PARALLEL JOURNEYS: PERCEPTIONS OF PALLIATIVE CARE

by

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ABSTRACT

The delivery of palliative care within contemporary society is discussed, with particular reference to Aotearoa New Zealand in the light of the recent publication of *The New Zealand Palliative Care Strategy* (2001). The viewpoint taken is largely descriptive rather than prescriptive, being based on a literature survey of international research and academic theory, which is also informed by the author's professionally gained knowledge. Four different perspectives, comprising a mix of providers and recipients of care are investigated: those of central government planning; specialist palliative care units; aged-care complexes; and patients, family and whanau. As an area of healthcare which current demographic projections indicate will become increasingly significant, the provision of palliative care to residents of and patients within aged-care complexes receives special attention.

A metaphor of "parallel travellers" on "parallel journeys" is used to provide a thematic basis to the paper. The lived experiences and perceptions of each group of "parallel travellers" are explored. Difficulties in defining and evaluating palliative care, the implications of mainstreaming, the scope of palliative care provision, the educative role of specialist palliative care providers and the current focus on mechanistic outcome measures are discussed.

It is contended that the values and goals, both explicit and implicit, of the four specified groups may not at present be sufficiently congruent to optimise the effective provision of palliative care from the point of view of all concerned. While adequate resourcing and a genuinely collaborative approach among healthcare providers are both acknowledged to be critical, the potential for palliative care nurse practitioners to be appointed to the role of "care co-ordinator" alluded to within *The New Zealand Palliative Care Strategy* (2001), is also seen as pivotal. Insights from a postmodern perspective are offered as one possible way of achieving greater congruence.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

Page number

LIST OF TABLES

Page number

GLOSSARY AND NOTES ON TERMS USED

Aged-care complex/nursing home/residential care institution: these terms are used interchangeably for the purposes of this paper.

Family/whanau/significant others: these terms are all used to describe the group of persons who are psychosocially close to the person receiving palliative care. "Whanau" is a Maori-language term loosely translated into English as "family", including extended family.

Hospice/specialist palliative care unit: although in many instances within this paper these terms have similar meanings, in practice a hospice is in general a stand-alone palliative care unit, whereas a specialist palliative care unit can be part of a larger health facility such as a hospital.

Macmillan nurses: this term is used in the United Kingdom to denote palliative care nurses in positions for which the initial funding was provided by the Cancer Relief Macmillan Fund, a voluntary sector source of funding in the United Kingdom (Robbins, 1998a, p. 56).

Palliative care/terminal care: terminal care is a subset of palliative care, referring to the care given to a person at the very end of their life.

Patient/client: these terms are used interchangeably for the purposes of this paper.

PREFACE

What does the reader need to know before reading this paper?

The writing of this research paper has given me an opportunity to explore the complex interplay of ideas, ideologies and other determinants that shape the provision of palliative care. As a nurse directly involved in administering this care I am often conscious of the competing discourses being overtly or covertly conducted and of the consequent gap between what is and what could be, in terms of optimal provision of palliative care. This disparity is of particular concern to me given my personal philosophy of the essentially facilitative role of the nurse. I see this role as a corollary of the enactment by the nurse of "catalytic presencing", by which I mean a professional interpersonal relationship which results in benefit to the recipient(s) of care without diminishment of the psyche of the nurse.

A significant feature of this paper is the distinctive textual and linguistic aesthetic which underpins it and which is intrinsic to the meaning of the work as a whole.

I have been encouraged by the freedom inherent in a postmodern perspective to employ the frequently oblique juxtapositioning of disparate texts. Each text is introduced by the posing of questions which the text then addresses but does not attempt to answer definitively. This use of a questioning, exploratory approach to the issues raised is in keeping with the "considering, wondering . . ." tenor of the paper. Fictionalised vignettes are interpolated to illustrate points made or to suggest an alternative viewpoint.

My linguistic style has evolved from my appreciation of the combination of imagery, compression of thought, and attention to cadence of word sequences more usually associated with poetry than with a research document. The implicit sound of the text and its appearance are both important to me. I believe that this style lends itself to the engagement of the reader with not merely the facts presented but also their multiplicity of meanings and connotations. This deliberate evocation of a

personalised, non-prescriptive response in the reader resonates with the complexity of palliative care and with the consequent inappropriateness of mechanistic responses to the many issues involved in its provision. I hope that this paper is both inviting and also thought-provoking, that it leads to an appreciation of difference of perception, and that it stimulates creative, even visionary insights.

This paper is multilayered and reflective, and seeks to encourage the reader to explore many different perceptions of what may appear to be simple phenomena.

SEARCH STRATEGIES

How was the information gathered? What were the criteria for inclusion?

Internet database searches of CINAHL and PUBMED under the combined headings PALLIATIVE CARE and STRATEGY were carried out for English-language references published between approximately 1990 and mid-2001. The COCHRANE database was searched under the heading PALLIATIVE CARE. Hand-searching of the journals *European Journal of Palliative Care, International Journal of Palliative Nursing, Journal of Palliative Care* and *Palliative Medicine* was carried out for issues published between 1995 and approximately mid-2001. Other sources of information include references located in the course of earlier studies, references suggested by colleagues, references located in the library of a local hospice and references come upon serendipitously elsewhere.

Efforts were made to survey a representative selection of items relevant to the subject and to the perspectives chosen. However because of ease of accessibility there is a predominance of references available within, firstly, the greater Wellington area and, secondly, New Zealand via the inter-library loan service.

CONSIDERATIONS

What is the purpose of this paper? What has been the motivation for choosing this topic? How is the paper structured?

In this paper my intention is to explore the essence of the experiences within Aotearoa New Zealand of persons with life-challenging illnesses who live and die within a professional healthcare environment, and those who care for and about them. I ponder over whose voices are heard and whose are suppressed, and I wonder how likely it is that people will die in the way they want to, the way their family or whanau want them to, or even the way government policy purports to want them to. These questions pose themselves to me at this time with a clarity and an insistence which is more than merely rhetorical.

I am approaching the end of a course of study towards a Master of Arts (Applied) in Nursing, during which the constant focus of my concern has been the dissemination of the hospice philosophy of palliative care to a wider group of recipients and health professionals. I have become more aware of the issues facing planners, protocol writers and policy makers. I have worked in a cross-section of the different environments in which people die, and have witnessed the opportunities thereby opened up to them, or conversely closed to them, to die in the way chosen by them and/or for them by their significant others.

From a practice perspective the concept of "a good death" is one that I would ideally like to refer back to the person him/herself to define, as the summation of individual life choices. In my experience however, for the terminally ill death rarely occurs in unmediated circumstances. I question whether the values and goals of the different parties involved in palliating the deaths of persons in Aotearoa New Zealand are sufficiently congruent to make likely the occurrence of a "good death". This question and the complex issues surrounding it have motivated me to create a considered, reflective response using pieces of text designed to give voice to people who would otherwise remain unheard.

I have structured the inquiry around a framework created by a metaphor of "parallel travellers" on "parallel journeys", who for the purposes of this study are specified as: central government and its policy; hospices and other specialist palliative care units and their philosophies and practices; aged-care complexes and their cultures; and the lived experiences of persons with life-challenging illnesses and their significant others.

I have explored the connotations that palliative care, in theory and in practice, in foresight and in hindsight, has for each of these groups. I have positioned the texts deliberately to have the widest relevance to all those involved in palliative care, from health practitioners involved in drafting policies through to those for whom the experience of a life-challenging illness is a current or future reality. My viewpoint is that the best decision-making is guided not only by factual information but also by an understanding of the feelings and perceptions of the persons affected by the decisions made. This stance is analogous to that identified by Parker (1998, p. xxi) when she makes it clear that her co-edited book *Palliative care: Explorations and challenges* is not an attempt "to provide recipe answers to complex issues. Rather it seeks to demonstrate the intricacies, the entanglements and the puzzlements that underlie our sometimes simplistic and routinised practices in the provision of palliative care".

My portrayal of the visions and goals of each group of "parallel travellers" takes into account the inadequacy of any one epistemological approach to capture the totality of the experience of palliative care. Thus in this paper, alongside a synopsis of viewpoints based on a selective review of relevant literature, interpersonal and dynamic experiential texts are presented as fictionalised vignettes to highlight the unique meaning to individual persons or groups of what is happening.

My personal philosophy of the facilitative role of the nurse, correlative to catalytic presencing, has guided my choice of a postmodern approach to conceptualise linkages between the paths ostensibly travelled by the different parties. In this approach I have used particular features of postmodernism such as provocative juxtapositioning; dissolution of boundaries; celebration of difference; multiplicity of

viewpoints; engagement; and contextualisation of all experiences (Parker, 1998). My aim has been to attain a level of understanding such as that described by Spretnak (1991, p. 213):

> One comes to understand the person as a unique but integral manifestation of the social whole and the cosmological whole. Since interbeing is the nature of existence, measures of reciprocity are the "internal logic" of life. One comes to experience them as extensions of states of grace and to cultivate greater awareness of what is drawn from and contributed to the creative unfolding of the person, community, and society, as well as the bioregion and the entire Earth community. Within such an orientation, community structures, education, and governance exist not only to provide basic services and protect citizens from one another, but to facilitate opportunities for such unfolding in ways that honor both freshness and continuity.

PALLIATIVE CARE AND A "GOOD DEATH"

What is palliative care? What is a "good death"? What persons and services are involved? How can such services and the experiences they generate be evaluated?

Death is the great certainty of life, but for some it comes with a relatively long lead-in time of conscious preparation. Persons diagnosed with a life-challenging illness are one example of this, as are those actively in the dying phase. Indeed in terms of philosophy and practice, palliative and terminal care have much in common. The premise upon which specialist palliative care is based is that access to professional help and guidance at such times can do a great deal to promote comfort and alleviate distress for all concerned (Lattanzi-Licht, Mahoney and Miller, 1998).

In February 2001 the New Zealand Ministry of Health published *The New Zealand Palliative Care Strategy*, a document which articulates a centrally directed strategy to provide access to co-ordinated and culturally appropriate palliative care services for all those who need it in New Zealand. This document defines palliative care as:

> the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has come to an end. Palliative care services are generally provided by a multidisciplinary team that works with the person who is dying and their family/whanau.
> (*The New Zealand Palliative Care Strategy*, 2001, p. 2)

This research paper is in part an indirect commentary on *The New Zealand Palliative Care Strategy* (2001), being mindful of Robbins' (1998b, p. vi) observation:

> The social and clinical sciences have a tremendous variety of perspectives and methods of relevance to the evaluation of health services; it would be regrettable if concentration on the three 'E's of effectiveness, efficiency, and economy, was at the expense of ignoring the three 'A's of appropriateness, acceptability, and accessibility.

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Palliative care seeks to make more likely the occurrence of a "good death", but criteria for deciding on the quality of the death will differ depending on from whom, amongst all those concerned with any particular death, an opinion is sought (Aranda, 1998; McNeil, 1998). The manner in which the death is perceived to have happened, rather than the place of death, is what is ultimately significant in creating memories of the "goodness" or "badness" of the experience.

> Categorizing a good death as a death at home because that was the patient's stated preference ignores the multitude of conditions that must be in place for a good death to occur. It is not the place of death that largely makes it a good or bad event. When the biological, psychological, social, and spiritual components are more or less in harmony, a good death can happen anywhere.
>
> (McNeil, 1998, p. 5)

Although for most people their home is their choice of place of death (McNeil, 1998; Wilkinson, 2000), this choice may change as the disease progresses, especially if symptoms become difficult to control and caregivers become fatigued or in other ways feel no longer able to manage adequately.

> There appears to be a large dichotomy between what patients want and what happens in reality. Although for 90% of dying patients their last year is usually spent at home being cared for by relatives and friends, few actually achieve a home death.
>
> (Wilkinson, 2000, p. 212)

New Zealand 1996 data by ethnicity indicate that for persons with cancer home ("private residence") was the place of death for 53.2% of Maori, 41.5% of Pacific peoples, and 30.8% of persons of other ethnicities. For persons with non-cancer diagnoses, 41.0% of Maori died at home, 38.6% of Pacific peoples, and 23.8% of persons of other ethnicities (*The New Zealand Palliative Care Strategy*, 2001, p. 33). For persons living in an aged-care complex the institution is in fact their home, despite being categorised differently for statistical purposes. The corresponding data for deaths in a "private hospital or other institution", a category which includes aged-care complexes and also hospices, are: for persons with cancer 8.5% of Maori, 16.4% of Pacific peoples, and 29.4% of persons of other ethnicities; for persons with non-cancer diagnoses 5.6% of Maori, 7.9% of Pacific peoples, and 29.4% of persons of other

ethnicities (*The New Zealand Palliative Care Strategy*, 2001, p. 33). These data do not indicate the number of aged-care complex residents who die in a public hospital after being transferred there for reasons similar to those that motivate the transfer of persons from private residences.

Adding a more human perspective to place-of-death data, Sahlberg-Blom, Ternestedt and Johansson (1998) consider core, care and cure aspects of terminal care. In a study of the last month of life of persons with cancer in Sweden these authors found that of those who died in an institution approximately the same number died in a care-oriented culture as in a cure-oriented culture, with the most important factor in fulfilling the patient's wishes being a truly patient-centred focus, regardless of site of care. A consistent multidisciplinary concentration on the core issues can overcome negative effects of lack of continuity of place or carer. Core issues address such questions as those given primacy by McNeil (1998, p. 5): " 'Who is this person?'" and "'What is this person expecting of the dying process and how likely is it to be as she [*sic*] anticipates?'"

> Where palliative care measures are used, not only do patients receive the supportive care they need but also the family does not feel that they have failed their loved one because they have not been able to provide care at home until the moment of death.   (McNeil, 1998, p. 6)

Robbins (1998b, pp. 126-127) lists among the stakeholders in palliative care the following groups: policy and decision makers; service funders or sponsors; evaluation funders or sponsors; service target participants; service management; service staff; evaluators; service competitors / collaborators; contextual stakeholders; and the evaluation community. This paper concentrates in particular on the interests of the policy and decision makers as articulated in *The New Zealand Palliative Care Strategy* (2001); service management as represented by hospice and palliative care team professionals; service collaborators as represented by aged-care complexes (both management and staff); and service target participants as represented by patients, family and whanau. Each of these stakeholders will have different criteria for excellence in palliative care according to the various meanings and purposes they

ascribe to this term (Norris, 1999). Many writers have discussed the problematical nature of the evaluation of palliative care (Fakhoury, 1998; Jarvis, Burge and Scott, 1996; Mino, 1999; Robbins, 1998b; Sahlberg-Blom, Ternestedt and Johansson, 1998; Salisbury, Bosanquet, Wilkinson, Franks, Kite, Lorentzon and Naysmith, 1999; Wiles, Payne and Jarrett, 1999). Examples of difficulties include the ethical issues inherent in conducting research with terminally ill persons and/or their families; communication problems when interviewees are very physically weak; different perceptions of symptom control and quality of care according to whether patients, family or staff are the data source; the timing of the data collection; implicit goals and expectations of interviewees; and the multidimensional nature of the care being provided.

> Palliative care is not a simple technical care procedure. It encompasses the management of several different aspects, including the physical, psychological, social and spiritual in the terminally ill and their families. The palliative care approach involves numerous medical and non-medical procedures implemented over a period of time by a multidisciplinary set of professions – unlike drug administration, which is based on certain clinical and paraclinical data.
>
> (Mino, 1999, p. 204)

Thus the nature of palliative care is complex and essentially elusive. Standardised methodologies such as, for example, grounded theory are inadequate to capture the totality and interplay of the phenomena involved. Definitions and evaluations are fraught with epistemological and ontological difficulties. Also, efforts to capture the spirit of this intensely personal form of care are in a sense intrusive. It is possible that attempts to "identify and articulate" may well distort, even destroy the very qualities for which definition and evaluation are sought. Nevertheless central government planners have a requirement for definitions and evaluations to assist them in formulating policies and assessing outcomes. The next section discusses the kind of political context which central government provides for palliative care.

CENTRAL PLANNING FOR PALLIATIVE CARE

For whom is palliative care currently available? Is it desirable and/or feasible to make palliative care more widely available? How can such palliative care provision be evaluated?

Writing of the situation in the United Kingdom, Wilkinson (2000, p. 212) notes: "A diagnosis of cancer appears to enhance one's chances of receiving a certain level of community palliative care". Of those currently accessing hospice palliative care services in New Zealand, approximately 90% have a cancer diagnosis (*The New Zealand Palliative Care Strategy*, 2001, p. 3).

Fairness, equality, equity, the duty to provide care to all, non-maleficence, beneficence, and respect for the patient's autonomy and best interests are among the many obvious and compelling ethical arguments in favour of extending palliative care to all, so that need for such care rather than nature of the diagnosis becomes the criterion for its provision (Wasson, 2000).   Dicks (1999, p. 133) points out that:

> many of the three out of four people who die from non-malignant causes have unmet needs for symptom control, psychological support, open communication, control over their final days and choice about the care they receive. Why then do specialist palliative care services play such a minimal role in the provision of palliative care for non-cancer patients when there is ample evidence to demonstrate that cancer is not the only cause of death which results in considerable distress in the final months of life?

When a market approach pervades systems such as public health which were previously wholly resourced from central funds on the grounds of the "public good", rationing is likely to be the preferred means of resource allocation (Hunt, 1996). The terminally ill, and also older persons, are disadvantaged by the outcome measures typically used to negotiate market shares of rationed health funding. Reasons for this include, for example, the difficulty of ascribing a positive economic score to a "good death"; the fact that older persons and the dying are in technical terms almost certainly categorised as non-productive economic resources; and the fact that the provision of palliative care comprises many non-quantifiable aspects. However, there is a human

dimension to such care whose reality and significance are not diminished by the failure of economic indicators to capture them.

> In palliative care, we are dealing with the whole of the rest of the patient's life, and the provision of adequate care is of correspondingly great importance . . . People's lives have a certain individual shape, determined, at least in part, by how they choose to live them. The endings of these lives can fit, or alternatively distort, that overall shape. In the light of this thought, there is an overall need for palliative care to maintain, as far as possible, the shape and integrity of the individual life, and where this is sadly not possible, there is a special need to pay attention to the patients' views on what treatments, and even what care, they should or should not undergo. (Garrard, 1996, pp. 93-94)

What can advocates for palliative care do in the light of this apparent conflict between what is required to be reported on via the available channels and what needs to be represented in order to describe human reality? It is apparent that numerical data provided in support of requests for funding or other resources are likely to be viewed as impressive (Gray, 1997), despite verbal homage being paid to the claim that such data do not provide a full picture of complex human issues such as palliative care. Thus epidemiological and statistical evaluation techniques are two currently popular ways in which palliative care professionals attempt to describe in quantitative terms both what they do and also the needs of the persons in their care. For example, using an epidemiological approach to assessing the need for palliative care among the total population, not just persons with cancer-related diagnoses, Franks, Salisbury, Bosanquet, Wilkinson, Kite, Naysmith and Higginson (2000) suggest that there are three broad categories into which persons who die can be retrospectively classified: those undergoing a palliative care period prior to death; those with stable disease, with few symptoms followed by sudden death; and those who suffer from stable disease, with periods of progression of symptoms which would benefit from periods of palliative care. However these authors also point out that symptom prevalence alone is an inadequate indicator of the quantity and type of palliative care needed. They suggest assessment of unmet need and attention to the delivery of palliative care not only within specialist units but also within public hospitals and community services, where the majority of patients are located.

But would this degree of enlightenment be sufficient or even always appropriate? Field and Addington-Hall (1999) identify at least five potential barriers to extending specialist palliative care services to persons with non-cancer diagnoses: many current specialist palliative care experts may lack skills in caring for persons with non-cancer diagnoses; non-cancer candidates for specialist palliative care services may be difficult to identify; palliative care may not be welcomed by all persons, for example because of a perceived association with death; extending specialist palliative care services to all would have significant resource implications in terms of not only increased caseload (an increase of 79% in caseload was the conservative estimate in a study in the United Kingdom cited by these authors) but also availability of funding and continued volunteer support; and there may well be vested interests in present arrangements with concerns as to whether specialist palliative care would replace or supplement current services.

Lindop, Beach and Read (1997, p. 287), writing of trends in the United Kingdom, note "an emerging consensus among health care professionals that there is a need for a new model of palliative care with a more dynamic professional and community orientation which embraces the care of people with terminal illnesses resulting from a range of disorders as well as cancer" and ascribe this development to not only the ethical basis of health professionals' philosophy of care but also the effect of the increasingly market-based structure of the health system in necessitating "a change in palliative care orientation from hospice to hospital and from hospice to community". These authors advocate a broad-based nation-wide palliative care service which is flexible enough to meet changing and unpredictable demands by co-ordinating the provision of palliative care rather than necessarily being the provider of such care itself.

> The requirement for a dynamic multidisciplinary model for the servicing of care, needs to be supported by courses which themselves espouse a dynamic multidisciplinary philosophy of education and practice. Such courses, while having academic credibility, must also facilitate appropriate practice . . .
>
> (Lindop *et al.*, 1997, p. 288)

This approach is an endorsement of the recommendations in *The New Zealand Palliative Care Strategy* (2001) for not only local and specialist palliative care services but also the development of a palliative care approach among all health professionals. Furthermore, education and partnership are specified as prerequisites for achieving it.

Mackie and Morton (2001) however, while acknowledging the key value of the concept of partnership in applying a palliative care approach, find that in the current situation in the United Kingdom the existence of true partnership in palliative care is more illusory than real. They discuss three types of partnership: bounded, permissive and integrative, which are increasingly inclusive in nature and increasingly focussed on patient choice and wellbeing. An example of a bounded partnership is a locality where all the palliative care services are provided by a specialist palliative care unit such as a hospice. Palliative care skills are controlled by an elite group of highly specialised health professionals. Permissive partnerships allow other more generalist agencies to participate in providing palliative care but enforce the supremacy of the local specialist service by, for example, controlling access to palliative care educational opportunities. In integrative partnerships, which the authors assert are rare and often dependent for initiation and maintenance of mutual trust on the personal attributes of one or two key professionals, specialist and generalist agencies work together for the good of the patient, and respect each others' roles and inputs. Governments would understandably expect all palliative care partnerships to be integrative, and most such partnerships would probably already see themselves as being so, but the authors allude to widespread reports of patient and family dissatisfaction with physical and psychosocial care. Their solution is for agencies to work together imaginatively to create local solutions to local problems, and they offer examples of very different situations where this has been successful in very different ways.

Writing twelve years before these authors, Regnard (1989, p. 88) also pointed out a disturbing tendency among many specialist palliative care teams to be competitive with rather than complementary to other care providers:

> The dynamic and pioneering approach of the early days of palliative care has, in some teams, given way to a frustrating preciousness which will prevent any attempt at self-appraisal. In addition, many teams have expended much time and effort in a financial and administrative struggle to develop and maintain their services. This can produce an insularity that is surprisingly resistant to change . . . It is sad that while we talk piously of team cooperation and multidisciplinary approaches, we cannot get on with the team next door.

An example of the potential "failure of success" when increased numbers of referrals to palliative care services are made without a simultaneous effort to make a palliative care approach more available within generalist agencies, is described by Bennett and Corcoran (1994) in their discussion of the impact on community palliative care services of a hospital palliative care team in East Leeds. The increase in workload of the community hospice nurses led them to consider managing their fixed staff resources either by reducing services to an advisory rather than a participatory level, or by limiting interaction to only the point of diagnosis and the terminal stages. The authors comment that with hindsight they realised the need for closer and earlier co-ordination with the work of primary health care teams, despite doubts about the current palliative care abilities of such teams. Frustration of specialists and generalists, and dissatisfaction of patients and families, have been the result.

> As they become more distant from the patient, the home care nurses may become little more than symptom control advisers and the valuable psychosocial care that they provide could be lost. The inadequate provision of psychosocial care was one of the main reasons that Macmillan nurses came into existence and is an aspect of care greatly valued by patients. It is not clear whether this need can be met as fully by the primary health care team.
>
> (Bennett and Corcoran, 1994, p. 243)

What can be done to provide the impetus for change rather than stagnation in such a multifaceted problem area? Despite the earlier acknowledged caveat that numbers do not tell the whole story, and the deservedly high regard in which qualitative research is held in all the caring professions, a simple quantitative approach can

sometimes be effective in providing crucial data as well as relatively easy to carry out. For example, an audit carried out in a hospital in Ireland on the referral of terminally ill patients to palliative care (Ling, 2000) confirmed that referrals increased after a specialist palliative care team was set up. This audit merely counted deaths, with no attempt at evaluating the service, but it did provide decision-makers with enough evidence to occasion the planning and introduction of a palliative care education programme for medical and nursing staff in the hospital, which it is thought will in turn lead not only to more referrals but also to improved clinical care.

Ellershaw, Foster, Murphy, Shea and Overill (1997) suggest an integrated care pathway for the dying patient as an initial step towards facilitating outcome-based practice in palliative care. Goals and an algorithm-type way of achieving them are specified in a plan that provides for continuing evaluation and improvement of clinical practice. In particular this approach has the potential to help disseminate basic principles of best hospice practice to community settings and hospitals. However the authors concede the difficulty of writing standardised care plans for the provision of palliative care prior to the terminal phase, because of patients' very different individual needs at this time.

A systematic literature review of the impact of different models of specialist palliative care on patients' quality of life (Salisbury, Bosanquet, Wilkinson, Franks, Kite, Lorentzon and Naysmith, 1999) found "little robust evidence that any form of organization of specialist palliative care offers significant advantages in terms of the impact on patients' quality of life. This finding may be interpreted as disappointing. However specialist palliative care may be justified on other grounds" (Salisbury *et al.*, 1999, p. 13), such as the preferences of patients or cost-effectiveness.

Another systematic literature review, this time into patient and carer preference for, and satisfaction with, specialist models of palliative care (Wilkinson, Salisbury, Bosanquet, Franks, Kite, Lorentzon and Naysmith, 1999) found few consistent trends in consumer opinion and satisfaction, and a paucity of methodologically sound research. Bosanquet and Salisbury (1999) edited a review which attempted to

establish an evidence base for the provision of a palliative care service. They included such criteria as appropriateness and cost-effectiveness of models of palliative care service delivery in hospitals and the community, but could likewise find few clear answers to any of the questions addressed.

One can conclude that at present, in New Zealand as in other countries, patients with cancer are relatively well provided with palliative care, largely owing to an historical community-based regard for their specialness, but that in other instances palliative care services are patchy and ad hoc. Indeed, as Kellehear (1999, p. xi) notes:

> These are troubling times for palliative care. Recognition of the importance of palliative care has peaked at a time when governments are attempting to reduce their health care budgets. Today, the desire of policy-makers and practitioners to embrace the holistic ideals of hospice and palliative care comes face-to-face with an ever-diminishing financial capacity to do so. Compromise is in the air.

The New Zealand Palliative Care Strategy (2001) articulates government support in principle for further promotion of palliative care, but specific and definite confirmation of support in terms of dedicated resources is lacking, especially in the key areas of education and partnership. For example although undergraduate education of nurses and doctors

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FICTIONALISED VIGNETTE
(Echoes of empty promises?)

"It is clearly desirable to make palliative care accessible to all. Funds will be made available . . . but there are many calls on the health dollar . . . We will set up a committee to make more recommendations . . ."

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is mentioned, what will be done to ensure ongoing education, or education for those already in the workforce? What will be done to foster an authentically collaborative approach among health professionals in all teams? What kind of future role in terms of, for example, leadership, collaboration or education, can be envisaged for the specialist palliative care units which are discussed in the next section?

SPECIALIST PALLIATIVE CARE UNITS

Why do these exist? How do they operate? What do they do? How do they fit into a wider framework of palliative care? How can the services they provide be evaluated?

It is axiomatic that specialist palliative care units, most notably hospices, have traditionally played a dominant role in the provision of palliative care. *The New Zealand Palliative Care Strategy* (2001) not only endorses this role but also foresees its enhancement, specifically through the two-tier system of specialist and local palliative care provision which it envisions. Thus it is timely to review the work of specialist palliative care units and to consider how well they perform relative to alternative providers.

Hearn and Higginson (1998) conducted a systematic literature review to investigate whether specialist palliative care teams do in fact have a greater effect than conventional health systems in improving health outcomes of patients with advanced cancer and their families or carers. The authors considered a variety of outcomes which addressed aspects of symptom control; patient, family and carer satisfaction; healthcare utilisation and cost; likelihood of death occurring in a place of the patient's choice; psychosocial indices; and quality of life. They found evidence that specialist palliative care teams did indeed improve satisfaction by identifying and dealing with more patient and family needs. Also, their multiprofessional approach to palliative care reduced the overall cost of care by reducing the amount of time patients spent in acute hospital settings.

The modern hospice movement, a revival of a medieval concept of holistic care when cure is no longer possible, emerged in England in 1967 and has since then spread around the world as a result of community demand and volunteer support (Johnson, 1998; Lattanzi-Licht, Mahoney and Miller, 1998; Lawton, 2000; Rumbold, 1998). Funding arrangements and specific services offered vary between communities but the fundamental philosophies of assisting terminally ill persons to live until they

die, and providing holistic care for them and their families, are universal (Parker, 1998). Specialist palliative care is predicated on a relatively predictable survival trajectory, which precludes many persons with chronic diseases, as Johnson (1998, pp. 11, 17) notes:

> Although hospice wants to serve all dying people, the typical hospice patient tends to be an adult, terminally ill with cancer, living in a stable home environment with an available caregiver and other supports. Those in greatest need may fall outside the mainstream, however, and differ significantly from the typical hospice beneficiary . . . Priorities for hospice care involve promoting maximum service utilization through research and outreach initiatives that quantify precisely what makes hospice the preferred approach to care of the dying. Intervention will minimize barriers and promote referrals. Hospice must demonstrate its commitment to maintaining the delicate balance among quality, cost effectiveness, flexibility, and regulation. Hospice organizations must play an active and aggressive role in ensuring and maintaining availability and quality of service for those in need.

Johnson (1998, p. 8) also asks "Why does hospice remain on the fringe of a traditional medical care system that has proven it cannot provide for a peaceful and dignified death?" and McCracken and Gerdsen (1991, p. 4) comment that:

> Hospices are a part of the continuum of health care, rather than an alternative to traditional care. Hospice care is usually chosen as the preferred mode of care when the patient and family judge that the burdens of aggressive treatment are greater than the benefits that can be expected from it. The objective of care then changes from cure to a comfortable and satisfying death. Treatment is directed toward controlling pain, relieving other symptoms, and focusing on the special needs of the hospice patient and the patient's family. This care is being delivered with increasing frequency in the home. Nursing homes are also a common place for death of an older person. The principles of care set forth are applicable in any setting in which sensitive caregivers are found.

Seale's (1989) review of research evidence comparing patient care (taking into account medical therapies; psychosocial care; disclosure of prognosis; carers' involvement in patient care; and relationships among staff members) in hospices with that provided in hospitals suggests that in many instances there are only minimal differences. Acknowledging that the research evidence is by no means definitive, he nevertheless postulates that the reason for the similarity may be the fact that hospitals

are increasingly adopting a hospice approach, or, conversely, that hospice staff are increasingly compromising their ideals. Rumbold (1998) likewise notes with concern the homogenising effect of the mainstreaming of palliative care, contending that this may lead to the compromising of "deeply held tenets of the hospice movement" (Rumbold, 1998, p. 4). Seale (1989, p. 558) makes the point that "[t]he issue of whether hospices preserve a special approach by virtue of excluding patients who do not conform to expectations remains to be resolved". Similarly:

> The cancer patient in a hospice has also a special social status which is different from that of the geriatric patient on a long-stay ward or nursing home. This is reflected in the fact that raising money to fight cancer is easier than raising money for the aged. (Seale, 1989, p. 557)

Are hospice staff also "special"? The factors motivating and sustaining palliative care nurses were investigated by de Vries (2001) who found that nurses who choose to work in this field perceive a greater level of professional autonomy for themselves, and also a more caring and meaningful dimension to the nature of their work. In liaising with non-palliative care colleagues, however, units providing a consultative specialist palliative care service find that requests for their help are largely confined to the areas of symptom control and psychosocial issues (Jarrett, Payne, Turner and Hillier, 1999; Ruszniewski and Zivkovic, 1999). This restricted view of the role of specialist palliative care professionals may mean for example that patients and their carers fail to communicate to members of the specialist

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FICTIONALISED VIGNETTE
(*Getting clear about being right?*)

"It's important that we position ourselves as a specialist service not a local provider, as a matter of status and influence. After all, would we want some other unit telling us what to do? We've spent years setting up our own way of doing things and that's what we're comfortable with. We feel sure it's the best way for patients and families too, all things considered . . ."

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palliative care team concerns such as a need for hands-on nursing assistance or income support, which the team could have handled in at least a referral capacity. Health professionals referring patients to the specialist team are likely to be unconsciously ambivalent in the extent to which they, as independent health professionals

themselves, actually want help, and hence possibly also remiss in the clarity of the information they share with patients and carers. "Professionals vacillate between a desire to improve patient care and an inability to share the privileged relationship that has been established with the patient" (Ruszniewski and Zivkovic, 1999, p. 12).

Nash (1992, p. 436) comments on a widely held critical viewpoint which regards the traditional hospice focus on persons with cancer diagnoses as elitist, given that:

> many patients in geriatric units or those supported at home by geriatric services are in need of such care . . . The staff in geriatric services may not consider referral to hospice services appropriate for many reasons. It would be useful, however, to develop supportive and educational relationships with such units to encourage the application of the principles of hospice care for those patients. Similar relationships to those needed with community hospitals may be usefully pursued.

Lee (1998, p. 216) also favours a collaborative approach, noting that:

> While specialist services are critical for the development of palliative care through education and research, generalist services are the tools by which we can spread that knowledge through the profession. By collaborating with specialist organisations, generalist organisations may utilise that focused environment to develop their own staff, and thus together they will increase the pool of knowledge and foster excellence in palliative care in a variety of care environments.

Foulkes (1996) discusses communication difficulties experienced by staff when making referrals from a hospital to a hospice, and also the potential for stress and anxiety to be experienced by patients and their families. Massarotto, Carter, MacLeod and Donaldson (2000) challenge Foulkes' assumption that the hospice will "take over" patient care, but support Nash's (1992) injunction to hospices to be specific, in both qualitative as well as quantitative terms, in describing what they have to offer to other health professionals.

> It is anticipated that the new hospital palliative care support service will act as an agent of change, encouraging hospital staff and patients to view hospice as an early intervention service, rather than "a place to die". Evaluation of the new service in terms of changing the attitudes of hospital staff is recommended. Importantly, while the primary focus of the hospice is no longer on providing long-term in-patient care for patients transferred from the acute hospital, the

perception of the hospital doctors that the hospice will "take over" the care of patients persists. A possible explanation for this is that the hospice has not yet been effective enough in its educational role of equipping health professionals with the knowledge and skills to participate in the care of dying patients. The changing role of hospices is a widespread phenomenon, which has as its goal the infusion of hospice ideals, standards, and philosophy throughout the spectrum of health care. As hospices enter this new phase of expansion, it is critical that they develop processes for communicating these changes to other service providers.

(Massarotto *et al.*, 2000, pp. 28-29)

Colquhoun and Dougan (1997) find a lack of clarity in the definition of what competencies are necessary for a palliative care nurse to be designated as "specialist". In what could be considered as a prototype by other institutions these authors discuss the standards of clinical practice, management, education and research jointly agreed on by two Edinburgh institutions. This and similar efforts to provide clarification are undeniably laudable, but in reality the very attempt to articulate in policy format the essence of palliative care may have the paradoxical effect of nullifying its expression. As Kellehear (1999, p. xii) comments:

Much has been made of the holistic mission of palliative care – care that is not only physical but also social, psychological, and spiritual. Yet the proliferation of models of what has come to be glibly called 'psychosocial' interventions seems to have little unity and even less theoretical and practical consistency. Social needs are too often conflated with psychological needs. Spiritual issues are frequently subsumed under psychological ones. Clarity, consistency, and definition have been the casualties in a field that gropes for theoretical organisation, for clear guidelines about facilitation of health-seeking behaviour at the end of life.

Evaluation of palliative care is similarly beset by difficulties (Robbins, 1998b). Nevertheless many authors have attempted to devise usable measuring tools. Hearn and Higginson (1999) for example discuss a palliative care outcome scale of acceptable validity and reliability which can be used for prospective assessment of care of persons with cancer. The scale comprises 10 questions which can be answered within 10 minutes by staff, and an almost identical set of questions which can be answered by patients if they are well enough. Good internal consistency between staff and patient answers during tests was found for the questions used. These questions cover physical, psychological and spiritual aspects of palliative care. There is

provision for development of additional questions for use within specific settings, for example aged-care complexes, given that increasingly people with cancer are being cared for in non-hospice settings. It is foreseeable that similar methods could be used to devise scales for the evaluation of palliative care for persons with non-cancer diagnoses.

But how effective will these quantitative scales be in measuring what they purport to measure? More importantly, how closely does what the evaluation purports to measure in fact approximate to the core business of a hospice? Are specialist palliative care units in danger of taking on, even being subsumed by an organisational life of their own, to the detriment of their traditional, socially sanctioned role? MacLeod and James (1997) allude to this danger when they warn against a mechanistic approach to palliative care education, and question the validity of measurable quality indicators in this context.

> Such an approach sees palliative care education as providing discrete answers to practice problems. This problem-solving view of teaching and learning where teaching is designed to achieve a set of predetermined behavioural objectives is not an appropriate one in this context. It would fail to do justice to the holistic character of palliative care with its multiplicity of interrelated, interconnected and dynamic facets of a personal, technical, practical, moral, social, cultural, emotional and spiritual kind.   (MacLeod and James, 1997, p. 376)

Specialist palliative care units have the opportunity to redefine their roles. There will be conscious, and probably unconscious, choices to be made. To what degree will palliative care expertise be shared with health professionals in other healthcare facilities by means of education? To what degree will specialist palliative care knowledge broaden from its current focus on persons with cancer diagnoses? To what extent will the current preoccupation with output measures of dubious validity be allowed to encroach on palliative care resources? To what extent will mainstreaming of palliative care continue to be accompanied by increasing medicalisation and institutionalisation of traditional palliative care practices? Will specialist palliative care units in fact become constrained by a reducing resource base to operate in ways increasingly similar to those of the aged-care complexes discussed in the next section?

AGED-CARE COMPLEXES (management, staff, culture) as service delivery agents

What currently constitutes palliative care in aged-care complexes? What else could be done? How could this be achieved? How can palliative care performance be evaluated?

According to New Zealand census figures (*Statistics and Information About New Zealand*, 26 April 2001) in 1996 slightly less than 5 per cent of older New Zealanders, that is persons aged 65 years of older, were living in residential homes, with another 1.2 per cent living in a public or private hospital. These percentages can be expected to increase in the future, with projected extended life expectancies concomitant with a decrease in the number of younger family members willing and able to provide care for older persons. Aged-care complexes are thus likely to be increasingly involved in palliative and terminal care. Staff of aged-care complexes often fulfil, at least partially, a surrogate family role as they attempt to care for increasingly frail older people in a relatively homely environment, until their death. Such a death can have its own dignified, all-encompassing beauty and meaning.

> Death in a nursing home need not be characterised either by hushed tones or by the frenzied activity of clinically imposed routines. Death need not be dominated by doctor's prescriptive decisions nor by nurses' opposing opinions. Inevitably there will be a wide range of human emotions reflected in resentment and relief, gossip and guilt, joy and sadness, frustration and fear, humour and anger, anxiety and cynicism. Given the range of relationships which develop (in some cases over many years) between residents, families and staff, each resident's death has the potential for profound impact. (Hudson and Richmond, 1994, p. 3)

However in many instances circumstances in aged-care complexes are far less than ideal. Kincade Norburn, Nettles-Carlson, Soltys, Read and Pickard (1995) describe an entrenched task orientation, reinforced by negative age stereotypes, and inflexible institutional routines which incorporate extensive and time-consuming documentation requirements. Any enthusiasm staff may have for more proactive individualised care plans is quickly lost owing to lack of time, resources and genuine managerial support. There are in reality many significant contextual differences

between a hospice and an aged-care complex. These relate to resourcing, education and qualifications of staff, relationships among staff, and medical condition of patients, as summarised in Table I.

Table I: Differences between hospices and aged-care complexes

<u>Hospice</u>	<u>Aged-Care Complex</u>
Mainly cancer diagnoses	Multiple medical diagnoses
Collegiality among all staff	More hierarchical (medical dominance)
Emphasis on holistic care	Curative/rehabilitative approach
Registered nursing staff	Predominantly minimally skilled caregivers, with consequent relative isolation of registered nurse(s)
Ready availability of extra resources	Low flexibility as regards extra resources

There is much support for the above in nursing research literature. For example, Parker and De Bellis (1999), in their profile of dying residents in South Australian nursing homes, note that most homes had the goodwill to provide palliative care for their residents but needed "improved medical management, increased funding to provide greater nursing care for residents and relatives, education for all levels of staff and increased liaison between nursing homes and palliative care services" (Parker and De Bellis, 1999, p. 164). In addition these authors comment that:

> The profile of the palliative care residents in this study was one of high dependence and marked deterioration as death approached. Deterioration occurred in all aspects, but the mental and emotional state of residents became progressively more difficult to assess, and behavioural problems were less pronounced as death approached, in the majority of cases. Almost all residents became bedbound, required regular pressure area care, mouth care, wound care, assistance with nutrition, and were incontinent of urine and faeces. This profile of dying residents differs from that of hospice patients who are generally more

independent until death and do not exhibit the same level of behavioural problems, cognitive decline and incontinence.

<div align="right">(Parker and De Bellis, 1999, p. 168)</div>

The relatively sanguine picture of hospice patients implied above is at odds with that given by Lawton (2000) in her ethnographic study of hospice patients in the United Kingdom, in which she notes that "the all-pervasive presence of deterioration, decline and death was impossible to avoid or deny" (Lawton, 2000, p. 76). Lawton (2000) also emphasises the aspect of physical decline and its effect on personhood, an aspect that is well-known within aged-care complexes but, according to Lawton (2000, p. 16) "'glossed over' or ignored within the hospice model . . . [making it] very difficult to enact the goals of hospice care *in practice*" (Lawton's italics).

One contextual difference which is well-authenticated is the lesser amount of time available in aged-care complexes for staff to spend with a patient receiving palliative care, or their families. This is frequently commented on (Blackburn, 1989; Rutman and Parke, 1992), and was also noted by Parker and De Bellis (1999, p. 169):

> The nursing staff consistently identified a lack of time to provide the quality of care they wanted to give to residents and their families. The nurses experienced guilt and stress in looking after residents who were dying, in particular because of their inability to sit and just 'be with' the dying resident when he/she had no family.

Clare and De Bellis (1997) in another study of South Australian nursing homes found that 9.5 per cent of the resident population were receiving palliative care at the time of their survey, that there was no increase in funding or other resources despite the marked increase in dependency and frailty when a resident became in need of palliative care, and the homes were mainly staffed by "unregulated, unqualified

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FICTIONALISED VIGNETTE
(What's actually happening?)

"Millie's past feeding herself now. We'll have to come back and feed her after we've done the other feeds in the dining room. Hurry up, we're already late. I know she's wet but just put a clean pad in meanwhile. She'll get a full wash later . . . I don't know why the RN doesn't put a catheter in . . . "
[RN: Registered Nurse]

and minimally skilled nurse assistants or personal care attendants and a registered nurse whose role is to supervise these staff" (Clare and De Bellis, 1997, p. 21). These authors also estimated that "[a]n average of 42 hours of nursing and personal care per week was provided for each resident receiving palliative care and when this extra care and attention was given to a dying resident other residents receive less attention" (Clare and De Bellis, 1997, p. 27). Lefebvre-Chapiro (1998) writing of experiences in a gerontological facility in France estimated the same time requirement, finding that each elderly patient receiving palliative care needed around six hours of high-quality care every day.

However, education of aged-care complex staff without a concomitant commitment on the part of management to increase resources – for example in terms of staff numbers; funding and time for ongoing staff education; and availability of specialised equipment such as syringe drivers and pressure-relieving mattresses – will not achieve an improvement in palliative care practices. As Froggatt (2001, p. 46) comments: "although educational courses have their place in developing new practices, they need to be undertaken in conjunction with other initiatives that ensure the organizational culture of the institutions involved is addressed". The same author also discusses the relative merits of encouraging aged-care complex staff to rely largely on outside specialist palliative nursing expertise when a resident is in need of palliative care, or alternatively providing palliative care education to aged-care complex staff themselves. She points out that the hospice model of care cannot easily be transferred to the different culture of an aged-care complex, and emphasises that aged-care complex staff have their own expertise and knowledge of their patients. A degree of openness to another set of circumstances, as well as an acknowledgement of the significance of aged-care complexes as an increasingly common chosen site of death, is needed.

> Nursing homes will continue to be a significant place where older people die. Practitioners, researchers and educators with a concern about the end of life care need to address the differing requirements of this care sector, but in a way that utilizes the knowledge and expertise already present in both the palliative care and nursing home worlds. Through collaboration an understanding of the needs of

older people who are dying will be developed. Appropriate interventions, educational or otherwise, can then be designed to promote the appropriate integration of palliative care with nursing home practices. This way the needs of older people living at the end of their lives can be addressed.

(Froggatt, 2001, p. 46)

Kellehear's (1999) concept of health promoting palliative care has particular relevance to aged-care complexes, whose traditional focus is largely rehabilitative. In terms of a nation-wide palliative care strategy, broadening the scope to involve aged-care complexes would be one example of the approach advocated by Kellehear (1999, pp. 17-18):

> The 'structural' approach of health promotion – that is, the serious attention paid to policy development and the wider context of health care – might also be adopted as a welcome aspect of palliative care. A health promoting palliative care might usefully seek a policy role in broader public-health developments that actively seek to reduce the idea that death and dying are marginal experiences. Such developments might combat the unhelpful idea that serious illness occurs when health and health care have failed. The idea that palliative care settings might also be more than interventionist clinical settings – that they might be positively health promoting – is also a challenge that is suggested by a structural approach to palliative care.

Will this challenge be accepted, or even acknowledged? How prepared are hospices and other specialist palliative care units to share their knowledge with other healthcare providers such as aged-care complexes on a truly collaborative basis? How receptive in practical terms will other healthcare providers be to offers of shared knowledge? Will they be willing and enabled to alter their own culture of care, for example via access to educational opportunities and increased resourcing, or will external palliative care specialists be accommodated on a merely ad hoc basis? Importantly, what will be the effects on the recipients of care? The following section attempts to convey some of the feelings and perceptions of the patients themselves and their significant others.

PATIENTS, FAMILY AND WHANAU

**What do they want? How well are they served? What else could be done?
How can the care they receive be evaluated?**

Despite the inevitability of death, its manner and meaning are concepts most people rarely contemplate in advance in a personalised way. Howarth (1998) argues that the process of growing older is not necessarily accompanied by an increasing degree of comfort with the notion of death.

> The fact that most people generally spend a lifetime avoiding thoughts of death and dying means that they do not know 'how to die'. In old age, and facing their own death and the loss of those they love, they are unlikely to be in a position to control the process of dying and to think of death in an 'accepting' and 'enlightened' fashion as the completion of the journey of life. People of all ages need to be helped out of life as they should be helped into it – with sensitivity, care and support. (Howarth, 1998, pp. 687-688)

> *FICTIONALISED*
> *VIGNETTE*
> *("Were you with him, nurse?")*
>
> *"I held his hand and told him you were on your way . . . He wasn't alone.
> I told him he was safe and loved and cared for. I said those words over and over again . . . He was very peaceful and then he just didn't take another breath . . . I know how much you cared about each other and how much he wanted to spare you extra grief . . . "*

With a similar regard for individual differences and difficulties, de Raeve (1996) relates these concepts more directly to the provision of palliative nursing care. After raising a number of thought-provoking issues in her discussion of the much-touted concepts of "a good death" and "death with dignity", and the prescriptive straitjackets which these terms can be seen to imply, she suggests that nurses might do well to concentrate not so much on the "manner of dying" as on the "manner of treating the dying . . . Dying and seriously ill people deserve to be treated with dignity in such as way as to try to preserve the dignity they have and help them regain the sense of dignity that feels lost" (de Raeve, 1996, p. 72). This author also explores aspects of the concept of dignity such as personhood, integrity, self-respect and sociopolitical role, emphasising the very individual way in which these aspects

affect different persons. In terms of truly effective palliative care nursing, de Raeve (1996, pp. 71-72) found a Buddhist nurse's comment particularly illuminating:

> He said that only when he stopped thinking that he was responsible for how people died did he find he could truly nurse them . . . It seems that this nurse was trying to convey the idea that such a view was liberating in that he was freed from a rather crippling and unrealistic sense of responsibility, and instead could look directly at the physical and emotional suffering of patients who were in the process of dying and offer what relief was possible. He could join them much more effectively in their journey if he did not feel responsible for their end.

A similar acknowledgement of the ultimate element of individual choice in attitude towards death is made by Lawton (2000). Her ethnographic study of hospice patients in the United Kingdom led her to question many of the traditionally held beliefs about, and current ideology of, the modern hospice movement. Reporting on patients talking about their own imminent deaths, she writes that "[t]he overwhelming impression I gained from patients was that their feelings were those of dulled resignation; of apathy, lethargy and exhaustion; of finally giving up" (Lawton, 2000, p. 80). She also discusses (Lawton, 2000, p. 52) " the ways in which patients' loss of bodily autonomy, and thus their unreciprocated dependence upon others, led to a debasement of their personhood". She emphasises this point in a discussion of the attitudes expressed by patients in a hospice day care centre, by contending that:

> the use of emotion concepts served on one level as a strategy for mediating and negotiating the potentially unequal relationship between 'carers' and 'cared for', by enabling the hierarchical (i.e. the physical) components of care to be masked and overridden by its more altruistic, emotional aspects. Indeed, the enactment and expression of emotions provided the one means by which patients were able to place themselves on an equal footing with staff and volunteers, precisely because emotions were the one aspect of care which they were actually able *to reciprocate* [Lawton's italics].   (Lawton, 2000, p. 64)

Undeniably the psychosocial aspect of palliative care is very significant and much recent palliative care literature focusses almost entirely on it (Oliviere, Hargreaves and Monroe, 1998). However basic physical needs are usually the first to become evident if not met (Lattanzi-Licht, Mahoney and Miller, 1998), and also the first to be referred on by health professionals. The current trend to delegate much of the physical care

aspect of community nursing work, such as hygiene cares, to less qualified healthcare assistants is an example of this. As Beaver, Luker and Woods (1999, p. 266) point out, this delegation " may indicate an increased burden for lay carers by restricting access to qualified nurses. In addition, if resources are stretched it may not be possible to provide a holistic service to all patients in the community". This effect may be compounded by a lack of awareness, and/or willingness and/or ability on the part of health professionals to make referrals to other appropriate professionals such as social services. Cartwright (1993, p. 429) mentions the "substantial amount of unmet need for help with shopping, cooking and cleaning" among older persons and notes with concern "the lack of responsiveness of the medical and nursing services to the needs of older patients in the last year of their lives. There is some evidence that general practitioners, community nurses, hospitals and hospices all fall short in this".

Maccabee's (1994) study of the effects of a transfer from a palliative care unit to a nursing home found that patients and families were almost invariably left feeling resentful, disappointed, and with many unmet needs, both physical and psychosocial. In effect they ended up paying more for a standard of care that was inevitably lower, given the resource constraints under which nursing homes and similar residential care institutions operate. One wonders how, given the contextual limitations, such negative outcomes could have been avoided. Turley (1998, p. 206) acknowledges the problem and argues for a more advocacy-based approach:

> *FICTIONALISED VIGNETTE*
> *(How might a family react?)*
>
> *"Why couldn't he stay in the hospice? We would have paid. Now we're paying anyway and he's so unhappy. There's hardly any staff and it's all so different from the hospice. He looks dreadful and I just hate visiting and seeing him like that . . ."*

Understanding the unique expertise of other disciplines and organisations, and choosing a more inclusive approach within and between organisations may facilitate client care and best use of scarce resources. Finally, our referral practices and care provision must respond to the uniquely individual whole person needs of our clients. Our aim should be to provide our clients with cohesive care that facilitates their sense of dignity, right to self-determination and physical, spiritual, emotional and social well-being.

Many research articles testify to the overwhelming commonality of certain basic preferences voiced by patients and families, specifically: the need for meaningful time spent with one another; time spent with them by staff; easy access to information; and an environment in which they feel at home (Beaver, Luker and Woods, 1999; Beaver, Luker and Woods, 2000; Goetschius, 1997; Grande, Todd, Barclay and Doyle, 1996; Higgs, MacDonald, MacDonald and Ward, 1998; Pierce, 1999; Wilson and Daley, 1999).

Grande, Todd, Barclay and Doyle (1996) conducted structured interviews with terminally ill patients being cared for in their own homes to elucidate what these patients valued most about the care provided by health professionals. Psychosocial factors, in particular the interpersonal relationship as evidenced by ease of communication, ability to provide cheer, and familiarity, were slightly more important than actions and significantly more important than clinical expertise.

> Within the interpersonal relationship communication was clearly important. In addition, one should note patients' appreciation of joking and cheerfulness, which perhaps emphasizes the human aspect of the interaction. The patient is still treated as a person with whom one can share the lighter aspects of life.
> (Grande *et al*., 1996, pp. 142-143)

Despite such confirmation of the value of non-clinical aspects of care, Street (1998, p. 76) voices concern that a medical or institutional discourse may nevertheless dominate:

> The desire for people to die 'pain free' can take precedence over other aspects of palliation which relate to the comfort of the person. The medical aspects can ignore the socio-ethical and spiritual aspects of the dying process. Nurses and relatives have reported concern that some people are maintained in a pain-free state but in the process lose their own identity . . .

A link between the physical and the psychosocial is illuminated by Lawton (2000, p. 106), who, writing of the loss of personhood among hospice patients and the effect of this on family members, notes that:

> When family members . . . reflected upon their personal experiences of caring for a patient at home, the intersubjective and intercorporeal impact of that patient's

deterioration became very evident. Their comments indicated that the body of the patient became closely enmeshed with their own sense of self, particularly when the patient's deterioration and level of dependency upon them was very extreme . . .

Other researchers also found evidence of more basic, pragmatic concerns. Beaver, Luker and Woods (1999) and Beaver, Luker and Woods (2000) describe how terminally ill home-based patients and their lay carers perceive primary care services. Information and support for lay carers were found to be lacking, and concern was also raised about fragmentation of care, with frequently inadequate communication among the variety of health professionals involved.

> Patients and lay carers were often confused regarding who was in 'authority' when care was being planned. This may be a consequence of different healthcare professionals believing that the care of terminally ill patients is their respective domain. Effective communication and multidisciplinary teamworking with appropriate referral to specialist services may help to counteract such apparent confusion about who is responsible for the care of the individual. The findings of this study indicate that users would welcome more effective communication between different professionals in planning a package of care.
>
> (Beaver *et al.,* 2000, p. 226)

The above studies relate to patients living in their own homes.   In a study designed to compare the satisfaction levels of nursing home residents with those of patients in a long-stay geriatric ward Higgs, MacDonald, MacDonald and Ward (1998) found that the "institutionalising capacity" of the latter was not as great as popular opinion would lead one to expect.

> The notion of homely settings is much less important than has previously been argued. The concepts of 'home' and 'institution' have had more symbolic importance than serving as concrete bases in the construction of policy for older dependent people. If policy is to achieve its objective of improving the lives of this group of people, then it needs to correct this bias.
>
> (Higgs *et al*., 1998, p. 205)

These authors point out that the notion of "home" popularly "encapsulates many positive elements such as independence, security, choice and privacy. This contrasts with the notion of 'institution', where many of these elements appear to be difficult to find or are non-existent" (Higgs *et al*., 1998, p. 199). These authors further argue that

the provision of care and the development of social relations which an institution offers to dependent older persons, often to a significantly greater degree than any feasible alternative, contributes to the unexpectedly high satisfaction levels found.

> The social and emotional life created by the institution can be as rich if not richer than that experienced previously by the older person. This aspect, allied to the high level of acceptance of the need for institutional care among older people themselves suggests a different framework for the understanding of institutional care. (Higgs *et al*., 1998, p. 204)

While acknowledging that the nature of "satisfaction" is itself ill-defined, Teno (1999, p. 169) nevertheless maintains that:

> This should not lead us to cast aside the patient voice concerning the quality of medical care. The patient voice is central to the care of dying persons. The ability to listen to older persons, educate them about their illness, learn from them, and help guide them through important life choices that balance quality of life concerns with patient longevity is at the core of both geriatric and palliative care medicine . . . the most important outcome variable for examining the quality of care of the dying is whether health care providers understood and responded to the expectations and preferences of the dying patient and their loved ones.

Teno (1999) further contends that a lack of genuine empowerment on the part of patients and their families, and reduced expectations regarding what is possible, are likely to skew responses to palliative care satisfaction measures in ways that may cause palliative care service provision to receive a spuriously high evaluation. She also notes that ratings made by persons receiving palliative care are likely to be very unstable over time, and further makes the point that "patient reports of technical quality may be overly based on the interpersonal skills of the provider. For example highly empathic skills may mask poor medical judgments" (Teno, 1999, pp. 170-171). In common with other palliative care providers, Teno (1999, p. 173) envisions that measures should "incorporate the patient and loved ones['] perspective, be clinically meaningful, and strive for high standards of reliability, validity, and responsiveness". Exactly how this can be achieved is not specified.

Morgan (2000) affirms the usefulness of measures of clients' quality of life in the evaluation of palliative care provision. Despite this, her research found that "quality of life" (QoL) is itself diffusely defined, and that methodologies to measure it were similarly confused.

> QoL is a descriptive construct, and as such provides a label for, but not an explanation of, behaviour. Quantitative approaches to QoL assessment will always be limited by the nature of the measures themselves, in that they cannot reproduce a true measurement of QoL. However, they do provide an indicative measure, which can raise the profile of QoL outcomes in assessments of care delivery. Much of palliative care remains an enigma; QoL research may be the way forward in unravelling a little of that mystery. (Morgan, 2000, p. 409)

Massaro and McMillan (2000) similarly regard quality of life as a particularly important outcome of palliative care provision and review a range of measures for its assessment. They found none of the tools in their study to be ideal for the purpose, being either adapted from other populations, insufficiently holistic in what they evaluated, or else relying on reports by carers rather than patients.

Thus although the need for valid measures of patient satisfaction, in particular in terms of quality of life indicators, is widely acknowledged, at present there seems no one measure which receives universal approval. Clinch, Dudgeon and Schipper (1998), who provide an overview of research to date in this area, comment on the unique problems it presents:

> Quality of life is patient-centred and subjective. It is multifactorial. It is also time variable. These properties distinguish this paradigm from many other outcome measures to which we are accustomed and add complexity to the interpretation of experimental results. (Clinch *et al.,* 1998, p. 92)

This is an area which fully merits further research, because of its high degree of relevance to the elucidation of what constitutes truly patient-focussed palliative care.

POSTMODERN LINKAGES

How can some degree of congruence among the differing goals and values of these parallel travellers be achieved?

Clearly the way ahead is neither easy to perceive nor simple to navigate. It is possible that what eventuates may differ significantly from the ideals of palliative care specialists.

> If an ideological perspective of palliative care continues, there is a real danger that the specialisation of palliative care will cease to exist and become a generalist tag-on to the roles of all health practitioners, with the possible exception of palliative medicine. The emerging knowledge base will end and care of the dying will lose out to the competing demands for healthcare funding. (Aranda, 1998, p. 31)

It is the contention of this paper that nurses and the profession of nursing have not only reason but also opportunity to play a remedial role here, by invoking a sophisticated replay of traditional activities. For example, in the sociopolitical context now burgeoning in Aotearoa New Zealand, there is a unique opening for palliative nurse practitioners to fill the role of "care co-ordinator" described in *The New Zealand Palliative Care Strategy* (2001, p. 8). At present the Nursing Council of New Zealand, consistent with its goal of articulating more precisely the role of nurse practitioners within specialties (Nursing Council of New Zealand, 2001) is defining the role of the palliative care nurse practitioner. Nurses thus endorsed would have the empowerment at a national level to revisit the premodern wise (wo)man role, at the heart of which can be seen the ability to facilitate. The nurse is the one health professional who interfaces with all others: members of the multidisciplinary team; patients; family and whanau; and carers. Facilitation can manifest in this nursing role as assistance, catalysis, direction or referral. All these aspects are captured by Johnson (1998, p. 19) in her discussion of the dissemination of specialist palliative care knowledge:

> Outreach contacts need an awareness of the general hospice concept, including local and national service availability, how hospice meets special needs associated with the loss of a loved one, the expertise and variety of support services

available, who may benefit from hospice care, and when and how to access hospice service. It is essential to provide information about when a shift to palliative care may be indicated and to emphasize the significance of sharing information about hospice with someone in need early enough to allow maximum therapeutic benefit from hospice service.

At a more intimate level, "Nurses can develop relations that enable the person and their family to define how they want to live and how they want to make their own transitions through the time leading to death" (Street, 1998, p. 73).

The facilitative nurse is characterised by not only an eclectic knowledge base but also by the practice of presencing - being before doing, ontology before action - so that the temptation of an automatic response is minimised. Presencing implies a partnership with another, embodying trust, engagement and contextualisation. Although in nursing contexts presencing is usually taken to refer to a relationship between a nurse and a patient, the concept could equally well apply to, for example, the relationship between a palliative care nurse practitioner and staff in an aged-care complex. Presencing also presupposes significant reflection, whereby contemplation and meditation combine with mirroring of the other to enable true empathy and insight. In this way postmodernism's qualities of juxtaposition, inclusivity and celebration of difference are powerfully invoked (Reed, 1995; Watson, 1995). Lawton's (2000) discussion of the dichotomy of subjective and objective embodiment, and its relationship to perceptions of the progress of the body receiving palliative care, can fruitfully be read alongside Hickson and Holmes' (1994) consciously provocative characterisation of nurses' diverse, often contradictory, constructs of the bodies they nurse. These imaginative approaches assist the adoption of the marginalised position so conducive to extraction and reconfiguration of nursing knowledge (Watson, 1995).

Kellehear's (1999) philosophy of health promoting palliative care can be seen as one way of providing a practical infrastructure for a postmodern approach. As he says, health promoting palliative care:

> focuses our attention on the worthy practice principles of participation, support, and consultation right up to the end of life . . . [and] renews our practical

commitment to the social side of life – in the very person before us, and in the wider society to which he or she belongs. Health promoting palliative care offers an opportunity to deepen our understanding of the finer distinctions of human need that go beyond the body – the needs of the spirit and mind, and of the social world that cradles and nurtures them both.   (Kellehear, 1999, p. 177)

The role of care co-ordinator, outlined in *The New Zealand Palliative Care Strategy* (2001, p. 8), provides an ideal opportunity for a palliative care nurse practitioner to facilitate health promoting palliative care. Is there, in addition to the official tasks of the co-ordinator's position, enough licence to allow an incumbent care co-ordinator to adopt a consciously marginalised, postmodern stance? Is there a place for making a virtue of, even capitalising on, difference? Does there exist the possibility for the seemingly separate strands of central government policy; specialist palliative care unit philosophy; aged-care complex culture; and patient, family and whanau preferences to be spun together in a truly and consistently patient-centred way? It is my contention that, combined by an expert facilitating nurse, they can indeed be interwoven to create for each individual person that most authentically beautiful of goals and legacies: a meaningful closure to a unique life.

REFLECTIONS

What inferences can be drawn from the research undertaken?

This paper has discussed aspects of the contemporary provision of palliative care, with particular reference to Aotearoa New Zealand. Goals and values of four different groups of stakeholders within palliative care have been examined: central government planning; specialist palliative care units; aged-care complexes; and patients, family and whanau. The context within Aotearoa New Zealand has been found to be similar to other contexts worldwide in that there is a desire to extend palliative care to a wider group of recipients but no clear pathways to enable this. Evidence as regards the quality of palliative care given by different types of healthcare institutions is conflicting.

It is contended that currently there may be insufficient congruence between the goals and values of the different stakeholders to ensure that optimal palliative care, in terms of availability, quality and acceptability, is given and received. Palliative care nurse practitioners, working as care co-ordinators within a context of postmodern openness and creativity, could in theory play a significant facilitative role in the dissemination of the philosophy and practice of palliative care to a wider group of health professionals and recipients and also in fostering a collaborative spirit. The initiative currently being undertaken by the Nursing Council of New Zealand in defining specialist roles for nurse practitioners (Nursing Council of New Zealand, 2001) has the potential to equip nurses with not only the requisite skills but also the mandate to apply them at a nationally endorsed level.

Besides the role of palliative care nurse practitioners as potential care co-ordinators, other issues referred to in this paper include the extension of palliative care to a wider group of recipients; implications of the mainstreaming of palliative care; the need for a truly collaborative spirit among health professionals; the need for further education and for sharing of expertise; and the need for appropriate evaluative measures. All these matters are succinctly summarised by Folland (2000, p. 173):

A patient can expect contact with a variety of nurse specialists during the course of his [*sic*] illness. It is therefore essential to adopt a collaborative approach to ensure that information and support available to patients and families is clear, non-conflicting and consistent. This can be facilitated by developing practice protocols and pathways, together with comprehensive and regular communication opportunities across hospital, hospice and community, to ensure that specialist input is appropriate and cost-effective and, most importantly, is of 'value' to patients and those that care for them . . .

The need to promote a shared approach to care is evident and especially important in today's primary care led services. The developments within cancer services have been substantial and have led to improved care for those people with complex cancer-related needs. But how well are others provided for? The principles of palliative care now begin to extend to patients with non-malignant conditions and those working in the field face a special challenge of striving to meet their needs with more equitable service provision. Demand for the education and support of other health workers will become greater. It may be an opportunity for nurses to rekindle the creative spirit of palliative care. Through developing the skill base and experience of own team members, nurses can learn to meet the needs of a wider patient group as role definitions may broaden. However, what must rapidly be learnt more adequately is to measure better the 'benefits' of specialist roles and their value to patient groups.

A similar sense of optimism tinged with disquiet characterises my own state of mind as I reflect on the current provision of palliative care and ponder on future developments. I am left with a host of questions at the microcosmic as well as the macroscopic level. Palliative care is not easy. It is often difficult to elucidate the needs and wants of individual patients and their significant others. It is often difficult to reconcile differences in the goals and values between patients and their significant others, or between different family members. What constitutes a "good death" for one particular person? How can it be provided? What particular blend of health professionals and resources could best provide optimal and appropriate symptom control and psychosocial care? If that blend is known, is it accessible, available and affordable? If not, why not? Could steps be taken to improve matters? Or could education enable delegation of care, through empowerment of others? What evaluation and outcome measures can be devised which not only encapsulate the realities of lived experiences but are also capable of influencing planners, policy makers and resource providers?

To return to the original metaphor: how likely is it that parallel travellers will be aware of the different perceptions of travellers on different parallel lines? Will they indeed be even aware of the existence of other journeys and of travellers with perspectives different from their own? Will parallel travellers therefore be constrained to journey on in a state of perpetual silence or miscommunication?

Palliative care nurse practitioners, as companions of so many travellers on so many diverse journeys, have been cited as possible facilitators of linkages between these metaphorical parallel lines. Will these nurses have not only the technical and communicative skills to connect in a meaningful way with their clients and colleagues, but also some element of insightful grace to enable them to hone in on and enact that which is desirable? To ascertain what is needed and wanted, and to bring it to pass? This is my hope, and I believe it is a realistic one, given motivation and opportunity.

This paper has been designed to stimulate readers both to reflect on the true nature of the complex issues involved and also to develop creative effective solutions. Palliative care is not easy, but wherever life is valued excellence in its provision is eminently worth striving for.

POSTSCRIPT

What are the acknowledged limitations of this paper? What are some suggested areas for future research?

Despite the temptation to explore a host of peripheral matters such as ethnicity; pediatric palliative care; living wills; euthanasia; and support for palliative care staff, I decided not to compromise my chosen focus on the circumscribed number of issues defined at the outset of this paper.

Nevertheless my exploration of these issues has alerted me to many areas in need of further research, including quality of life from the perspective of personhood; palliative care evaluation measures especially as regards quality of life indicators for patients and carers (evaluated separately); educational needs of the staff of aged-care complexes; and the views of specialist palliative care unit staff on both the dissemination of palliative care knowledge and also the extension of palliative care to patients with non-cancer diagnoses.

These and no doubt many other related topics await investigation, illumination and consideration.

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