currow, D. C. (2011). Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: Community facilitator pilot. *Palliative Medicine, 26*(7), 917-23.

Halpern, D. (2005). *Social Capital.* Cambridge: Polity Press.

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J.P. (2013). Working together apart: exploring the relationships between formal and informal care networks for people dying at home. *Progress in Palliative Care, 21*(6), 331-336.

Horsfall, D., Noonan, K., & Leonard, R. J. (2012). Bringing our dying home: how caring for someone at end of life builds social capital and develops compassionate communities. *Health Sociology Review, 21*(4), 373-382.

Howarth, G. (2007). *Death and Dying: A Sociological Introduction*. Cambridge: Polity Press.

Hudson, P. (2003). Home-based support for palliative care families: challenges and recommendations. *Medical Journal of Australia, 179,* S35- S37.

Johansson, S., Leonard, R., & Noonan, K. (2010). Caring and the generation of social capital: two models for a positive relationship. *International Journal of Social Welfare, 21,* 44–52.

Keating, N., & Dosman, D. (2009). Social capital and the care networks of frail seniors. *Canadian Review of Sociology, 46*(4), 301-318.

Kellehear, A. (1999). Health-promoting palliative care: Developing a social model for practice. *Mortality, 4*(1), 75-82.

Kellehear, A. (2005). *Compassionate Cities: Public Health and End-of-Life Care*. Oxfordshire UK: Routledge.

Kellehear, A. (2007). *A Social History of Dying*. Cambridge: Cambridge University Press.

Kellehear, A., & O'Connor, D. (2008). Health-promoting palliative care: A practice example. *Critical Public Health, 18*(1), 111-115.

Kenny, S. (1994). *Developing Community for the Future: Community Development in Australia*. Melbourne: Thomas Nelson.

Kumar, S. (2007). Kerala, India: a regional community-based palliative care model. *Journal of Pain and Symptom Management, 33*(5), 623-627.

Leonard, R., & Onyx, J. (2003). Networking through loose and strong ties: an Australian qualitative study. *Voluntas, 14*(2), 191-205.

Leonard, R., Horsfall, D., & Noonan, K. (2010). Models of caring from India and Australia and their relationship to social capital. *Nepalese Journal of Public Policy and Governance, xxvi*(3), 15-25.

Leonard, R., Horsfall, D., & Noonan, K. (2013). Identifying changes in the support networks of end-of-life carers using social network analysis. *British Medical Journal Supportive and Palliative Care*. doi: 10.1136/bmjspcare-2012-000257 appeared on line 20.11.2013 (Epub ahead of print)

Lewis, J. M., DiGiacomo, M., Luckett, T., Davidson, P.M. & Currow, D. (2013). A social capital framework for palliative care: supporting health and well-being for people with life-limited illness and their caregivers through social relations and networks. *Journal of Pain and Symptom Management, 45*(1), 92-103.

Masucci, L., Guerriere, D. N., Cheng, R., & Coyte, P. C. (2010). Determinants of place of death for recipients of home-based palliative care. *Journal of Palliative Care, 26*(4), 279-286.

Mayer, M., & Rankin, K. (2002) Social capital and community development: a North/South perspective. *Antipode, 34*(4), 804-808.

McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science and Medicine, 70*(7), 1035-1041.

Mills, J., Rosenberg, J.P., & McInerney, F. (2014). 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. *Critical Public Health.* Online first. DOI: http://dx.doi.org/10.1080/09581596.2014.945396

Noonan, K., Leonard, R., & Horsfall, D. (2011). You can’t do that! Researching alternative stories of community participation at end of life. *Third Sector Review, 17*(1), 75-89.

O’Brien, M., & Jack, B. (2010). Barriers to dying at home: the impact of poor coordination on community service provision for patients with cancer. *Health and Social Care in the Community, 18*(4), 337-345.

Palliative Care Australia. (2004). *The hardest thing we have ever done: the social impact of caring for terminally ill people in Australia*. Canberra: Palliative Care Australia.

Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for All Australians*. Canberra: Palliative Care Australia.

Palliative Care Australia. (2010). *Health System Reform and Care at the End of Life: a Guidance Document*. Canberra: Palliative Care Australia.

Palliative Care Australia. (2011). We need to talk about dying – survey (media release). Ret. Nov2013. Available from http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf

Putnam, R. (2000) *Bowling Alone: The Collapse and Revival of American Community*. New York: Simon & Schuster.

Ray, R. A., & Street, A. F. (2005). Who's there and who cares: age as an indicator of social support networks for caregivers among people living with motor neurone disease. *Health & Social Care in the Community, 13*(6), 542-552.

Rosenberg, J. (2011). Whose business is dying? Death, the home and palliative care. *Cultural Studies Review, 17*(1), 15-30.

Rosenberg, J. P., & Yates, P. M. (2010). Health promotion in palliative care: the case for conceptual congruence. *Critical Public Health, 20*(2), 201-210.

Rumbold, B. (2010). Health promoting palliative care and dying in old age. In M. Gott & C. Ingleton (Eds.), *Living with Ageing and Dying*. Oxford, UK: Open University Press.

Salau, S., Rumbold, B., & Young, B. (2007). From concept to care: enabling community care through a health promoting palliative care approach. *Contemporary Nurse, 27*, 132-140.

Sallnow, L., Kumar, S., & Kellehear, A. (2012). *International Perspectives on Public Health and Palliative Care*: Oxford, UK: Routledge.

Stajduhar, K. I., Funk, L., Toye, C., Grande, G. E., Aoun, S., & Todd, C. J. (2010). Part 1: Home-based family caregiving at the end of life: a comprehensive review of pulished quantitative research (1998-2008). *Palliative Medicine, 24,* 573-593.

Stjernsward, J. (2007). Palliative care: the public health strategy. *Journal of Public Health Policy, 28,* 42-55.

Street, A. F. (2007). Leading the way: innovative health promoting palliative care. *Contemporary Nurse, 27,* 104-106.

Tang, S. (2003) When death is imminent: where terminally ill patients with cancer prefer to die and why. *Cancer Nursing, 26* (3), 245-251.

Thomas, K., Hudson, P., Oldham, L., Kelly, B., & Trauer, T. (2010). Meeting the needs of family carers: an evaluation of three home-based palliative care services in Australia. *Palliative Medicine, 24*(2), 183-191.

Weibull, A., Olsen, F., & Neergaard, M. (2008). Caregivers' active role in palliative home care - to encourage or to dissuade? A qualitative descriptive study. *BMC Palliative Care, 7*(15), 1-8.

White, K. (2007). Rural palliative care: exploration of the pivotal role of primary healthcare providers. *Cancer Forum, 31*(1): 22-5.

Zapart, S., Kenny, P., Hall, J., Servic, B., & Wiley, S. (2007). Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care. *Health and Social Care in the Community, 15*(2), 97-107.