

THE PARTICIPATION OF VOLUNTEERS IN CONTEMPORARY PALLIATIVE CARE

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ABSTRACT

Historically, in Australia, individuals with widely differing interests, skills and values have engaged collaboratively, in a voluntary capacity, to establish services to assist persons experiencing particular need or hardship. Gradual recognition and acceptance by the State of its social responsibilities to citizens with various needs in areas of health, welfare, education and others, have seen the provision of a range of statutory services available to all Australians. Volunteer participation in the delivery of modern health services, therefore, is not usual; palliative care is an exception rather than a norm.

This article explores the relationship between understandings of death and dying in Western culture and the participation of volunteers in contemporary palliative care. The author presents a view that volunteers provide a distinctive contribution to the quality of care delivery and to enrichment of the social environment of the wider community also. The topic is of relevance to all nurses and especially those involved in the care of dying persons and of their families.

INTRODUCTION

Until the second half of the 20th century in Australia, most terminally ill patients were cared for at home and died there. A small number only of hospices conducted by Catholic and Anglican communities offered care and support exclusively to dying patients and to their families (Redpath 1998). In subsequent decades, persons dying of life-threatening illnesses were cared for in acute hospitals where the ideas and ethos under-lying services gave emphasis and priority to those interventions directed towards prolonging life and eradicating disease.

Patients whose illness was unresponsive to medical interventions received limited information as to their health status and the choices open to them in relation to care (Redpath 1998; Kasap et al 1997). Most patients admitted to acute care institutions died there. Nevertheless, some people expressed a preference to die at home (Kingsbury 1980). During the 1980s, a variety of community-based programs, offering alternative approaches to care of dying persons emerged across the country. Financed, in the main, by charitable and/or non-profit organisations, such programs gave visibility to the independent and varied efforts of individuals and groups (both lay and professional) who sought to bring about change in the care of patients living with terminal illness (Redpath 1998; Elsey 1998).

Since 1989, the Australian Federal Government has provided monies for a range of palliative care programs in all States and Territories of Australia.

'Palliative care' is defined as 'specialised health care of dying people aiming to maximise quality of life, and assist families and carers during and after death' (Palliative Care Australia 1999, p.v). A common feature of contemporary models of service delivery in Australia is the participation of volunteers in care programs, where appropriate. The inclusion of 'non-professional' volunteers as care team members directs attention to considerations of social attitudes towards the phenomenon of death and the care of dying persons and their families (however defined). What do volunteers offer when caring for vulnerable and dying persons?

This paper explores understandings of death and dying in Western society and elements of volunteering, using selected theoretical and philosophical assumptions and research findings, where available. Approaches to hospice/palliative care are outlined and are used to provide a context for discussion of aspects of volunteer involvement in contemporary palliative care and what volunteers may offer patients and society generally. No attempt is made to consider the economics of volunteer participation in care programs.

Death and dying in contemporary Western culture

In itself, death is a mystery. Our attempts as embodied beings to conceptualise our own death in terms of non-being, non-existence or nothingness are futile and nonsensical (Bury 1997, Bauman 1992). Yet the meanings of death to individuals and communities are profound. The unfathomable nature of mortality and its inevitability, commonly provoke feelings of anxiety, fear and insecurity and challenge the meaningfulness of human life. Each culture handles the actuality of death, of dying and of living in its particular way, constructing its own sets of meanings, belief systems and patterns of social activity which seek to ensure ontological security of individuals and continuing social stability of communities (Giddens 1991).

In his study and analysis of Western attitudes to death from the 1400s until the 1970s, Ariés (1981) postulates a series of models to describe changes in meanings of death and associated events which occurred over that period, situating each model in the context of alterations in the prevailing world view and its underlying ideologies, beliefs and systems of thought. Ariés (1981, p.28) claims that in earlier times, that is, prior to the 15th century, dying was perceived as another event in the natural order and humankind's destiny. Death and rituals associated with it were of public concern; a shared and 'resigned' approach to death, he asserts, tamed its meanings. The model of the 'tamed death' contrasts markedly with that which Ariés identifies in modern culture, where he maintains, death is perceived as an 'invisible', silent event controlled by technologies (Ariés 1981, pp.611-612).

Stoddard (1992, p.223), suggests that issues surrounding death, trauma, and bereavement are discussed more openly today and that members of society have integrated these concepts within the reality of their everyday world. However, Mellor (1993) considers death in contemporary society is 'sequestered' rather than integrated. He holds a view that present day responses to death and related issues are becoming increasingly privatised, individualised and absent from public space. He attributes such responses to features of high modernity identified by Giddens (1990, 1991), wherein individualism, reflexivity and skepticism prevail. Under such conditions, Mellor suggests, individuals construct and rely on their own meanings of living and dying.

Aspects of Mellor's perceptions of social attitudes to death are reflected in Walter's (1994) thesis of the contemporary nature of the dying experience. Walter claims that there appears to be a 'revival of death' in Western society and that death is re-entering the public sphere. He attributes this situation to an emerging language which gives voice to the private feelings and responses of dying persons and their loved ones. In addition, he suggests, dying persons are making individual decisions regarding their approach to the dying experience. Walter proposes a typology of cultural responses to death as a basis for interpreting and understanding dying and bereavement. He describes three forms of death: *traditional*, *modern* and *neo-modern*, differentiated on a thematic framework including contexts, authority, coping, the journey, and, values (Walter 1994, pp.48-60).

Traditional death, Walter suggests, is typified by the death of young persons, commonly occurring as the outcome of major infectious diseases or on the other hand, by individuals who survive to old age. Persons both young and old live as members of a social and functional community and death is a 'public' event. The dying process is short; respect for the dying person and for traditional practices are of paramount value.

Essentially, dying is a journey of the soul. Support is provided to the dying person by family members, neighbours and clergy, and through established rituals known to all. The image of the good death is the opportunity to farewell family and to prepare for life after death. The bad death is perceived as one for which dying persons are unprepared, unbelieving and denying their God.

Heart disease or cancer are identified by Walter as common causes of the *modern form of death*. Typically, death is that of an adult person. The dying pathway in the modern form of death is hidden; privacy and dignity are valued. Essentially, dying is a journey of the body. Authority is vested in medical expertise and the dying person is supported through technology and medications and members of the immediate family. The good death is one where dying is painless and quick. The bad death is seen when the dying person lacks the will to live and exhibits dependency on others.

Walter suggests that common causes of the *neo-modern form of death* are cancer and AIDS. Death is typically that of an older person. The dying process is 'prolonged' and although the dying person interacts with others, the person's moment of death is a private event. Choice and autonomy are valued and authority lies with the person who is dying. Essentially, the dying journey extends deeply within the self. Support is provided by communities of counsellors and self-help groups and through selected rituals. The good death is one where persons are aware of death, have followed their own idiosyncratic pathways during the dying process, and

psychological closure of all personal matters has occurred. The image of the bad death is seen as isolation from others and 'psychological denial'.

Walter's constructions of dying as outlined above, are theorised, in the main, in the context of Western society and English-speaking communities, in particular.

While providing a cogent representation of aspects of the dying experience, the various forms of death are essentially abstractions. In a multicultural society, such as Australia, it is argued there is diversity in beliefs and understandings of mortality and immortality and in faith traditions, mores, language use and the social practices associated with death and the dying experience (Taylor and Box 1999; Prior 1999; Kanitsaki 1998).

Essentially, meanings of illness, dying, death, and, afterlife, are unique, individual and personal. They can change as we live our lives. Confrontation with impending death requires that we give 'final meaning' to the phenomena of life and death (Janssens et al 1999). In such circumstances, many people explore more deeply their understandings of God or their faith traditions. Some persons seek to 'befriend death' (Nouwen, 1982, p.189) and to experience dying as potential opportunity for personal growth and spiritual transcendence or as a pathway, ultimately, to dwelling in love with the 'Eternal', the 'Divine'. Others may perceive dying as transition towards rebirth or transition towards meaninglessness and annihilation. Tillich (1952, p.42) claims that the threat of non-being, which follows confrontation with the reality of one's mortality, generates 'inescapable' anxiety. The actuality of dying may not only threaten, sometimes it may overwhelm the integrity of the person, who can experience a life-world that is chaotic and 'out of control' (Turley 1988, p.60).

The diversity and complexity of responses to phenomena of death and dying shape the nature of care appropriate to dying persons in their wholeness and to their families. Awareness of and sensitivity towards the plurality of spiritual and cultural values and customs among Australian communities is required of all persons involved in patient/family care services. For the purposes of this paper, care of dying persons relates to care of persons of non-indigenous communities and to specialist palliative care services only.

Approaches to palliative care and service delivery

Modern approaches to palliative care were developed in England during the 1970s under the leadership of Dame Cicely Saunders. Saunders' philosophy of care (Saunders and Baines 1989) has been adopted in some form by many countries throughout the world, including Australia. As a concept, hospice/palliative care encompasses holistic care of patients who are terminally ill and support for patients' families. In collaboration with patient and/or family, as culturally appropriate, interdisciplinary teams of health professionals and others, plan, provide and evaluate care.

Activities of the care team are directed towards prevention and treatment of a patient's disease symptoms and to addressing issues raised by patient and family as changes occur in life style and in meanings and understandings of the patient's living/dying journey.

Services are commonly offered in a range of settings: hospices, hospitals, private homes, day care centres, and, nursing homes. They are delivered, where possible, in the environment of the person's choice.

Since Saunders' pioneering work at St Christopher's Hospice, changes have occurred and continue to occur in palliative care practice and its emphases and palliative care as a concept continues to evolve (Aranda 1998; Corner and Dunlop 1997; Neale 1993; Small 1993). For instance, present day palliative care is seen to extend beyond the care of patients in the final stages of life to include also care of persons at an earlier stage of irreversible illness, although for some people with AIDS, the end-stage of the disease may not be readily identified (Nicholson, 2000).

Continuing development of new drugs and other technologies can result in episodes of disease quiescence and, in some situations, temporary cessation of palliative care services may follow. In addition, multiple understandings of the nature of death and dying, differing systems of care management across service settings and integration of most palliative care programs within mainstream health care bring with them changes in understandings of effectiveness, efficiency and outcomes of care programs and associated practices.

Where appropriate and available, volunteers may be involved in care programs in any setting where services are delivered. Activities of volunteers are complementary to those delivered by the palliative care team and do not replace or reduce services offered by health professionals and others. As 'non-professional' members of the care team, volunteers with their diverse cultural backgrounds, life experiences and occupational skills, may bring a 'fresh attitude and outlook' and way of thinking to that shared by other groups within the healing community (Buckingham 1983, p.46).

Volunteers and the nature of volunteering

Broadly defined, volunteering is an activity in which individuals of their own free will choose to provide services to a community without financial return. Formal volunteer groups commonly organise for purposes of self help, to provide services or to address social change through civic/community development. Informal volunteering refers to those activities which are performed casually outside the family, to friends, neighbours, and others. In this paper, formal volunteering only is addressed.

Profiles of volunteers in the general community

In Australia, almost one of every five persons over the age of 15 years (19% of the population) participate in

some kind of formal volunteering in any one year, the rate being highest in the 34-45 year age group (Australian Bureau of Statistics (ABS) 1996, p.1). Persons in all States and Territories who live in capital cities are less likely to volunteer than persons who live outside capital cities.

Gender and age differences are evident in relation to several aspects of volunteering rates, areas of activity and the nature of tasks undertaken (ABS 1996). For instance, the ratio of females who participate in voluntary work is higher than that of males (21.3% compared with 16.6%), the higher rate for women being consistent throughout all States and Territories (ABS 1996, p.1). A large proportion of female volunteers are involved in areas such as welfare/community and education (ABS 1996, p.4); in areas of welfare/community the rate steadily increases until 64 years of age (ABS 1996, p.2). In contrast, a large proportion of male volunteers tend to participate in the area of sport, hobby and recreation (p.4), the rate in that area decreasing after 45 years of age.

The reasons people give as to why they volunteer vary widely. In the main, statements cluster around a desire to help people, gain personal satisfaction, engage in social interaction, learn new skills, and, gain work experience (ABS 1996; Noble 1991; Vellekoop-Baldock 1990).

Metaphors of volunteering

Within discourses of volunteering, there are various metaphors which seek to portray aspects of the phenomenon and values associated with it. These metaphors include notions of volunteering as a 'gift' to 'strangers' (Titmuss 1970); a form of social capital (Onyx and Leonard, 2000; Noble 2000); and, 'a caring and compassionate practice' (Wuthnow 1991).

During the 1960s, Titmuss (1970) examined the giving, receiving and payment of supplies of human blood for distribution through blood transfusion services in Britain, the USA and elsewhere. Titmuss (1970) described the giving and receiving of blood in Britain as 'a gift' by individuals to 'strangers' - a freely chosen, non-economic act offered without obligation, right or wish for return. This was not to claim however, that the gift transaction was without reciprocity; it might comprise elements of self-interest as well as generosity and kindness. In the USA, by contrast, blood was considered a product for market consumption and the giving of blood an economic transaction.

Sets of circumstances similar to the giving and receiving of blood within the blood transfusion system in Britain are seen to relate to other community services involving volunteer participation. In selected areas of social life, individuals freely choose to engage in activities of various voluntary organisations, giving their time, skills and experiences without obligation or wish for return, in order to further 'the common good' or to enhance the

well-being of persons or groups, who are strangers to them (in most instances).

Social capital, according to Cox (1995, p.11), is 'a collective term for the ties that bind us'. In a similar vein, Putman (2000, p.19) describes social capital as 'connections among individuals - social networks and the norms of reciprocity and trustworthiness that arise from them'. The establishment of social networks through volunteering offers opportunity for establishing and strengthening social cohesion, integration and interdependence among persons and groups with differing interests, skills, concerns, institutional and occupational experiences.

Participation of volunteers in palliative care services, for example, requires volunteers to develop co-operative relationships with peers, members of professional and administrative groups within health care, patients, family members and others. Interpersonal relationships within patient/family care programs are founded on trust and respect for the integrity of the individual; such relationships are covenantal. The networks created through social linkages between professional carers, non-professional carers and patients and families offer potentially rich media for enhancing the social wealth of the care team and extending to the wider community also.

Subsequent to his study of volunteering in the USA, Wuthnow (1991) concluded that, while upholding values of individualism, freedom and self-interest, paradoxically, Americans are committed to caring and giving also. To explain this situation, Wuthnow suggests that volunteering is a means by which citizens express care and compassion. Volunteering, Wuthnow (1991, p.266) claims, is a 'way of envisioning a better society'.

The word compassion is derived from the Latin *com* - with and *pati* - to suffer and is defined as: 'sympathetic consciousness of others' distress together with a desire to alleviate it' (Longman Dictionary 1991).

From a philosophical perspective, Nussbaum (1996, p.28) claims, compassion 'is a central bridge between the individual and the community; it is conceived of as our species' way of hooking the interests of others to our own personal goods'.

Preparation of volunteers for participation in contemporary palliative care

The vulnerability of patients admitted to palliative care programs and the potentially stressful nature of the volunteer experience necessitate establishment of formal management systems to assess suitability of applicants to the volunteer role. Individual agencies determine selection criteria, screening procedures, appointment processes and induction programs appropriate to the responsibilities of volunteers and the services they offer (Palliative Care Australia 1999). To ensure information transfer and

ongoing appraisal of care activities, clear channels of communication between volunteers and members of the interdisciplinary health team are required. Although processes of communication vary among palliative care agencies, it is usual for volunteers to communicate directly or indirectly with nursing personnel or with client support workers. In some instances, volunteers may communicate directly with the care team manager, who, frequently, is a nurse.

Subsequent to involvement in care services, volunteer monitoring and support processes and continuing education programs are entrained.

Volunteers in palliative care services

The role of the palliative care volunteer is 'to strengthen' and support the abilities of patients and their carers 'to live as fully and as richly as possible' during the varying phases of the illness experience (Palliative Care Australia, not dated). Examples of activities commonly performed by volunteers may include: providing transport and company for patients to and from out-patient clinics and day care centres; participating in day care centre programs; visiting, on a regular basis, 'house-bound' patients who live alone; providing opportunity of respite, on a regular basis, to a family member, who may be a sole lay carer; providing support to patients admitted to in-patient hospice/palliative care services and to family members; and, participating in bereavement 'follow-up' and remembrance services.

As disease progresses, patients may experience changes in body image, fluctuations in energy levels, changes in functional capacities and social roles, and, increasing dependency. Unable to continue regular employment or recreational activities, or to venture far from home, patients can experience loneliness, vulnerability and social isolation.

Interaction with volunteers in a non-threatening relationship provides opportunity for patients to remain engaged in a wider world and to shape and define their life-world. For those patients living alone, regular visitation by a volunteer provides opportunity for participation in activities of interest to them and which are within their capabilities. Volunteer anecdotes commonly instance activities such as: a leisurely walk to the post box to mail a letter or to exercise an aged terrier; quiet conversation; a game of cards; watching/listening to and discussing favourite television programs, music or sport; and, accompanying a person on a visit to the dentist or optician.

Like patients, family carers may become socially isolated also. In addition, they may become fatigued and stressed by the burden of care and the impending death of their loved one. Studies of the effects of home care on lay carers, usually family members or friends, (Payne et al 1999; Grande et al 1997; Hinton 1996), suggest that lay carers be viewed as 'co-clients', who require needs

assessment separate from that required by patients. Findings from such studies also indicate that the kind of support appropriate to carers may differ from that offered to patients. Opportunity for lay carers to share time and space with friends, neighbours or their own selves, outside the home, can enhance coping strategies and contribute to improvement in the quality of life of both carers and patients. In addition to institutional respite services, volunteers can provide regular intervals of respite for lay carers at different stages of a patient's illness experience, including end-of-life stage.

Aware of and responsive to the diverse and changing needs of individual patients and families during the illness experience, palliative care nurses are deeply involved in planning and evaluating with the patient/family and other members of the health team, the delivery of comprehensive care services - including the appropriateness or otherwise of volunteer involvement in patient/family care.

Trust and respect for the integrity of the other allows professional relationships between nurses and volunteers and between volunteers and other health workers to develop and strengthen. Shared understandings and open communication among individuals as members of the interdisciplinary care team are seen to facilitate the provision of coordinated and sensitive services and achievement of care goals.

In their activities with patients and families, volunteers offer time, presence and a part of themselves to others, as 'strangers'. Presence, in this sense, connotes *being there* and *being with* (Gilje 1992, p.56). *Being there* and *being with* may require dwelling in companionship and friendship with the other in their silence and in their moments of anguish, anxiety and uncertainty or sharing their laughter or their unexpected joy. Presence invites connecting more deeply with patient and family members and their meanings of suffering, living and dying. Being present requires the volunteer to listen attentively to patient and family members as they reminisce about significant and less significant events in their life stories, or ponder aloud, with feelings of anger or acceptance, what tomorrow might bring and how things might be for them and to respond appropriately.

Being present to persons who are suffering, is demanding emotionally. Caring for and caring about dying patients and their loved ones require that volunteers (like nurses and other members of the palliative care team), learn to cope with and manage, in thoughtful and sensitive ways, the many and varied emotions surrounding the reality and meanings of death and of dying experienced by the individual patient and family members. As James (1992, 1989) points out, in some situations, the emotions one feels may not be what one expects to feel or 'should' feel. Handling complex emotional responses requires energy and effort and is considered by some researchers

(Staden 1998; Bolton 2001, 2000) as a form of work - 'emotion work'.

'Emotion work' is a term coined by Hochschild (1979, p.560) to describe 'the act of trying to change in degree or quality an emotion or feeling' so as to convey to others those emotions deemed 'appropriate' to a situation. Hochschild (1983) considers 'emotion work' requires something extra on the part of the worker whereby a part of the self is offered as a gift to another. The 'emotion work' of members of the palliative care team, both professional and 'non-professional' is seen to offer a distinctive contribution to the quality of care delivery.

CONCLUSION

Volunteering in the context of palliative care is an expression of a person's choice of involvement in caring about and commitment to the welfare of others. Volunteer participation in care delivery broadens the range of services hospice/palliative care agencies can offer and contributes to the quality of life of patients and families. The sets of relationships created between volunteers and professionals with specialised knowledge and skills in caring for dying patients and between volunteers and patients/families facilitate awareness among disparate community groups of services available to dying and bereaved persons. Such relationships also provide a medium for interchange of understandings and expectations about care of dying persons and bereaved others, for death is an event which is both private and public.

Reports in the nursing literature of studies of volunteer participation in the delivery of palliative care in Australia are few. Given the continuing development of palliative care services, it would seem appropriate in terms of future planning, that comprehensive studies of the role, functions and experiences of volunteers in both community and institutional settings be undertaken and that volunteer inclusion in care programs be evaluated.

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