A study of the integration of health promotion principles and practice in palliative care organisations.

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KEY WORDS

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*Ottawa Charter for Health Promotion*

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Community action
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Mixed methods
Documentation review
In-depth interviews
Focus groups
Self-administered questionnaires
Matrices
Abstract

The modern hospice movement emerged in the 1960s as a grassroots social movement that attempted to restore an holistic and contextualised approach to the care of people at the end of life. This approach embraced the lived experience of the dying person at the centre of care across physical, emotional, social and spiritual domains of life. To achieve this, the care of dying people was largely removed from mainstream health care systems to promote more holistic and socially contextualised dying. In recent decades, the evolution of palliative care demonstrates the gradual return of palliative care services to the mainstream. It has been asserted that, in this process, palliative care services have progressively abandoned the social context of dying people, increasing instead an emphasis on “physical care [while] simultaneously de-emphasizing psychological, social and spiritual care” (Kellehear, 1999a, p.76). Kellehear and others have proposed that the repositioning of palliative care within mainstream health care systems has increased a focus upon illness and disease at the expense of health and wellbeing. Subsequently, conventional palliative care services have been criticised for not adequately locating end of life care within the social contexts in which death and dying take place.

In an attempt to address this problem, Australian sociologist Allan Kellehear proposed an approach to end of life care that brought together the core concerns of palliative care with the principles and practices of health promotion (Kellehear, 1999b). Whilst their congruence is not immediately apparent, these two fields have been increasingly examined for their potential benefits in the
Abstract

provision of end of life care. In the current policy climate in Australia, there is an imperative to consider how end of life support services might be improved through adopting a health promoting palliative care approach.

The aim of this study has been to investigate the integration of health promotion principles and practice by a selected palliative care service by examining the qualitative impact of this change on the organisation. Specifically, it endeavoured to identify the factors that advanced or impeded this integration by examining how the structures and processes of, and outcomes for, the organisation reflected a health promoting approach. To meet these aims, this study undertook an in-depth examination of the implementation of a health promoting palliative care model by a community based palliative care organisation. Based in a constructionist-interpretivist paradigm, a mixed-method (QUAL+quant), instrumental case study research design was utilised to capture multiple perspectives of the implementation process. Data collection comprised examination of 127 organisational documents, 32 in-depth interviews with staff, volunteers and consumers, 5 focus groups with staff and volunteers, and 25 carer questionnaires. Qualitative data were subject to thematic analysis, with supplementary quantitative data analysed to generate descriptive statistics.

The findings demonstrated a large number of complex and interrelated enabling and impeding factors to the implementation in the case study site. These factors have been grouped into four key themes which have been examined in light of the aims of this study and the issues identified in a comprehensive review of the literature. This study found that:
Conceptual congruence between health promotion and palliative care was a fundamental starting point in the implementation of a health promoting palliative care model.

Where conceptual congruence was clear, activities associated with the model that were regarded as beyond conventional approaches to palliative care core business were viewed favourably by stakeholders and were less likely to encounter resistance within the organisation.

When systematic approaches to organisational change, such as quality improvement systems, were rigorously applied, the impact of the transition upon stakeholders was qualitatively less.

Where this transition had been effectively made, consumers, staff, volunteers and members of the wider community were seen to benefit.

This study adds to the current discourse regarding the intersection between end of life support and health promotion, and provides insight into how palliative care organisations might undertake the transition from conventional models to a health promoting palliative care approach.
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ABBREVIATIONS

A number of acronyms and abbreviations appear in this dissertation. Whilst noted in full when first appearing in the text, they are listed here also.

<table>
<thead>
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<th>Term</th>
<th>Definition</th>
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<tr>
<td>ACHS</td>
<td>Australian Council on Healthcare Standards</td>
</tr>
<tr>
<td>CPCRE</td>
<td>Centre for Palliative Care Research and Education (Australia)</td>
</tr>
<tr>
<td>DoHA</td>
<td>Department of Health and Ageing (Australia)</td>
</tr>
<tr>
<td>DVA</td>
<td>Department of Veterans’ Affairs (Australia)</td>
</tr>
<tr>
<td>FPMT</td>
<td>Foundation for the Preservation of the Mahayana Tradition</td>
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<tr>
<td>HPPC</td>
<td>Health Promoting Palliative Care</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-government organisation</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service (UK)</td>
</tr>
<tr>
<td>PCA</td>
<td>Palliative Care Australia</td>
</tr>
<tr>
<td>PCOC</td>
<td>Palliative Care Outcomes Collaborative (Australia)</td>
</tr>
<tr>
<td>PCQ</td>
<td>Palliative Care Queensland (Australia)</td>
</tr>
<tr>
<td>PEPA</td>
<td>Program of Experience in the Palliative Approach (Australia)</td>
</tr>
<tr>
<td>QUT</td>
<td>Queensland University of Technology (Australia)</td>
</tr>
<tr>
<td>SPO</td>
<td>Structure – Process – Outcome Framework (after Donabedian)</td>
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<tr>
<td>TQM</td>
<td>Total Quality Management</td>
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<td>WHO</td>
<td>World Health Organization</td>
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DEFINITIONS

A number of terms specific to the fields of palliative care and health promotion are used in this document. Definitions are provided below and are essential to understanding their usage throughout this dissertation.

The term **palliative care** is used to describe the services provided to “people of all ages who have a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life” (Palliative Care Australia, 2005a, p.10). This care is provided to the patient, their family and informal caregivers, and incorporates early involvement in care, thorough assessment, and attention to physical, psychological and spiritual care. It includes support during bereavement (World Health Organization, 2005, ¶1). In this dissertation, this term is sometimes augmented to **palliative care services** when referring specifically to the organisations providing such care.

**Palliative care** is also used in this dissertation to describe a philosophy of care that is underpinned by values such as viewing death as a normal part of living, neither hastening nor postponing death, and incorporating holistic views of being (World Health Organization, 2005, ¶1). The specific meaning of this term in this dissertation is able to be differentiated by its usage in context.

**Hospice** is a term sometimes used interchangeably with ‘palliative care’ when specifically used to describe the philosophy or services of palliative care. More
commonly it is used to refer to the buildings and programs in which that care is delivered. In North America, ‘hospice’ is often specifically used to denote home-based programs of palliative care (DeSpelder & Strickland, 2002). It is also used as an historical description for early palliative care services. In this dissertation, it primarily refers to the modern hospice movement and its philosophy.

The modern hospice movement refers to the social movement which began in the 1960s in the UK and spread to much of the developed world in the decades since. It preceded the professionalised palliative care defined above. It was characterised by the rapid establishment of buildings and programs where care at the end of life took place away from the mainstream health care system, with a strong emphasis on community participation in care of the dying (Clark & Seymour, 1999).

End of life is defined as “that period of time marked by disability or disease that is progressively worse until death” (Lynn, Schuster, & Kab cenell, 2000, p.349). When used in the form end of life care, it sometimes has been used interchangeably with ‘palliative care’ and ‘hospice’. It reflects an attempt to broaden the scope of the patient populations who may receive palliative care services. In this dissertation it is used in the sense defined above and includes, but is not limited to, the remit of palliative care.

The palliative approach is a term that describes an approach to palliative care used by non-specialist palliative care services or practitioners. It is characterised
by attention to the holistic needs of patients and their families and the promotion of quality of life without the formalised structures of a designated palliative care service (Palliative Care Australia, 2005a).

The term **public health** describes “a concern with social efforts led by governments and actioned by communities, often in partnerships with health and other social organisations, to lessen disease and/or improve health at the broadest population level” (Kellehear, 2005, p.19). These strategies include education, building community capacity and social capital, public policies and laws promoting health of communities, collaboration between health and other sectors, and the promotion of social and physical environments that are both sustainable and safe for members of society. Health promotion is a framework within the public health paradigm.

**Health promotion** is the process of enabling people to increase control over, and to improve, their health. (World Health Organization, 1986). Put simply, health promotion is “any combination of strategies that are designed to improve people’s health” (Kellehear, 1999b, p.10). In this dissertation, the five components of health promotion as defined by the *Ottawa Charter for Health Promotion* (World Health Organization, 1986) are crucial to understanding this study. These components are (a) building public policy (b) creating supportive environments (c) strengthening community action (d) developing personal skills and (e) reorienting health services. Full descriptions of these components are given in the dissertation.
Health promoting palliative care is a term coined by Australian sociologist Prof. Allan Kellehear to describe a social model of palliative care (Kellehear, 1999a) based upon the application of health promotion elements to the principles and practices of palliative care and the organisation of palliative care services (Kellehear, 1999b). In addition to the components of the Ottawa Charter, it emphasises a participatory role for members of the community.
STATEMENT OF ORIGINAL AUTHORSHIP

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

SIGNATURE: [Signature]

DATE: 9th November 2007

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I’m grateful for the guidance given by my supervisory team, comprising my principal supervisor Professor Patsy Yates, my associate supervisor from QUT Associate Professor MaryLou Fleming and my associate supervisor from industry Mrs Margie O’Kane.

The leaders, staff and volunteers of the case study site made me feel welcome throughout the course of my data collection, and I salute their generosity in accommodating me so willingly in their premises and in their work, and for participating so enthusiastically in this study. I wish to acknowledge in a special way the patients and carers who opened their homes and hearts to me, despite their challenging circumstances and the burdens they carried. I hope this work does justice to what they entrusted to me.

I acknowledge my many colleagues from the palliative care community and QUT, and those other postgraduate students who have travelled this journey with me, particularly Debbie Long; my peers from N Block and IHBI, especially Deb Parker and Dr Shirley Connell; and the members of the QUT-KG interpretive researchers’ group led by Dr Stephen Cox. The solidarity and encouragement I’ve received from these many people has provided me with necessary sustenance.
at key points along the way. I’m especially indebted to those who have provided their wise, insightful and critical input into the development of this dissertation, particularly Deebs Canning and Dr Judi Greaves. Also, my dear friend Catherine Wilson has been a tower of emotional strength and support in trying to keep me sane during this time.

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Lastly, I wish to acknowledge the extraordinary commitment to the success of this endeavour shown by my beloved wife, Caren Rosenberg-O’Brien. Conspiring with our daughter, Lucy Isabella, she has cleared the path on so many levels to enable me to achieve this longstanding goal. Actions do indeed speak louder than words, and this achievement would have been simply impossible without her.
DEDICATION

This work is dedicated to the memory of

EVELYN LUCY DOWNING

29 November 1909 – 27 August 1980

whose death taught me that time is precious

and can make all the difference in the world.
1.1 Background

Death is a defining feature of all peoples and all cultures (Munley, 1983). The support and care of people at the end of their lives, in some form or other, is an enduring characteristic of all societies. What is referred to today as palliative care represents a particular response to death and dying set in specific historical and cultural contexts (Clark & Seymour, 1999).

1.1.1 Sociological contexts of palliative care

Palliative care originally emerged, at least in part, as a response to the perceived neglect of dying people by the dominant biomedical model of health care in parts of the Western world during the post-war period (Moore, 2004). The biomedical model has been criticised for its removal of the sick or dying person from their social context (Bunton & Macdonald, 2002) and consequently undertaking diagnoses and treatments that fail to correspond to the day to day reality of health and illness experienced by “ordinary people” (Moore, 2004, p.304). The grassroots social movement historically known as the modern hospice movement sought to restore “an holistic approach to patient care, the family as the focus of care, and importance of multidisciplinary collaboration on a day to day basis” (Hockley, 1997, p.84).

Since its emergence in the 1960s, the modern hospice movement – specifically in the UK, USA and Australia – established programs for the care of
dying people primarily through localised community action, with the momentum for their development often led by individual clinicians and idiosyncratic funding decisions (Palliative Care Australia, 2003). This unregulated growth resulted in palliative care services demonstrating highly varying models of service delivery and highly variable outcomes for their clientele. Attempts to regulate the provision of palliative care have seen it drawn back into mainstream health care systems.

It has been asserted that, in this process of mainstreaming, palliative care services have progressively abandoned the social context of dying people, increasing instead “the emphasis on physical care [while] simultaneously de-emphasizing psychological, social and spiritual care” (Kellehear, 1999a, p.76). Kellehear and others have proposed that the repositioning of palliative care services within mainstream health care systems has increased a focus upon illness and disease at the expense of health and wellbeing. Whilst this claim is debated in this dissertation, concerns remain that many contemporary conventional models of palliative care do not adequately locate death and dying in the social context of people’s lives (Howarth, 2007; Kellehear, 1999b, 2005, 2007; Moore, 2004).

This thesis contends that death and dying cannot be considered as solely a health care event, but as a societal concern affecting individuals, their personal, interpersonal and social contexts, as well as whole communities (Kellehear, 2005). In this dissertation, dying is understood to refer to “…a self-conscious anticipation of impending death and the social alterations in one’s lifestyle promoted by ourselves and others that based upon that awareness” (Kellehear, 2007, p.2). In a health promoting palliative care model, the nature and practice of
palliative care are fundamentally shaped by the location of death and dying in society, rather than solely upon their location in health care.

1.1.2 Health promoting palliative care

In an attempt to redress these perceived inadequacies and return palliative care to its original intent, Australian sociologist Allan Kellehear proposed a social model of support for dying people. Within a public health framework, Kellehear (1999b) has suggested that the application of the principles of health promotion to palliative care could be of benefit to dying people, their families, and society more broadly. Further, he adds, it may prevent avoidable morbidity in individuals, families, communities and societies through a health promoting focus on issues of death and dying and in the provision of palliative care services. Health promoting palliative care represents a paradigm shift that attempts to apply the philosophies and practices of both palliative care and health promotion to the provision of support of people at the end of life, in order to embrace a social model of palliative care (Kellehear, 1999a).

Such an approach demands reflection upon the conceptual underpinnings of each of its two theoretical sources. Palliative care aims to achieve the best possible quality of life for dying people and their families (Commonwealth of Australia, 2000). Health promotion aims to assist people to live as healthily as possible (World Health Organization, 1986). In a trajectory similar to the evolution of palliative care, health promotion emerged during the latter decades of the 20th Century from growing concern with the overemphasis in health care upon disease and its diagnosis, treatment and cure (World Health Organization, 1978). The emergent view was that the dominant biomedical model failed to adequately
embrace whole population issues and the complex interrelationships between the physical, psychological and social components of health and wellbeing, through its artificial dissociation of the disease from the person, and the person from their social context (Bunton & Macdonald, 2002).

Whilst some might question whether these two paradigms are compatible, over the past 15 years or so there is evidence of increasing interest in how a public health or health promoting approach to palliative care might benefit people at the end of life. A growing body of literature suggests health promotion and palliative care are not only conceptually compatible, but in practice may have individual, communal and societal benefits. Whilst some discussions of both health promotion and palliative care have been identified and are examined in detail in the literature review of this dissertation (Buckley, 2002; Clough, 2002; D'Onofrio & Ryndes, 2002; Faulkner, 1993; Lloyd, 2000; Maslen, 1998; Rao, Anderson, & Smith, 2002; Rosenberg, 1992; Russell & Sander, 1998a; Russell & Sander, 1998b; Scott, 1992; vanderPloeg, 2001; Weaver, 2004; Zeefe, 1996), there are only a few reports of empirical studies into its integration (Buckley, 2002; Currow, Abernethy, & Fazekas, 2004; Gallagher, 2001; Pegg & Tan, 2002; Rao et al., 2005; Richardson, 2002). Scant attention has been given to the impact of the integration of health promotion principles and practice upon palliative care organisations (Kellehear, 2005; Kellehear, Bateman, & Rumbold, 2003; Salau, 2006).

1.1.3 Organisational models

By their nature, health care organisations are complex entities intensely engaged with the broader socio-political contexts in which they exist. This is no
less so for palliative care services. Organisational theorists have developed a view of organisations as *organisms*. That is to say, organisations demonstrate a complex interrelatedness between their human, business, and technical components and are geared towards modifying themselves in light of the influences exerted by these components and other contextual factors (Begun, Zimmerman, & Dooley, 2003). In response to these influences, health care services have increasingly integrated various means that promote organisational adaptation to change (Mickan & Boyce, 2002). This view of organisations as complex adaptive systems facilitates this study of the potential and actual impacts of integrating the principles and practice of health promotion in palliative care organisations that underpins this study.

Health promoting palliative care incorporates three key attributes that can be recognised in all models of health care. Firstly, it is based upon a particular conceptual perspective that promotes optimal health – even in the presence of incurable disease – utilising palliative care philosophy and the *Ottawa Charter for Health Promotion* (World Health Organization, 1986) to inform organisational mission, values and strategic directions. Secondly, health promoting palliative care makes these concrete through application of the five action areas of health promotion to supply parameters for determining the scope of goals and objectives. Finally, a health promoting palliative care model provides organisational structures and processes that assist in the planning, implementation and evaluation of services in ways consistent with its underpinning conceptual base, although this remains the most underdeveloped element in health promoting palliative care.
These conceptual and practical elements collectively describe the health promoting palliative care model.

1.1.4 Current imperatives for health promoting palliative care

The Australian government introduced a reform package for end of life care in its *National Palliative Care Strategy: a National Framework for Palliative Care Service Development* (Commonwealth of Australia, 2000). Its implementation through the *National Palliative Care Program* included building community capacity, development of the skills of family carers and policy development for end of life care; these elements resemble health promotion and public health concepts.

In 2003, the national peak advisory body Palliative Care Australia [PCA] provided a planning guide for palliative care organisations that, notably, includes public health strategies (Palliative Care Australia, 2003). A year later, the Australian government released an evaluation guide for palliative care services and programs that similarly contained elements of health promotion and public health (Eagar, Cranny, & Fildes, 2004). The following year, PCA published revised standards for palliative care provision that utilised a population-based approach and explicitly mentioned health promotion (Palliative Care Australia, 2005a).

Consequently, it is clear that there is a current imperative for the consideration of how a health promoting palliative care model might influence existing palliative care organisations in the provision of services to dying people and their families. A number of palliative care services in the Australian setting have begun to integrate health promotion principles and practices into their
organisations and have reported on their programs through the *Palliative Care and Public Health Network* (Palliative Care and Public Health Network, 2003a, 2003b, 2004a, 2004b).

### 1.2 Aim of the Study

This research addresses what impact might be experienced in organisations that implement a health promoting palliative care model. It is underpinned by two research questions:

- What impact does the implementation of health promotion principles and practices have upon palliative care organisations?
- What factors advance or impede integration of health promotion principles and practice to palliative care service provision?

The aim of this study has been to investigate the integration of health promotion principles and practice by a selected palliative care service by examining the qualitative impact of this change upon the organisation. Specifically, it endeavoured to identify the factors that advanced or impeded this integration by examining how the structures and processes of, and outcomes for, the organisation reflected a health promoting approach.

To meet these aims, this study undertook an in-depth examination of the implementation of a health promoting palliative care model by a community based palliative care organisation. Based in a constructivist-interpretivist paradigm, a mixed-method instrumental case study was designed to capture multiple perspectives of this organisation’s implementation of health promotion principles and practice.
1.3 **Significance of the Study**

This study adds to the growing body of knowledge in the emerging field of health promoting palliative care by contributing to theory development and model refinement and raising awareness amongst health professionals of the potential benefits of health promoting palliative care. It is significant to the fields of palliative care and health promotion in addressing a gap in the literature regarding the integration of health promotion principles and practice in palliative care organisations. It responds to the current imperative evident in public policy and standards for palliative care service provision to address health promotion issues in service planning.

At the service level, it provides information to service planners and health organisations about the potential organisational issues in implementing a health promotion model of palliative care. In doing so, it may facilitate the transition of palliative care services towards a health promoting approach. In the practice of palliative care, this study is significant as it presents an examination of a social model of care that addresses deficits in conventional models of palliative care and facilitates the critical examination of current practice. This examination offers insights to the implementation of health promotion principles and practice that may be considered by other palliative care organisations.
1.4 Structure of the Dissertation

This dissertation is comprised of nine sections that are summarised below.

Chapter 1: Overview

This chapter briefly outlines the conceptual development of this research study, summarising the key issues that contextualise this research. It presents the aims, significance and limitations of the study and describes the structure of the dissertation.

Chapter 2: Literature Review

The literature review provides a critical review of the literature relevant to the development and implementation of health promoting palliative care. This review examines the influence of changing social perceptions of death and dying upon the development of palliative care services and traces the unregulated evolution of palliative care from its origins in the hospice movement to its current status as a professionalised discipline within mainstream health care. Further, it explores the emergence and evolution of health promotion as an approach to understanding wellbeing. It then considers the proposal of health promoting palliative care as a specific approach to providing end of life care through a social model of palliative care. Finally, the literature review considers contemporary understandings of organisational change to inform analysis of the integration of health promotion principles and practice in palliative care organisations.
Chapter 3: Methodology, Design and Methods

This chapter is presented in three sections. Firstly, it considers the theoretical assumptions of the research methodology. Secondly, it provides description of, and rationale for, the study design, including the schematic illustration of the conceptual framework for this study and the strategies employed to establish and maintain the rigour of the research. Finally, it gives detailed descriptions of the methods utilised, including sampling techniques, data collection and management methods, and data analysis strategies.

Chapter 4: Case Description

This brief chapter contains contextual information about the case study site. The case description contains primarily descriptive data, with some evaluative statements, and sets the scene for the presentation of data analysis in the chapters that follow.

Chapter 5: Findings: Impacts, Enablers and Barriers

The findings chapter reports the findings of the first level data analysis. Its purpose is to deepen the understanding of the case study site by exploring the key issues pertinent to the implementation of health promoting palliative care and identifying the factors that advance or impede this implementation. The structure of this chapter is based upon the five key components of health promotion of the Ottawa Charter for Health Promotion (World Health Organization, 1986), with subsections for each component detailing the issues related to that component’s implementation, and identifying the enablers of and barriers to its integration.
Chapter 6: Examination of Key Themes and Discussion

This chapter examines deeply the four key themes that emerge from further data analysis. The themes are (a) establishing conceptual congruence, (b) determining core business (c) managing organisational change and (d) anticipating outcomes of health promoting palliative care. This chapter is analogous to a Discussion chapter, as it examines how the findings of the study address the aims of this research study, with regard to current thinking about health promoting palliative care demonstrated in the literature review.

Chapter 7: Conclusions, Limitations and Recommendations

This chapter provides a summary of the study in its concluding remarks, considers the limitations of this study and gives recommendations for further research.

Appendixes and References
Chapter 1: Overview of the Study
CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The purpose of this chapter is to provide a critical review of the literature relevant to the development and implementation of health promoting palliative care. This review examines the influence of changing social perceptions of death and dying upon the development of palliative care services and traces the rapid and unregulated evolution of palliative care from its origins in the hospice movement to its current status as a professionalised discipline within mainstream health care. Further, it explores the emergence and evolution of health promotion as an approach to understanding health and wellbeing. It then considers the proposal of health promoting palliative care as an alternative to current conventional models of end of life care. Finally, this literature review considers contemporary understandings of organisational change to inform analysis of the integration of health promotion principles and practice in palliative care organisations. This literature review provides the theoretical and lived-world contexts for understanding the nature and implementation of a health promoting palliative care approach within palliative care organisations.

The scope of this review resulted in extensive searches of the palliative care, thanatological, health promotion, organisational and other social science literature. It utilised MEDLINE, PubMed, EBSCO Host and CINAHL databases,
as well as accessing historically pertinent texts, and grey literature from relevant palliative care and health promotion organisations and their websites.

2.2 The Development of Palliative Care

Contemporary palliative care has evolved in response to historically and culturally determined understandings of death and dying (Clark & Seymour, 1999). In all societies, the support and care of people at the end of their lives in some form or other is unfailingly evident. As noted in the introductory chapter of this dissertation, death is a defining feature of all peoples and all cultures (Munley, 1983) and death and dying cannot be considered as solely a health care event, but as a societal concern affecting whole communities (Kellehear, 2005). The nature and practice of palliative care, therefore, is fundamentally shaped by changing social perceptions of death and dying.

2.2.1 Social perceptions of death and dying: setting the scene for hospice

Confronted with their own mortality, human beings tend to regard death and dying with a mixture of fear and fascination. Indeed, mortality is fundamental to the human condition, circumscribing collective and individual meaning-making, self-awareness, decision-making and behaviour. As stated by Clark & Seymour (1999), “it is our awareness of our own mortality which somehow provides the preconditions for all human thought and action” (p.5). Whilst its place in the collective awareness throughout history has varied, death and dying has generated rituals and customs, legends and superstitions, each functioning as secular or
religion explanations for the inexorable outcome of human existence – *that living ends*.

2.2.1.1 **From daily life to technological event**

It is this insight into human impermanence that underscores the response of societies to the needs of its dying members. In his influential book *Western Attitudes Toward Death: from the Middle Ages to the Present*, Philippe Ariès (1976) referred to “tamed death” (p.2) in the Middle Ages, which was so commonplace in everyday life as to induce little dread. However, the Industrial Revolution wrought fundamental changes to families and their structures – families became smaller, more mobile, more isolated, and more fragmented (DeSpelder & Strickland, 2002), creating new patterns of dependency (Clark & Seymour, 1999). As societal attitudes moved from collective to individual awareness, an understanding of death as an individual – rather than communal – event emerged (Kellehear, 2007). Indeed, Walter’s (1994) criticism of post-modern constructs of death is directed towards their profound subjectivity and focus on the individual – an illustration of which can be found in the first anniversary ceremony of the 9/11 terrorist attacks, where the reading of the full name of every individual who perished at the World Trade Centre site took up the greatest proportion of the time allocated for this public mourning ritual.

Moreover, medical progress in the 20th Century “transformed the experience of dying from a part of daily life to a highly technological event” (Connor, 1998, p.4). Death left home, as it were, its stewardship increasingly relinquished by families to charitable institutions, newly emerging acute hospitals or simply left to chance. Indeed, by the end of the Century, two-thirds of all
deaths in the UK occurred in hospitals, with a further 12% in other institutions, leaving just 22% of all deaths at home (Ellershaw & Ward, 2003). The past 100 years also saw fundamental changes in social perceptions of human living and dying. Death in the developed world became, for the most part, a taboo matter, with modern medicine viewing death as an enemy to be vanquished (Connor, 1998). As a consequence of advances in medical science, such as the advent of antibiotics prior to the Second World War, life expectancy in the developed world more than doubled over the course of the 20th Century. Where once palliation – that is, the easing of distress – was the rule (Doyle, Hanks, & MacDonald, 1993), the growing capacity of medical science to cure disease saw the predominant causes of death shift from infection and trauma to degeneration (DeSpelder & Strickland, 2002). A presumption emerged that death is what happens to the old, rather than the young (DeSpelder & Strickland, 2002). Early death came to be seen as an unnatural; unpreventable death as someone’s fault (Connor, 1998). Death’s custodians were changing identity: “death…disappeared from community life and communal awareness and [was]…relocated as an individual experience occurring within the defining power of the medical expert” (Clark & Seymour, 1999, p.90).

2.2.1.2 Modern constructs of death

The experience of global conflict substantially changed Western thinking about death. Ariès’ concept of tamed death was lost on the battlefields of the 20th Century (DeSpelder & Strickland, 2002). While direct contact with death in the West has become mostly absent from daily life, it has been observed to be omnipresent in the mass media (Clark & Seymour, 1999). Romantic depictions of
death in art, literature and religion have been replaced by bloodied photojournalism. Today, mass death has been watched live on television, when passenger planes explode and skyscrapers fall, ‘smart’ bombs deliver a bird’s eye view from the cameras on their warheads, and the tsunami-ravaged Third World is the stuff of First World concerts and documentaries. Ironically, the West is considered to be simultaneously death-denying and death-obsessed – infatuated with unnatural death, yet avoiding natural death (Connor, 1998).

Clark and Seymour (1999) offered a framework to categorise these modern constructs of death, suggesting that modern experience views death as gradual, premature, or catastrophic. Clearly, catastrophic death has been witnessed in recent decades in acts of terrorism, but also, for example, in the massacres in Rwanda, the euphemistically named ‘ethnic cleansing’ in Bosnia-Herzegovina, and in the mass murders of civilians at Port Arthur and Tiananmen Square. Significantly, the distinguishing characteristic between these events and mass death as a result of natural disasters – such as the many thousands who died in the tsunamis in south Asia – is human agency. The collective consciousness of death in the developed world seems to be most disturbed by catastrophic death as the result of deliberate human action.

A high-profile, contemporary example of premature death is the HIV/AIDS epidemic (Clark & Seymour, 1999), a view held by the views of numerous commentators on its impact on hospice services (Beresford, 1993; Kelly et al., 1991; Sendor & O’Connor, 1997). Conversely to catastrophic death, human agency is not an explicit factor in accidental deaths from traffic accidents,
cancer, or AIDS, (although some may argue that these could be disputed, given the contribution of risk-taking behaviours to these events in some instances).

Finally, Clark and Seymour’s (1999) consideration of gradual death is contextualised by the vastly increased life expectancy resulting from the advancements in medical science discussed previously. Death in the developed world primarily takes place at the end of a period of increasing old age frailty or chronic illness – and it is here that the remit of palliative care is mostly situated (although some contextual factors may include premature death – for example, a 20 year old dying of metastatic melanoma is considered differently to an 80 year old with prostate cancer). Health promoting palliative care asserts its potential to influence experiences of premature and catastrophic death through reducing death denial, strengthening the resilience of communities to deal with issues of death and dying, and promoting early intervention in bereavement support (Kellehear, 1999b).

2.2.1.3 From the religious to the secular

It is also evident in an increasingly secular world that religion’s stewardship of mortality had been gradually relinquished to the medical and social sciences. Despite some death rituals and customs reminiscent of former religious practices, the place of religion in meaning-making around death and dying in the contemporary developed world is now very different to 100 years ago. The certainty once provided by religious belief no longer satisfies many who encounter their mortality. This trend was already underway at the end of the 19th Century as a response to the progressively reduced immediacy of death (Humphreys, 2001). Clark and Seymour (1999) proposed that juxtaposition exists
between collective consciousness and individualisation and is evident in the placement of religion in traditional and modern societies. Traditional societies with a more highly developed collective consciousness tend to place religion more centrally than a modern society with substantially more emphasis placed upon the individual. The decline in religious allegiances in the developed world is clearly evident where it is generally viewed as one of a set of lifestyle choices from which to choose (Clark & Seymour, 1999).

However, some researchers (McCullough, Larson, Koenig, & Lerner, 1999) have questioned the adequacy of the measurement of religious affiliation by mortality researchers. They have argued that measurements of religious membership fail to capture the complexity and diversity of religious expression and spiritual belief systems. Further, McCullough and his colleagues argue that membership measurement inadequately addresses the interaction between dying people, their families and religious confréres, and the modern health care system sanctioned to provide support at the end of life. Notably, this secularisation of the care of dying people has carried with it the Judeo-Christian values of its origins, that are still evident in the core values of palliative care such as the affirmation of life and the refusal to hasten death (World Health Organization, 2005). These remain fundamental considerations in understanding how palliative care operates in contemporary Western societies. As will be seen below, health promoting palliative care proposes a secular but values-based approach to the care and support of dying people.

These contemporary social perceptions of dying underscore some of the influences facing the implementation of social models of palliative care today.
This overview of changing social perceptions of death and dying lays a foundation for understanding the rapid and unregulated growth of palliative care services.

### 2.2.2 A “small rebellion”\(^1\): the emergence of hospice

The establishment and development of hospices and other types of palliative care services is widely discussed, with British medical sociologist David Clark leading the way in describing the history of the modern hospice movement (Clark, 1993, 1994, 1998, 1999a, 1999b; Clark, Hockley, & Ahmedzai, 1997; Clark, Malson, Small, Daniel, & Mallett, 1997; Clark & Seymour, 1999; Clark, tenHave, & Janssens, 2000). The origins of contemporary palliative care which provide the context for this study are found in the modern hospice movement of the 1960s. Beginning as “a small rebellion against the way dying people were cared for…” (Connor, 1998, p.xiii), the modern hospice movement was predisposed to a reactive and erratic trajectory. Whilst the dominant biomedical model of care enabled the development of proficiency in the cure of disease and prolongation of life, others argued modern medicine had lost its human face (Kearney, 1992). With a primary focus upon acute illness and rehabilitation, conventional medicine by and large neglected the needs of the dying (Clark & Seymour, 1999). Times were ripe for an alternative approach.

#### 2.2.2.1 Hospice Palliative Care in the UK

The establishment of St Christopher’s Hospice in 1967 by the late Dame Cicely Saunders is widely regarded as the beginning point of the modern hospice movement. Whilst this facility represents a tangible response to the perceived shortcomings of modern medicine of the time, it was perhaps the result of “the

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\(^1\) (Connor, 1998, p.xiii)
culmination of a...process in which several factors conjoined to create the condition of possibility for hospice expansion” (Clark, 1999a, p.225). However, a predilection for the use of the term ‘hospice’ by historians may have overlooked the work of other institutions where care for dying people took place. In an examination of the development of the first hospices in England around the end of the 19th Century, Humphreys (2001) suggested that closer scrutiny might benefit understanding of the modern hospice movement; she names five institutions providing care for the dying poor during this period. Origins of the later segregation of dying may be found here, for where the dying and living once received care side by side, they were now separated for the first time – not as an act of death denial, but as a means to distinguish the unique needs of the dying. Notably, each of these institutions seems to have developed independently of the others, although they were somewhat shaped by common religious and philanthropic trends of the day.

The focus of this post-war development in care of the dying in the UK was, for the most part, on people with cancer, whose epidemiological, social and clinical profiles were surveyed in detail in the National Health Service [NHS] Joint National Cancer Survey in 1952 (Clark, 1999a). Despite the recommendations of this report to increase the provision of places of care, improve the information given to cancer patients and provide more ample home care, there is little evidence of a systematic response. An exception lay in the establishment of the Marie Curie cancer nurses who undertook to provide places and programs of care for people dying of cancer. However, this apparent failure of the NHS to provide adequate support for terminally ill people was strongly
criticised by Glyn-Hughes (1960), given his survey results that demonstrated that 40% of cancer deaths in 1956 occurred in NHS hospitals. Moreover, nearly as many of the year’s cancer deaths took place at home with the likely need for skilled terminal care. This report concluded that there was a clear need for comprehensive supportive care of the terminally ill outside of the NHS system, with improvements in staffing ratios, nursing training in terminal care, and built environments all urgently required (Glyn-Hughes, 1960).

Significantly, Saunders’ preference for a separation of acute and terminal care services prevailed during this period, with the first modern UK hospices established separately from mainstream NHS hospitals. Saunders procured the support of senior government officials whose allegiances advanced the realisation of what would become St Christopher’s Hospice. The unique approach taken by Saunders advocated an approach to care focussing on improved quality of care for dying patients, provision of multidisciplinary care at home or in hospice, education and support to other health professionals, and research (Faull, 1998). In this approach, the emergent core values of palliative care can be seen:

First, there would be the delivery of high quality terminal care, the ‘total care’ to which she had referred in her writings, which would encompass physical, social, psychological and spiritual dimensions. Second, there would be an emphasis upon teaching in this developing area of work, so St Christopher’s would be a centre for education, not just of doctors and nurses, but also for social workers, chaplains, volunteers and others. Third, it would be a place for research into pain and symptom control and
into the wider view of terminal care which was emerging. (Clark, 1999a, pp.240-241)

The lecture tours of the USA by Saunders in the 1960s show her early emphasis on pain control, which was subsequently viewed as the “cornerstone of the hospice movement” (Beresford, 1993, p.xxii). Whilst this has led to improved knowledge and practice, this perceived overemphasis by palliative care practitioners on pain and symptom management was later criticised as symptomatology (Kearney, 1992), or a set of medico-nursing interventions provided at the expense of psychosocial interventions (Kellehear, 1999a). However, whilst Saunders’ ideas were grounded in the context of the contemporary medical culture of the day, her published works progressively demonstrated the influence of a much wider, multidisciplinary discourse (Clark & Seymour, 1999), and her development of the concept of ‘total pain’ has had a direct influence on contemporary understandings of holism in palliative care. Total pain is a description of distress in the physical, emotional, social and spiritual realms of human existence and to which, in the context of this discussion, palliative care services must comprehensively respond (Clark, 1999b). Whilst it still represents a mainstay concept in both conventional and health promoting palliative care services, it has been criticised for placing emotional, social and spiritual needs under the jurisdiction of medical practice and, in so doing, shoring up the medical dominance over dying (Howarth, 2007). In considering a paradigmatic shift to a social – rather than biomedical – model of palliative care, this is a substantial contextual issue for this study.
2.2.2.2  Hospice Palliative Care in the USA

In the USA, similar developments were taking place. During this period, Glaser and Strauss’ (1965, 1968) seminal works examined patterns of death and dying in the USA. Their attempt to describe the dying processes they observed in three hospitals initiated the development of awareness theory (Copp, 1998). Glaser and Strauss went on to build on their earlier work to explore the character of dying trajectories, examining the relationship between certainty of death and time. Significantly, they acknowledged that some capacity existed in mainstream hospitals to care for dying people despite the imperative to cure and save. All the same, they concluded that care of dying people was deficient, especially on social and psychological levels. This early work demonstrated an emerging awareness of palliative care issues, including the training of medical and nursing personnel, planning and review of psychological, social and organizational aspects of terminal care, planning for phases of dying that occur outside hospital, and encouragement by medical and nursing personnel of public discussion of issues that transcend professional responsibilities (Glaser & Strauss, 1968).

Towards the end of the 1960s, the late Swiss-American psychiatrist Elisabeth Kübler-Ross (1969) published her groundbreaking book, *On Death and Dying*. In interviewing a number of people as their lives drew to a close, Kübler-Ross devised descriptions of various emotional and psychological reactions to death of dying people. Her stages theory emerged as a result, but its subsequent uncritical use as the principle theoretical explanation of the dying trajectory was subject to some criticism. Whilst Copp (1998) speculated that this occurred as a probable reaction to the legitimisation of previously taboo subject in a systematic form, she pointed out a number of methodological flaws and presumptions in the
application of Kübler-Ross’ framework which drew its generalisability into question. Nevertheless, *On Death and Dying* has proved to be one of the most influential written works in the field and Kübler-Ross’s stages theory gained populist traction despite the methodological criticisms noted above. When dying people themselves began to reveal their dissatisfaction with being treated as failures in an unsympathetic health care system (Kübler-Ross, 1969), health care professionals and others in the USA were galvanised to find a better way to care for the unique needs of the dying. This sense of purpose in reforming the care of dying people was found in Australia also.

### 2.2.2.3 Hospice Palliative Care in Australia

Despite the extensive chronicling of the development of hospice palliative care in the UK and USA, its history in Australia has received less attention until recently (Hunt & Maddocks, 1997; Kellehear, 2000; Lewis, 2007). In Australia, like elsewhere, many palliative care services came about through localised community action, the influence of local clinicians, and *ad hoc* funding arrangements (Palliative Care Australia, 2003). In the early 1980s, Australian health care professionals with an interest in addressing the needs of dying people formed a national association to “share their ideas and establish training” (Lewis, 2007, p.141). This group eventually formed the Australian Association of Hospice and Palliative Care, the beginning of what has become Palliative Care Australia [PCA].

With a range of services already established at this time and an increasingly vocal collective of health care professionals, a national discourse on the nature of care for dying people was gaining momentum and reaching the ears
of the national government. A review of hospice, palliative care and community health services was undertaken in the mid-1980s with the national government committing funds for the provision of palliative care services within existing health care frameworks (Lewis, 2007).

However, a consistent national approach to the development of Australian palliative care services was not evident until the earlier years of this century (Lewis, 2007). Replicating the patterns apparent in other parts of the world, a dominance of cancer-related life limiting illness in the consideration of policy and planning was obvious. Whilst in practice settings, some non-cancer patients were receiving care, the inclusion of life-limiting illnesses such as neuromuscular degenerative diseases, organ failure, HIV/AIDS and others was, for the most part, a later addition to policy and planning of Australian palliative care services, particularly since the introduction of population based planning and the palliative approach (Palliative Care Australia, 2005b).

2.2.3 Development, diversity and definitions

The early years of the modern hospice movement was characterised by the unregulated development of service organisations driven by nascent core values, resulting in disparate models of care delivery to dying people.

2.2.3.1 Rapid expanse of services

In the UK in particular, a great number of hospices were opened during the 1970s. Diversification of services for people at the end of life was a common feature, with the development of increased home support day care and hospitals with palliative care outreach services (Clark & Seymour, 1999; Lewis, 2007). The Macmillan Nurses were established to provide specialist care directly to
people dying from cancer and their families both in institutions and at home (Seymour et al., 2002). A steady rate of growth in the number of inpatient services was evident, and remarkably, the number of home support services increased approximately tenfold across the 1980s (Clark, Hockley et al., 1997).

Similar exponential growth was evident in Canada (Scott, 1992) and Australia (Clark, Hockley et al., 1997). Again, diversification was notable, with establishment of hospices for children, day hospice units, and home-based respite care (Clark, Hockley et al., 1997). In the USA, a period of burgeoning interest was also underway, following the earlier establishment of hospice programs in the 1970s. As in the UK, there is some dispute over the detail of USA hospice development, with some scholars reporting the founding of the first modern US hospice in 1971 (Kastenbaum, 1997) whilst others suggest that, like the UK, there were places of care for dying people in the USA as early as 1899, with the first modern hospice established in 1974 (Bennahum, 1996). Notwithstanding this discrepancy, a small but committed hospice movement – including the establishment of the National Hospice Organization in 1978 – was active in service provision and education, with a distinctive slant towards home care rather than inpatient care (Beresford, 1993; Connor, 1998).

2.2.3.2 From ‘hospice’ to ‘palliative care’

This evolution brought with it a shift in the nomenclature relating to the services supporting dying people. The term hospice was being used interchangeably with palliative care, yet the former term was more likely to describe a place of care rather than a philosophy or model of care. With the recognition in the UK of palliative medicine as a subspecialty of internal medicine
in 1987 (Doyle et al., 1993), the term ‘palliative care’ increasingly came to refer to specialist clinical care of people dying, typically, of cancer (Kellehear, 2007). The term ‘hospice’, where not viewed as simply passé, became more associated with places of care sequestered from mainstream services (Howarth, 2007), such as freestanding ‘cottage’ hospices. Debate over the definition of palliative care has remained an enduring feature of its development (Doyle, 1993; Kearney, 1992; Levy, 1988; Librach, 1988; Maddocks, 1990; Scott, 1988).

These changes in the nomenclature of services for people at the end of life accompanied shifting understandings of the scope of such services. Indeed, a change in language is observable very recently with the use of the term life-limiting illness in preference to ‘terminal illness’ or ‘incurable disease’, implying the inclusion of palliative care in the support of people long before death is imminent (Palliative Care Australia, 2005a). Arguably, issues around early stage palliative care have received less attention and are a concern for health promoting palliative care (Kellehear, 1999b).

Former definitions of palliative care have demonstrated “a cluster of understood principles and practices” (Ford, 1992, p.91) which could be broadly applied to wherever services supported people at the end of life. This cluster has utilised different language at different times and in different places; the current version of these core values and associated characteristics of palliative care is illustrated below in Table 2.1.

However, Librach (1988, p.23) warned that the principles and practices that are affiliated with palliative care must not be allocated as the province solely of a group of specialists, given the broad spectrum of health conditions which
result in death. Moreover, he reminded the reader of the origins of palliative care in the failure of the health care system of the day to respond to the needs of dying people and their families. Again, Howarth’s (2007) commentary noting the link between philosophies of holism and the scope of medical practice in palliative care suggested that the care of dying people is not the sole province of a single specialty or discipline. Kellehear (1999b) has pointed out that a multidisciplinary team is not the same as simply having a specialist doctor and a specialist nurse with the support of a chaplain, but requires a more comprehensive approach to partnerships.

**TABLE 2.1: Core Values / Characteristics of Palliative Care**

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as normal.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of care.
- Offers comprehensive support to promote quality of life.
- Offers support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patients’ illness and in bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(From the World Health Organization, 2005, ¶2)

### 2.2.3.3 Evaluations of hospice palliative care

Significantly, this period of rapid – but erratic – growth and consolidation precipitated an examination of the effectiveness of hospice and palliative care services. A significant feature of the modern hospice movement at this time was its continued sequestration from the mainstream health systems. Yet despite the substantial developments in service delivery and refinements in definition, the segregation of the modern hospice movement from mainstream health care was increasingly being questioned:
While the early hospices had often sought to stand outside the constraints of health care planners and their associated bureaucracies, the maturation of the movement was to bring about a growing interdependence with the wider structures of health care delivery. This interrelationship between the hospice movement and the mainstream health care system is central to any full understanding of the history and development of hospices and specialist palliative care services. (Clark, Hockley et al., 1997, p.60)

Major governmental reviews were undertaken in various locations around the world. As noted above, major health reforms of the NHS in the 1980s saw hospices viewed as part of the bigger picture of mainstream health care, and new accountabilities gave rise to increased tension between hospice services and health authorities (Clark & Seymour, 1999). Nevertheless, the global movement towards a more integrated relationship between hospice and mainstream care was substantially advanced in 1987 with the acknowledgement in the UK that palliative care was a recognised and distinct discipline of internal medicine (Doyle et al., 1993). This was followed four years later by the inclusion of palliative care services in contractual arrangements with the NHS, involving the mandatory obligations required of all UK health services (Clark, 1993). The collective impact of the Wilkes Report (Wilkes, 1980), The Principles and Provision of Palliative Care: Joint Report of the Standing Medical Advisory Committee and the Standing Nursing and Midwifery Advisory Committee (Department of Health, 1992) and, later, the Calman-Hine Report (Department of Health, 1995) was substantial on planning for support of people at the end of life. Notably, they
included concepts that are evidenced in the health promoting palliative care approach:

- Palliative care is an important part of the work of all\(^2\) health professionals.
- Palliative care should be regarded as a vital and integral part of health care for many patients and should complement other health care in a parallel, not sequential, model of care.
- Central role of the primary health care team (including General Practitioners).
- Specialist palliative care complements, rather than replaces, the care provided by others.

In a clear indication of the need for hospice palliative care to move into the mainstream health care system, these reports demonstrated the impetus provided by governmental endorsement of particular approaches to palliative care service provision in the UK. Similarly, there were efforts to mainstream palliative care services in Australia (Lewis, 2007) and this becomes a particularly pertinent point when considering conventional health promotion as an established and, typically, government-sanctioned approach to health care.

Investigations into the nature and effectiveness of the hospice movement were also undertaken in the USA. Most significantly, Mor, Greer and Kastenbaum (1988) undertook the *National Hospice Study USA*, examining the hospice movement and its services; in particular, it was focused upon home hospice services. They identified that home hospice care was overall less expensive than conventional palliative care, although this cost-saving reduced over time. Pain and symptoms were better controlled in hospice care programs,

\(^2\) Researcher’s emphasis
and with the support of a hospice program, patients remained at home longer. The study concluded that the integration of community based programs into mainstream health systems would contribute to the improvement of care for people at the end of life.

### 2.2.3.4 From local to global

As palliative care was gaining wider acceptance as a legitimate endeavour within mainstream health care, there was increasing interest on the part of government and other agencies in the regulation of palliative care services. Indeed, the World Health Organization [WHO] *Cancer and Palliative Care Program* explicitly warned against the “unplanned spread of hospices” (Clark & Seymour, 1999, p.77). The rapid proliferation of palliative care services has led to a broad range of models of care, from purpose-built cottage hospices to sub-acute palliative care units in major hospitals, from discrete teams within existing domiciliary services to specialist palliative care community services. As has been described in the Australian setting, the wider experience of palliative care service expansion has been an erratic one:

> The growth of specialist palliative care services for patients has been mostly unplanned and uncoordinated by Health Authorities. Development has been largely in response to local pressure, enthusiasm, and fundraising activity, and remained mostly within the charitable, independent sector. (Faull, 1998, p.2)

The WHO (1990) report on *Cancer Pain Relief and Palliative Care* proposed palliative care as a global priority, not just a concern for the health care programs of individual countries. The report emphasised the need for definite
clinical and policy strategies to relieve suffering from incurable illness, favouring a public health oriented approach in preference to the continued erratic expansion of palliative care services. That is to say it recommended instead that the substantial existing knowledge in palliative care be better utilised throughout mainstream health care systems, that strategies for the relief of suffering be implemented at governmental levels, and that the marshalling of the necessary resources to achieve this outcome be attempted. Notably, this represents an early attempt to influence the integration of public health approaches into the governance by national governments of palliative care service delivery. Within five years, Johnston and Abraham (1995) observed that whilst some significant progress had been made toward achieving the WHO objectives, equally important work remained to be done.

Nevertheless, the momentum towards the integration of conventional palliative care services into the mainstream seemed an inexorable destination for the discipline. By the end of the 1990s, evidence of the extent of palliative care’s mainstreaming was reflected in Faull’s (1998) statement that “palliative care is not an alternative to other care but is a complementary and vital part of total patient management” (p.1). This was a destination perhaps not envisaged by the pioneers of the modern hospice movement, and some authors expressed concern that such integration represents a threat to the founding principles of hospice and palliative care through its routinisation and medicalisation (Clark & Seymour, 1999; Hart, Sainsbury, & Short, 1998). Conversely, Clark (1994) warned the palliative care discipline not to self-destruct through protective custody of specialist knowledge, instead becoming more involved in the resourcing of mainstream services.
2.2.3.5 The palliative approach

This mainstreaming led to reconsideration of the roles of specialist and generalist services in the provision of support to people at the end of life. If good palliation was to be viewed as the province of all health care providers as Faull (1998) suggested, then the mainstream health care system required a way of thinking about palliative care free from notions of specialisation. A distinction emerged between specialist palliative care and the care of dying people provided by generalists, with the assertion that care of the dying is a “core skill of every clinician, who may seek expert specialist help to ensure the best possible quality of life for the patient” (Finlay & Jones, 1995, p.754), in some ways reflecting the principles put forward by the UK reports noted above – the Wilkes Report (Wilkes, 1980), The Principles and Provision of Palliative Care: Joint Report of the Standing Medical Advisory Committee and the Standing Nursing and Midwifery Advisory Committee (Department of Health, 1992) and the Calman-Hine Report (Department of Health, 1995).

More recently, the term palliative approach has entered the palliative care profession’s idiom to describe the care given to people with life-limiting illnesses by generalist clinicians (Palliative Care Australia, 2005a). The resulting relationship between specialist and generalist services is an adjunct one, rather than presenting a parallel alternative stream of care. The palliative approach harnesses the specialist knowledge and skills of one group in order to complement the generalist practices of the other in the support of, and to the benefit of, dying people in their care (Lewis, 2007). For example, in residential aged care, a palliative approach has been proposed as a strategy for providing palliative care for residents dying of old age, where “palliative care can be long-term, not just at
the end of life” (Phillips et al., 2006, p.421). In this example, the palliative approach, whilst not providing ‘specialist’ palliative care services described by PCA (2005a), has been designed to advance the integration of aged and palliative care knowledge and skills, the development of professional practice and the establishment of organisational structures and processes that promote residential aged care facilities as places of quality care for dying people.

The evolution of palliative care services has taken an erratic path, and contemporary models of palliative care have taken many forms. Increasingly, care of dying people is within the regulation of mainstream government-funded health care, including but not limited to specialist palliative care services. It is in this context that health promoting palliative care has been proposed as a model of care that reinforces the core values of palliative care, accommodates both specialist palliative care and the palliative approach and may possess the potential to return care of the dying to its societal roots. To substantiate these claims, this literature review turns to the health promotion literature.

2.3 Health Promoting Palliative Care

In a trajectory similar to the evolution of hospice-palliative care, health promotion emerged during the latter decades of the 20th Century from growing concerns with the overemphasis in health care upon disease and its diagnosis, treatment and cure. Again, it was perceived that the predominant biomedical model failed to adequately embrace whole population issues and the complex interrelationships between the physical, psychological and social components of health and wellbeing, through its artificial dissociation of the disease from the person, and the person from their social context (Bunton & Macdonald, 2002).
Unlike the earlier incarnations of palliative care, however, proponents of health promotion formed a more structured, global movement and health promotion was more quickly integrated into health care and social support systems.

2.3.1 Origins of health promotion

Health promotion was placed squarely on the global agenda for health by the WHO which orchestrated an international meeting in the former USSR city of Alma-Ata in 1978. This meeting was convened specifically to address growing concerns about the need for a broader understanding of health than that provided by the dominant paradigm of the day. Delegates affirmed WHO’s concept of health, which stated that “health is a complete state of physical, mental and social wellbeing and not merely the absence of disease or infirmity” (World Health Organization, 1978, p.1). Yet it was acknowledged that the determinants of such a state of health required not simply the engagement of individuals in health services, but rather could come about through a complex set of circumstances across individual and societal domains. The meeting formulated a key document, the Declaration of Alma-Ata (World Health Organization, 1978), which proposed several core concepts necessary for improved health, including equity, community participation and maximum community self-reliance, health promotion and disease prevention, involvement of government departments other than health, and political action (Wass, 2000).

2.3.1.1 The Ottawa Charter for Health Promotion

Eight years after the Alma-Ata meeting, the 1st WHO International Conference on Health Promotion was convened in Ottawa, Canada, to appraise progress towards Alma-Ata’s goal of ‘Health for All by the Year 2000’
(McMurray, 2003). Whilst many foundations for health promotion had been laid in the intervening period, a watershed document entitled the *Ottawa Charter for Health Promotion*³ (World Health Organization, 1986) devised specific five specific key action areas for the improvement of health that are described in Table 2.2 below. Whilst these key action areas were described discretely, their interrelatedness was acknowledged by the *Ottawa Charter’s* authors; each represents an area of strategic action to promote the physical, social and personal aspects of health and wellbeing. Significantly, the *Ottawa Charter* explicitly asserted that responsibility for health promotion rests not simply with the health sector but with governments, social and economic sectors, industry and the media, and communities themselves. Health promotion therefore, was proposed not as just another health program to run but an entire approach to the health and wellbeing of people.

Most notably, foundations upon which health promoting palliative care has been built are evident in a number of places in the *Ottawa Charter*. In the key action area of *developing personal skills* for example, it makes explicit mention of lifelong learning for people preparing themselves for *all of life’s stages*.⁴ Whilst dying is not mentioned in the *Ottawa Charter* or for many years hence in the health promotion literature, it is interesting to note this phrasing in such a key document in light of the development of health promoting palliative care.

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³ Abbreviated hereafter in this dissertation to the ‘Ottawa Charter’. This convention applies to other WHO documents, such as the ‘Jakarta Declaration’ and the ‘Bangkok Charter’.

⁴ Researcher’s emphasis
Table 2.2: The Ottawa Charter - Key Action Areas for Health Promotion

<table>
<thead>
<tr>
<th>Key Action Area</th>
<th>Summary Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building public policies that support health</td>
<td>Health is on the agenda of all policy makers, who must consider the health consequences of policy decisions. Obstacles to the adoption of healthy public policies need to be identified and removed.</td>
</tr>
<tr>
<td>Creating supportive environments</td>
<td>Health cannot be separated from other societal goals. A sociological basis for health embraces the links between people and their environment.</td>
</tr>
<tr>
<td>Strengthening community action</td>
<td>Communities set their own health priorities, make decisions, and plan and implement strategies to promote their empowerment. Community development enhances participation in, and direction of health matters.</td>
</tr>
<tr>
<td>Developing personal skills</td>
<td>The enhancement of life skills through personal and social development promotes people exercising control over their health throughout life.</td>
</tr>
<tr>
<td>Reorienting health services</td>
<td>Responsibility for health promotion within the health care system rests with all participants. Health services must move beyond clinical and curative services to support individuals and communities for a healthier life. Health research, professional education and training are necessary strategies for refocusing health services toward the needs of the whole person.</td>
</tr>
</tbody>
</table>

(From The Ottawa Charter for Health Promotion, World Health Organization, 1986)

2.3.1.2 Endorsements of Health Promotion

Further endorsements of the Ottawa Charter goals were provided at subsequent WHO Health Promotion conferences. In their critique of key WHO documents since the ratification of the Ottawa Charter, Talbot and Verrinder (2005) trace the progressive shift from local to global perspectives of health promotion. It is worth noting that two documents particularly show relevance to the advancement of health promotion in the context of this study. Firstly, the Jakarta Declaration on Leading Health Promotion into the 21st Century (World Health Organization, 1997) emphasised the broad application of health in society and the subsequent need to strategise beyond the health sector to attain levels of health. It presented an alternative paradigm of health care that countered the dominant biomedical model, endorsing instead the notion of partnership between members of the community with the health care professions in order to achieve
health. It emphasised, for the first time, the promotion of partnerships with the private sector in the development of health promotion policy. Some delegates to the Jakarta conference were critical of this, citing conflicts of interest within the private sector. Hancock (1998) argued that a fundamental conflict existed between profit making and the utilitarianism of health promotion which made the sector’s inclusion potentially harmful to “people, communities and the environment” (p.193). The non-government organisation [NGO] sector – typically non-for-profit, charitable organisations – was not included in this criticism and has long been viewed as an appropriate partner in systems attempting the promotion of health. It is also worth noting at this point that the NGO sector historically and contemporarily participates substantially in the provision of end of life care services (Clark & Seymour, 1999).

Further, the Jakarta Declaration reiterated the importance of the social and environmental contexts in which individuals live, work and find leisure. Therefore, effective strategies for health could no longer be targeted solely at changing the health behaviours of individuals, but must also include action at social, environmental and political levels. Ironically, it has been more recently asserted that it is no longer safe to assume that the values of social justice, equity and community participation are core concerns of governmental health policy (Talbot & Verrinder, 2005) and that health systems are primarily concerned with providing an “illness management system” (p.xi) rather than health promotion. This focus upon illness rather than wellness is a recurring theme in both the health promotion and palliative care literature.
Where earlier documents have shown the transition from the health of individuals to the health of societies, the *Bangkok Charter for Health Promotion in a Globalized World* (World Health Organization, 2006) sought progress towards the health of the global community. Whilst reiterating what has been written previously about health promotion, the *Bangkok Charter* presents a robust set of strategies for global development of health, undertaking to ensure that the promotion of health is:

- *Central to the global development agenda*
- *A core responsibility for all of government*
- *A key focus of communities and civil society*
- *A requirement for good corporate practice*

(World Health Organization, 2006, p.1)

There has been an increasing emphasis upon the effective implementation of health promotion principles and practice through a whole systems view within which individual organisational change is undertaken (Talbot & Verrinder, 2005). Recently, Stjernsward (2007) traced the history of WHO’s encouragement of public health strategies for the provision of palliative care services, emphasising the need for governments to oversee national agenda for end of life care that promote societal and community ownership of palliative care. Significantly, he emphasises that “a community approach is absolutely essential; the only realistic model for reaching those who might benefit…” (pp.51-52). Again, these are relevant issues in the development of health promoting palliative care, with both organisational and systemic issues requiring consideration.
2.3.1.3 **Theoretical foundations**

As is found in the story of the modern hospice movement, after the formation of the *Ottawa Charter*, debate began regarding the foundations and nature of this distinct set of approaches to the promotion of health. Each of the many disciplines from which health promotion theory has been drawn can be seen to have made an important contribution to the theoretical foundations of health promotion. In describing the theoretical foundations of health promotion, Bunton & Macdonald (2002) distinguish between *primary* and *secondary* feeder disciplines; academic fields such as psychology, sociology, education and epidemiology have provided greater theoretical influence, with social policy, politics, economics, ethics, philosophy and communication providing a lesser influence. Not surprisingly, the perceived significance of each discipline to theory development in health promotion varies according to each particular disciplinary agenda. This has, in turn, perpetuated confusion and fuelled continued debate about the application of health promotion theory to the various practices of improving health. Bunton & Macdonald (2002) view this diversity as creating a healthy tension, a necessary characteristic of a complex and multifaceted phenomenon such as health promotion. In a statement with convincing parallels to palliative care, Nutbeam and Harris (2004) agree, stating:

> It follows that no single theory dominates health promotion practice, and nor could it, given the range of health problems and their determinants, the diversity of populations and settings, and difference in available resources, skills and opportunity for action among practitioners. (p.7)

These broad theoretical foundations have retained an important role in evaluating the implementation of health promotion programs. In their study of a national
health promotion health services framework, Whitelaw and colleagues (2006) demonstrated how they moved beyond simply monitoring potential impacts to include examination of their case data in light of the theoretical perspectives of health promotion. This enabled them to understand the “dynamic interplay of factors influencing implementation” (p.138). Effective implementation, they argued, required organisational will, awareness of the broader social context of health and health policy, competency in health promotion including the establishment of a “critical mass” (p.139) of personnel with relevant skills and knowledge, and a defined framework for implementation.

2.3.2 A healthy death?

Despite the shared chronology and other similarities between palliative care and health promotion, there is little evidence of any explicit consideration of their union until the 1990s. Whilst it can be seen that elements of the Ottawa Charter are familiar to the practice of palliative care – such as creating supportive environments and developing personal skills – the seemingly paradoxical nature of suffering and the promotion of health may have been considered conceptually incompatible. Yet it has been suggested that this only presents a paradigmatic difficulty when “…the perception of health [is] the absence of disease and demands are made for medical services when treating ill health to have as their goal the absence of disease” (Pegg & Tan, 2002, p.25). The aim of health promotion to enable people to increase control over and to improve their health is not incompatible with the goals of palliative care to relieve pain and distress, and promote autonomy and self control, even in the absence of a likely cure (Pegg & Tan, 2002). However it is unclear how palliative care services promote the health
of their consumers, given their centrality to the defining of a healthy death. Is it possible to die healthy? The key to grasping this question lies in an understanding of what it is to die well.

### 2.3.2.1 Dying well

Wholeness and health have close conceptual associations – early definitions of health were built upon pre-Second World War assumptions about the relationship between health and disease, where to be healthy was to be without disease (DeSpelder & Strickland, 2002). WHO’s definition, in acknowledging the multifaceted and interrelated nature of health and wellbeing, instead asserted the place of a whole person approach (World Health Organization, 1978). The concept of wholeness for people at the end of life presents few philosophical hurdles to commentators on health promotion in palliative care. Suffering is regarded as a complex, subjective experience, the amelioration of which produces an optimal state in a person even in the presence of incurable illness (Woodruff, 1996). Saunders (1987) herself described good palliative care in terms now commonly ascribed to holism, namely that care should be directed from the time of diagnosis at the physical, psychological, social and spiritual dimensions of a person’s experience, by a team comprehensively representing the various disciplines with the expertise to address these areas of need. She is joined by others who describe a whole person response to the whole person experience (Woodruff, 1996), moving beyond a philosophical position to providing guidelines for the provision of care.

Significantly, public health has explored in detail the relationship between human health and well-being with social and environmental factors (Talbot &
Verrinder, 2005). Contemporary understandings of health recognise the impact of disease, illness and health-related issues upon all aspects of human existence (McMurray, 2003) and, notably, the role of participation of individuals, communities and societies in determining their own health outcomes. Recipients of care, and their families and carers, are placed at the centre of the palliative care endeavour, with sympathetic stakeholders in the wider public enrolled in the kind of local activism that has borne many hospice and palliative care services (Small, 2003). A central tenet in the support of dying people is the relief of suffering for the whole person – a state often described as a *good death*. Indeed, the hospice pioneers’ work shows that to die well was to die with ease of distress across the range of domains of human existence – physical, psychological, social and spiritual. This researcher first publicly speculated upon the place of healthy dying in palliative care service provision models in a presentation to the *Australian National Primary Health Care Conference* more than a decade ago (Rosenberg, 1992).

However, with few exceptions, a good death has largely been measured by nurses’ perceptions of patients’ and families’ acceptance of the death and the degree of peace with which it was met (McNamara, Waddell, & Colvin, 1994). One of these exceptions is found in Kellehear’s (1990) interviews with 100 dying people, where the core elements of a good death were identified as an awareness of dying, preparations for death, capitulation of roles and responsibilities, and making goodbyes with others. However, in their critique of his study, Hart, Sainsbury and Short (1998) note the methodological limitations of Kellehear’s
inclusion criteria and question its generalisability. Nevertheless, they noted his emphasis upon:

...the active and critical role that dying people played in the social management of their dying as they engaged in separations and made preparations for the end of their lives. [A good death] is a set of culturally sanctioned and prescribed behaviours set in motion by the dying, through which their death is made more meaningful for all concerned...

(Hart et al., 1998, p.71)

Such a socially approved form of dying begs the question whether “the choices of dying people [are] increased or constrained by the ideology of the good death?” (Hart et al., 1998, p.66). If the latter is true, then the apparent disenfranchisement of dying people within today’s mainstreamed palliative care services is cause for concern. In Australia, McNamara, Waddell and Colvin (1994) explored whether the gold standard of the ‘good death’ was congruent with the fiscal, administrative and organisational priorities of palliative care facilities. The concern of palliative care providers for the achievement of a good death now presents them with one of their greatest contemporary challenges – can the palliative care profession defend its claim of patient-centred holistic care and respond to changing consumer expectations of how dying can take place? If a palliative care service is to be truly responsive to its users (as part of its patient-centred claim), it surely must be prepared to challenge the common assumptions of what a good death might be.

2.3.2.2 User involvement in palliative care

Paradoxically, Small (2003) pointed out that whilst the modern hospice movement has always held local activism in high esteem, the systemisation of
hospice into the health care specialty now called palliative care had again
disenfranchised the very groups the palliative care professional community must
rely on for its survival. Small (2003) stated that “…user voices were squeezed
out, indeed health professionals were given more authority to define users’
involvement and there was a tendency to conflate user involvement and public
participation” (p.16). This assertion directly confronts the modern hospice
movement’s – indeed, health promotion’s – view of empowerment. Small went
on to explore the problematic nature of user involvement in palliative care,
arguing that only consumers of palliative care can truly assess what constitutes a
good death, and therefore what good palliative care might resemble. Firstly, he
cautions against the hybridisation of consumers as some kind of homogenous
group, despite their very different needs and priorities, compounding the existing
generalisations made on the basis of ethnicity, family roles and conceptualisations
of suffering. An example of this problem is found in Pegg and Tan’s (2002)
work, where health professionals were viewed as appropriate sources for
identifying user need. In the context of discussing advocacy, Pegg and Tan
considered professional interventions aimed to assist the dying person to develop
the personal skills required to adjust to their changed circumstances. However,
their exploration was limited to the nurse participants’ perceptions of the impact
of caregiving upon family members and others who take this informal role and did
not discuss possible actions by dying people and their supporters.

Secondly, Small (2003) suggested that the very involvement of users in
palliative care can paradoxically inhibit opposition to the status quo. That is to
say, evidence of user involvement can be used to justify narrow definitions of
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need that again fail to address the complexity of dying and the human experience of suffering that often accompanies it. In a related commentary, Clark and Seymour (1999) warned of the dangers of uncritically pigeonholing individuals as ‘clients’, ‘patients’, or ‘informal carers’, labels which denote “a monodimensional perspective which is capable of seeing human beings only in relation to the formal organisations of health and social care” (p.11). That is to say, viewing the recipients of palliative care simply as consumers of services takes those services as the reference point from which the persons’ illnesses are understood, and might risk losing sight of the social context of people’s daily lives. Nevertheless, advantages remain in the user involvement approach insofar as it provides a voice for consumers in their own dying. This has a significant potential influence upon dying people, as “death, far from being meaningless, has the capacity to make life meaningful” (Russell & Sander, 1998a, p.266). A health promoting approach to palliative care is one that claims to provide a vehicle for user involvement in core issues relating to death and dying, and the provision of responsive health care.

Is it that past models of care are no longer useful to many health care consumers? Some authors (Scott, 1992; Weaver, 2004) believe that the paternalism demonstrated in a “commitment to the medical model from cradle to grave” (p.508) no longer meets the changed expectations of health care consumers. In addressing life-threatening illness and end of life care in the context of health promotion in families, Weaver (2004) suggested health care consumers face challenges as never before, where new end of life choices are more complex than imagined when the modern hospice movement began.
Weaver saw these circumstances as having a direct impact upon family health and endorsed family-centred health care as a health promoting concern, linking family health promotion to holistic care. This shift of focus from the individual health care consumer to the collective provides an indication of the integration of health promotion in end of life care.

Given the congruence evident in both palliative care and health promotion regarding the centrality of the consumer in the promotion of optimal health, evidence of the five key action areas of the *Ottawa Charter* can be found elsewhere in the palliative care literature.

### 2.3.3 Health promotion at the end of life

“Does the end of life [possess] the characteristics of a public health priority? Firstly, in absolute terms, death has a universal incidence…” (Rao et al., 2002, p.215). Given this imperative, a discourse on death and dying as a key issue for the public health agenda was able to be located in the literature. Within the remit of public health, health promotion has been specifically identified as an approach to end of life care that embraces the core concerns of palliative care described above and is amenable to the application of health promotion principles and practices.

#### 2.3.3.1 *Kellehear’s model of health promoting palliative care*

Whilst others had presented the notion of utilising health promotion in the practice of palliative care prior to 1999, Kellehear’s book *Health Promoting Palliative Care* (1999b) was the first substantial attempt to theoretically and systematically integrate these two parallel but distinct fields. In his application of the principles of health promotion to the core concerns of palliative care,
Kellehear’s premise was that “…if health is everyone’s responsibility then it is also the responsibility of those living with a life-threatening or terminal illness as well as those who care for them” (p.31). In a routinised and medicalised health care system, he called for a broad debate on the ways in which a health promoting approach to palliative care might be implemented in theory and practice. In his text, Kellehear explored the core concerns of palliative care, citing the WHO definition of palliative care, the key action areas of the Ottawa Charter, and the foundational work of Saunders (1987) and others, emphasising the centrality of holism as a response to the multidimensional nature of care at the end of life. Critical of the discrepancy between rhetoric and reality, Kellehear referred to a number of examples that illustrate the overemphasis on physical – and, to a lesser extent, psychological – symptomatology at the expense of the social and spiritual domains, referring to the concerns expressed by Kearney (1992).

A health promoting approach to palliative care, Kellehear claimed, addresses five underdeveloped aspects of conventional palliative care. These are examined below in light of contemporary developments in palliative care policy and practice.

**Social science and public health components.**

Despite its origins as a social movement, Kellehear (1999b) contested that there is a “palpable” (p.7) absence of social science and public health components in palliative care leading, ironically, to the neglect of the social domain within the framework of holism so central to the core values of palliative care. It is interesting to note that in the time since Kellehear’s work was published, there is
some evidence the inclusion of public health in palliative care has received some attention.

Internationally, in the *Charter for the Normalisation of Death, Dying and Bereavement*, the International Work Group on Death, Dying and Bereavement (2005) argued that the combining of public health and end of life can “facilitate knowledge transfer across each field that will enhance [the] joint goal of developing a seamless health care response toward the human experiences of death, dying and loss” (p.158). Figure 2.1 is reproduced from this Charter and illustrates a perceived intersection between public health (which includes – but is not limited to – health promotion) and end of life care (which includes – but is not limited to – palliative care).

**Figure 2.1: Intersection between Public Health and End of Life Care**

![Intersection between Public Health and End of Life Care](From International Work Group on Death Dying and Bereavement, 2005, p.158)

In the USA, a critique of public health approaches to end of life care was offered (D’Onofrio & Ryndes, 2003). In considering WHO’s definition of health, consumer stakeholders identified the preservation of social relationships at the end of life as a priority. However, the authors considered the emphasis on increasing longevity as an outcome of health promotion as incompatible with the goals of palliative care. Moreover, they identified a structural barrier within the public health system that would have end of life care currently assessed as a lower
priority in the allocation of scarce public health resources. Despite these criticisms, D’Onofrio & Ryndes (2003) suggested that public health approaches could bring about improvement to care at the end of life through its whole population perspective and policy development. To achieve this, public health systems would need to acknowledge death as the outcome of chronic disease and ageing, find new means to measure quality of dying and consider a re-evaluation of resource allocation policies.

In the Australian setting there has been a shift in promoting the inclusion of public health perspectives in palliative care. A national service planning guide utilised population health approaches to inform identification of potential need and recommended community development, public education, prevention of social morbidities, and social policy development as potential strategies (Palliative Care Australia, 2003). More recently, PCA (2005b) elaborated on the population-based approach by placing end of life care services in the broader context of health care delivery in Australia. To guide the development of palliative care, PCA attempted to present a population based framework that captured the highly social nature of end of life care, the highly variable clinical settings within which this care is provided, and the resources needed to do so. It emphasised the role of community capacity building and other social strategies that promote the health and participation of communities in end of life issues. However, whilst the Australian government’s Department of Health and Ageing [DoHA] has offered some funding support for health promoting palliative care programs, the implementation of these approaches is not uniform and conventional models of palliative care appear to dominate service types in Australia.
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The social aspects of care.

Kellehear’s (1999b) concern that the social aspects of care were neglected features of conventional palliative care directly challenges the claim to the inclusion of the social domain in the practice of holistic palliative care. His argument is that the hybrid term ‘psychosocial’ results in the provision of ‘psychological’ interventions at the expense of interpersonal, family and community concerns. This individual (ie: psychological) rather than collective (ie: social) emphasis sees social concerns linked with psychological concerns even when they are distinct areas of need.

Measures to assess the adequacy of social aspects of care may be addressed on a service provider level, although detailed frameworks to do this have been scant, beyond client satisfaction surveying. Whilst many multidisciplinary palliative care teams include a social worker, this itself does not necessarily equate with an equal emphasis upon the social aspects of care. The challenge arises, Kellehear (2005) later claims, in the “addressing [of] social care issues in non-clinical ways” (p.52). That is to say, to move from the individualistic (ie: client and family) perspective to a community one where the social development of all members in issues of death and dying is addressed.

Notably, in the Australian context, one facet of the social aspects of caregiving has been addressed in PCA’s National Inquiry into the Social Impact of Caring for Terminally Ill People (Palliative Care Australia, 2004a) emphasising the physical, psychological, social and financial burdens carried by caregivers of those with life-limiting illness. Further, PCA’s strategies for community capacity building described above are significant initiatives to address under-attended
social aspects of care and very recently have included a working group to specify PCA’s role in policy development proposals for consideration by DoHA.

**Early stage care.**

It is evident in the nomenclature of palliative care that the early involvement in patient care has joined the core values listed in Table 2.1, which states that palliative care “is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life” (World Health Organization, 2005, ¶2). Despite recognition of this principle of early involvement, early referral to palliative care services is not routine (Kellehear, 2005).

In one earlier study of cancer patients, Dudgeon et al. (1995) linked higher levels of physical distress with late referral to palliative care, although interestingly, no significant differences were identified in psychosocial needs between those patients referred early or late in the disease trajectory. Given the study was conducted within a biomedical framework, it is not clear whether a health promoting palliative care model could result in different outcomes. Nevertheless, another benefit of early intervention has been identified in situations of high risk bereavement, both for patients (Lynn, Schuster & Kabcenell, 2000) and surviving family members and significant others (Holley, 2005). Some attempts have been made to monitor and influence referral patterns within health systems (Lynn, Schuster & Kabcenell, 2000) and organisational strategies to reorient health systems to the practice and benefits of early stage palliative care require further investigation.
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**Active treatment of disease.**

Similarly, the active treatment of disease in the presence of life-limiting illness has been a debated issue for decades within palliative care. With Kearney, Kellehear (1999b) asserted that “curing as well as caring can also take place as part of palliative care” (p.8). Whilst the amelioration of symptoms has been portrayed as curing, it is moreso Kellehear’s contention that a difference comes with the intent of treatment. The apparent dichotomy between promoting comfort and actively treating disease possesses blurred boundaries; these approaches, he claims, are in fact often coexistent.

An example is found with the advent of HIV/AIDS in the mid-1980s. A central tenet of the modern hospice movement at this time was that curative treatments were to be relinquished (Howarth, 2007), yet many people with HIV/AIDS sought sometimes quite aggressive, active treatments even when death was imminent (Selwyn & Forstein, 2003). Many AIDS patients of the day were willing to continue aggressive curative treatment right up to the point of death (Beresford, 1993), whilst receiving skilled attention to the relief of symptoms.

A health promoting approach, Kellehear claimed, addresses the apparently competing issues of active treatment of disease in the palliative care setting. In general, palliative care was slow to accommodate a preference for active treatment within its paradigm. Eventually, the inclusion of the phrase “active, total care” (World Health Organization, 2005, ¶3) in definitions of palliative care demonstrated some concession on the part of palliative care and is still in use today.
**Life-threatening illness (not just terminal care).**

The principles and practices of palliative care need not be constrained to terminal care or cancer care (Kellehear, 1999b). Whilst this would be agreed in principle, in practice palliative care has largely been for those dying from cancer. Yet neurodegenerative diseases, organ failure, AIDS and even trauma are disease or injury groups where good control of distressing symptoms, attention to psychological, social and spiritual needs in the presence of certain death rather than recovery are palliative care strategies that may contribute to more appropriate dying.

Again, a pertinent example of this comes from the story of HIV/AIDS. The track record of palliative care services during this period in including patients with non-cancer diagnoses was patchy at best (Beresford, 1993). Most recipients of mainstream palliative care services were older persons with advanced cancer, and the social stigma attached to sexual and intravenous transmission of HIV appeared to challenge the capacity and willingness of hospice to provide services to people with AIDS. This was viewed with some scepticism:

> Some AIDS support agencies and advocacy groups...have been suspicious of hospices...they view entering the hospice as an act of surrender...leaders have also questioned the motivations and commitment of hospices and wonder whether they can respond sensitively and appropriately to the special needs of AIDS patients, who have already experienced many rejections by the system. (Beresford, 1993, p.138)

This seems to have contributed to the establishment of some AIDS-specific hospices, or hospices with AIDS-specific programs (Beresford, 1993), despite a growing trend towards mainstreaming of palliative care services within the health
care system. Whilst there were isolated exceptions, ironically neither the mainstream, nor hospice services generally, demonstrated the capacity to address this challenge when it first appeared.

These five deficiencies of palliative care identified by Kellehear have been proposed at a time when integration of health promotion is on the national agenda. In the Australian context, whilst some attempts to address these have occurred, the impact of this upon organisations providing palliative care has not been addressed to date. Further, Kellehear (1999b) notes that a genuine embracing of the social domain can lead to a paradigmatic shift wherein patients are participants in the identification of need, and in the direction of care and support; these are clearly sentiments close to both health promotion and conceptualisations of patient-centred care and holism so evident in the palliative care literature. He goes on to apply the five action statements of the Ottawa Charter to palliative care, identifying five core concerns of health promoting palliative care:

- *Provide education and information for health, death and dying.*
- *Provide social support at both personal and community levels.*
- *Encourage interpersonal reorientation.*
- *Encourage reorientation of palliative care services.*
- *Combat death-denying health policies and attitudes.*

(Kellehear, 1999b, pp.19-20)

Kellehear’s health promoting palliative care is a social model of care based upon a conceptual perspective that promotes optimal health even in the presence of incurable disease, utilising palliative care philosophy to inform the development of organisational mission, values, and strategic directions, and the Ottawa Charter to supply parameters for determining the scope of goals and objectives.
Collectively, these conceptual and practical elements describe health promoting palliative care.

To consolidate this, further work by Kellehear, Bateman and Rumbold (2003) developed *Practice Guidelines for Health Promoting Palliative Care*, summarised in Table 2.3. These guidelines offered a profile of a number of organisational features of a health promoting palliative care organisation. They suggested that, in addition to the provision of death education and support for consumers of palliative care services, strategies should also target the structures and processes of the organisation.

Staff support programs, non-clinical partnerships, social research, policy initiatives, and staffing profiles were all suggested elements of a health promoting workplace. Notably, these were presented as guidelines only and made no apparent claim to be prescriptive in nature, other than to say that *all* of the five goals should be present in a palliative care service if it wishes to adopt a health promoting approach. Nevertheless their importance in the refinement of health promoting palliative care is significant in the conduct of this study.
TABLE 2.3: PRACTICE GUIDELINES FOR HEALTH PROMOTING PALLIATIVE CARE

<table>
<thead>
<tr>
<th>Guideline</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Extend the activities or complement existing support groups with additional adult learning groups:</td>
<td>Two programs per year</td>
</tr>
<tr>
<td>◦ Small groups of 5-7 people</td>
<td></td>
</tr>
<tr>
<td>◦ Weekly reading material</td>
<td></td>
</tr>
<tr>
<td>◦ Reading includes individuals’ health care but flexible to group’s needs</td>
<td></td>
</tr>
<tr>
<td>◦ Death education</td>
<td></td>
</tr>
<tr>
<td>◦ Limited durations of 6-8 weeks</td>
<td></td>
</tr>
<tr>
<td>◦ Patients only groups; carers only groups</td>
<td></td>
</tr>
<tr>
<td>1.2 AND/OR Offer opportunities for one-on-one patient information sessions with a health educator about life changes, health maintenance, and death education.</td>
<td>As needed</td>
</tr>
<tr>
<td>2 Demonstrated evidence of death education for:</td>
<td>At least two</td>
</tr>
<tr>
<td>◦ Patients</td>
<td></td>
</tr>
<tr>
<td>◦ Staff</td>
<td></td>
</tr>
<tr>
<td>◦ Caregivers</td>
<td></td>
</tr>
<tr>
<td>◦ Community (including talks, publication, media)</td>
<td></td>
</tr>
<tr>
<td>3 Demonstrated evidence of education in social approaches to care for:</td>
<td>At least two</td>
</tr>
<tr>
<td>◦ Staff (including volunteers) such as in-service education and higher education</td>
<td></td>
</tr>
<tr>
<td>◦ Caregivers</td>
<td></td>
</tr>
<tr>
<td>◦ Community (including talks, publication, media)</td>
<td></td>
</tr>
<tr>
<td>4 Demonstrated evidence of non-clinical partnerships (with the aim of understanding prevention, harm-minimisation, early intervention, community development, participatory health care, health ecology and the Ottawa Charter):</td>
<td>At least a) and one other</td>
</tr>
<tr>
<td>◦ Membership of Health Promotion / Public Health Associations</td>
<td></td>
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<tr>
<td>◦ Regular meetings with Community Health Agencies</td>
<td></td>
</tr>
<tr>
<td>◦ Annual attendance at a public health conference by some staff/volunteers</td>
<td></td>
</tr>
<tr>
<td>5 Education resource material for clients and professionals, including literature / audiovisual material concerning:</td>
<td>Library evident</td>
</tr>
<tr>
<td>◦ Death education</td>
<td></td>
</tr>
<tr>
<td>◦ Alternative therapies</td>
<td></td>
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<tr>
<td>◦ Health promotion</td>
<td></td>
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<tr>
<td>◦ Spirituality</td>
<td></td>
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<td>6 Social Research:</td>
<td></td>
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<tr>
<td>◦ Partnerships concerned with social issues</td>
<td></td>
</tr>
<tr>
<td>◦ Staff reading groups or journal clubs focusing on social issues</td>
<td></td>
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<tr>
<td>◦ Actual social research projects</td>
<td></td>
</tr>
<tr>
<td>◦ Promotion and encouraging of staff toward future education in social science fields</td>
<td></td>
</tr>
<tr>
<td>7 Policy:</td>
<td></td>
</tr>
<tr>
<td>◦ Evidence of regular submissions to:</td>
<td></td>
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<tr>
<td>◦ Local members of parliament</td>
<td></td>
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<tr>
<td>◦ Government committees of inquiry</td>
<td></td>
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<tr>
<td>◦ Departments of human services</td>
<td></td>
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<tr>
<td>◦ Local municipal councils</td>
<td></td>
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<tr>
<td>8 Staffing Profile:</td>
<td>Proportion of funding allocation</td>
</tr>
<tr>
<td>◦ Employment of socially trained professionals (eg: social worker, pastoral care)</td>
<td></td>
</tr>
<tr>
<td>◦ Access to health promotion / health education worker</td>
<td></td>
</tr>
<tr>
<td>◦ Staff profile reflecting cultural and social profile of community</td>
<td></td>
</tr>
<tr>
<td>9 Evidence of health promoting settings</td>
<td></td>
</tr>
<tr>
<td>◦ Minimisation of impact of clinical settings</td>
<td></td>
</tr>
<tr>
<td>◦ Environments that recognise and enhance individual identity</td>
<td></td>
</tr>
<tr>
<td>◦ Environments that provide opportunities for community access and participation</td>
<td></td>
</tr>
<tr>
<td>◦ Environments that provide genuine opportunities for health improvements</td>
<td></td>
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</tbody>
</table>
Six years after *Health Promoting Palliative Care*, Kellehear published his second book about the subject. In *Compassionate Cities* (Kellehear, 2005), he again observed the historical transference of responsibility for dying from the community to the health care professions, with many of the conceptual and practice parameters determined by clinical services rather than by consumers of those services. Moreover, he suggested that the palliative care profession continues to focus upon individualised responses to need rather than social change, as this quote illustrates:

*Dying, death and loss are defined as personal problems rather than targets of social change in community attitudes, values and behaviour.*

*This reinforces the view that clinical rather than community skills should take priority in palliative care education and training* (Kellehear, 2005, p.9).

In Kellehear’s view, progress towards the social model of palliative care he proposed in *Health Promoting Palliative Care* has been slow. *Compassionate Cities* provided an in-depth examination of the social nature of compassion and its exercise in the provision of care and support for people at the end of life, with concrete strategies for its implementation. This later work is examined further in Chapter 6 of this dissertation.

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During the course of this research study (2004-2007)
2.3.3.2 **Wider discourse on palliative care and health promotion**

Commentators from both the palliative care and health promotion disciplines have argued the case for the conceptual congruence of these two fields. Whilst Kellehear’s work has been the most comprehensive in calling for the integration of health promotion into palliative care, other authors have argued for the inclusion of public health perspectives and health promotion components in palliative care. Indeed, one author’s contention was the potential of a public health approach to palliative care in radically reshaping the social and professional experiences of death and dying, drawing upon a precedent in obstetrics, suggesting “…just as a family-centred philosophy has radically changed obstetrics in the past decade, palliative care has the potential to revolutionize the way we experience suffering and death” (Scott, 1992, p.48). A review of this discrete body of literature revealed a number of the central concepts of health promoting palliative care.

**Public health/epidemiological approaches to service planning.**

In an increasingly ageing society, a proportionate increase in the demand on palliative care services has been anticipated and Scott (1992) put forward health promotion and education as a means to address this escalating burden of suffering. Fearing the reduction of services or cancellation of programs in the process of Canadian health reform of the day, Scott claimed that the relief of suffering has benefits for the cost effectiveness of palliative care, and suggested that the application of public health principles to the palliative care endeavour could lead to an acceptance by government of the value of these services in promoting public health. He argued that an epidemiological examination of life-threatening illnesses showed that a significant proportion of the population were
not likely to survive these ailments, demonstrating an ongoing need for comprehensive and responsive palliative care. Scott was particularly critical of the Canadian Cancer Society for its perceived over-emphasis upon the prevention of cancer at the expense of education for the palliative care phase, in light of the prevalence of incurable cancer, and the suffering it caused. This signified a clear need for the education of palliative care patients and their families, which represents a core health promoting activity, limited in both policy and funding.

Byock and colleagues (Byock, Norris, Curtis, & Patrick, 2001) had also undertaken substantial work towards facilitating a transition from end of life care that focussed upon individuals, to a community – that is, social – approach. Their justification for this links strongly to the principles of social models of palliative care:

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

*These events are personal, but also fundamentally communal. Medical care and health services constitute essential components of a community’s response, but not its entirety.* (Byock et al., 2001, p.760)

These authors saw the community’s engagement in end of life issues as having a reciprocal effect – the community members’ perspectives of death and dying inform their engagement whilst their engagement reshapes their perspectives. Others have discussed the impact of healthy public policy upon end of life care and the potential improvement of access to palliative care services (Clough, 2002; D'Onofrio & Ryndes, 2003). In particular, it has been suggested that a more accurate estimation of the potential usage of palliative care services through a
public health approach could promote timely access and contribute to the prevention of poor outcomes for consumers of palliative care and their families.

With the integration of population health and health promotion into key policy documents of PCA noted previously, a public health basis to planning end of life care in Australia is expanding. The implementation of these policies in concrete terms, however, is piecemeal, with the constraints of funding and resource allocation presenting a substantial barrier to their integration within existing palliative care service delivery. Whilst some funds have been allocated by DoHA to public health programs within existing models of palliative care, a broad policy platform inclusive of public health approaches to end of life care is lacking from government policy in Australia.

Death education.
The responsibility of the palliative care profession to educate at professional, patient, volunteer and public levels was evident in Scott’s (1992) discussion of the use of health promotion and health education strategies, where he argued that the role of palliative care education is not simply about an attempt to increase knowledge about the needs of dying people. Rather, at its core, “the real power of our educational message lies in its ability to overcome fear, to relieve helplessness, and to promote health” (p.47). This statement of the promotion of health as an outcome of palliative care education demonstrates an early linkage of the two paradigms.

Almost a decade after Scott’s paper, another Canadian author described an innovative public awareness and education tool that demonstrated the limited extent to which user participation has been assimilated. Gallagher’s (2001)
survey of trade-show visitors assessed respondents’ knowledge of issues about
dying and anticipated needs if they were to face a terminal illness. He identified
divergent knowledge between health professionals and the general public about
death, dying, care services, and euthanasia. Whilst this had not demonstrated any
correlation to educational level, religion or gender, it did lessen with the
increasing age of respondents. Gallagher concluded that the provision of
information to the community was successful when attitudinal and behavioural
changes within organisations underpinned the new information.

Scott (1992) and Gallagher’s (2001) attention to the need for education of
the public demonstrated a clear attempt at the integration of a health promotion
approach to palliative care. Each author saw education as the primary tool in
informing and equipping members of the public for their involvement in palliative
care – albeit only when the need arises. In other words, the reference point for
both authors in promoting educational activities in the general public about death
and dying related specifically to the possible need for palliative care services in
the future. This contrasts somewhat with the notion of death education, where the
personal skills requiring development are not limited to caregiving or anticipated
need.

**Personal skills education.**

Russell and Sander’s (1998) set of personal skills for professionals
demonstrated core elements of a health promotion approach. **Enabling** requires
both symptomatic expertise and social sensitivity to promote autonomy and
control. **Advocacy** acknowledges the role of the health care professional to
facilitate control back to the dying person. **Mediacy** influences the practices of the
multidisciplinary team, and the wider context of health care. The framework also described the potential influence of nurses in reorientating health services in the care of dying people, in tandem with informing public policy. A health promoting approach to palliative care, Russell and Sander suggested, requires the development of a set of skills for professionals that could change the nature of health care practice. Their endorsement of the political role of nurses is a clear link to the core components of health promotion, particularly in participating in developing public policy relating to issues of death and dying.

Little attention has been paid to the personal skills required by patients, although family carers have long been supplied with practical and supportive strategies for skill attainment. For example, instruction manuals for informal caregivers are readily available through most palliative care services and through the mainstream market (eg: Hudson, 2004).

Creating supportive environments.

A number of authors demonstrated a perspective of health promotion that did not possess the ‘big picture’ perspectives of others, focusing instead upon the impact of health promotion upon individuals or small collectives such as families. For example, Weaver’s (2004) commentary focused mostly on the needs of families during life-threatening illness and at the end of life, with its primary focus limited to promoting the health of the family unit. The dying patient was not seen as a recipient of health promotion strategies in this example. In a qualitative study of patient’s perceptions of the therapeutic relationship with their nurses, another author proposed a “definition of health promotion relevant to palliative nursing in the primary setting” (Richardson, 2002, p.432). Using semi-
structured interviews, Richardson described twelve patients’ perceptions of the therapeutic relationship with their nurses, which enhanced their feelings of health and wellbeing. The therapeutic interventions contained in these relationships were modelled on health promotion principles, distinguishing between the therapeutic relationship and the attention to the disease and its related symptoms.

The centrality of holism in the practice of a health promoting approach to palliative care was discussed by Buckley (2002), viewing the existential journeys of dying people as a process of adaptation. Empowerment was a crucial attribute of the health promoting approach she proposed. In their study, Pegg and Tan (2002) similarly identified a link between suffering and quality of life, caused by lack of knowledge and limited empowerment. As noted, the importance of support networks in the promotion of healthy bereavement was briefly described by Faulkner (1993), who integrated it into a risk-assessment tool titled *Pre-Bereavement Predictors of Poor Outcome*. In particular, she considered the impact of absent or unsupportive family members, and detachment from traditional cultural and/or religious contexts on bereavement outcomes. Such use of preventative interventions in bereavement is commonplace today and is strongly congruent with the tenets of health promotion, given its potential to reorientate health services providing end of life care.

In an attempt to reorientate occupational therapists’ service provision to dying patients, vanderPloeg (2001) challenged her peers to extend their professional boundaries to optimise quality of life for their palliative care clients through the application of health promotion principles. Whilst she urged occupational therapists to optimise quality of life for palliative care clients.
through the use of a health promotion approach, van der Ploeg’s discussion paper cited mostly other discussions in the literature and offered little empirical evidence to demonstrate the efficacy of her strategies. Again, this discussion paper’s goal was to provoke thought about individual practice rather than the wider issues of health care systems.

**Health service reform and reorientation to health promotion.**

Scott (1992) addressed systematic issues within his own country, believing that the Canadian governments’ health care reform, with a changed emphasis from institutional care to a focus on prevention and health promotion, had not adequately harnessed the potential of palliative care to improve quality of life for dying people through a health promoting approach. He regarded the philosophy and governance of palliative care as fundamentally linked. In his view, responsibility for advocacy for change in public policy rested with both professionals and the wider public, a course of action which is indicative of the participatory nature of health promotion. He described demographic changes in Canada that were accompanied by a change in the expectations of health care services by the public. He observed an increasingly empowered health care consumer group who feared a loss of control over end of life decision making and who were mobilised to demand more effective relief of suffering. Despite their anticipation of economic efficiency, the public equally expected a sophisticated, effective and responsive health care system, including the provision of appropriate care for dying people. Scott cautioned that, without an adequate response from the palliative care profession, some form of sanctioned euthanasia was a possibility.
This response, he argued, should consist of the palliative care profession’s embracing of a public health agenda and a greater engagement of the public. Through education of the public in issues of death and dying, community support for and action in end of life issues could grow.

This broader target for education in death and dying as a strategy in reorientating health services was supported by Zeefe (1996) who discussed the place of death education for staff, patients and families, and society more widely, as a pre-emptive strategy in equipping people with the life skills necessary for a healthy engagement with death and dying. This perspective reflects elements of health promotion in the Ottawa Charter in its use of empowerment and education to strengthen communities and develop personal skills of community members.

Rao and colleagues (Rao et al., 2005; Rao et al., 2002) have been asserting the need for the concrete inclusion of a public health foundation in palliative care service planning for a number of years. They have argued that connecting health to the community, providing information and establishing partnerships will raise death awareness, empowering the community to contribute to debate of issues of quality of life at the end of life is a sound basis for end of life care. Indeed, in their study of public health priorities for end of life initiatives, Rao and colleagues (2005) identified nine clusters of public health activity that were directly relevant to the provision of palliative care. Of these, five were identified as most feasible:

- Public education
- Patient, family and caregiver education
- Research, epidemiology and evaluation
- Professional education
• Policy and planning

Importantly, each these clusters were accompanied by a set of recommendations for action. For example, in the public education cluster, Rao et al. (2005) advised the use of strategies to raise public awareness of palliative care, increase the use of advanced health directives, integrate end of life issues into chronic disease educational materials, and operate some form of information clearing house for end of life issues. These five clusters have contributed to the analysis of data in this study.

Whilst conceptually, these numerous perspectives demonstrate how health promotion principles and practice might be integrated into palliative care organisations, there remains a gap in evidence of the impact of such a transition. As an emerging field, the health promoting palliative care literature has primarily offered theoretical discussions. There is limited empirical data examining what impact health promotion approaches might have on palliative care organisations, despite substantial existing approaches to the study of organisational change. This begs the question of how health promoting palliative care can be understood as a realistic alternative to existing conventional models of palliative care?

2.4 Shifting Paradigms: Studying Organisational Change

The history of the development of palliative care demonstrates that multiple models of care exist for palliative care organisations and the examination of existing discourse of health promotion at the end of life shows widely variant degrees of existing integration. It can be anticipated that a paradigmatic shift to a health promoting palliative care model would bring about complex organisational changes in palliative care services. In this section, the organisational literature
was examined to provide conceptual parameters for this study in seeking to understand the impact of health promotion principles and practices upon palliative care organisations.

2.4.1 Remodelling palliative care

There is evidence of widespread attempts to consolidate disparate models of palliative care services in the developed world. Notably, Australian governments and palliative care stakeholders including PCA have reiterated the core tenets of palliative care whilst attempting to guide palliative care service development to be responsive to demand and sustainable in the current climate. However, the evaluation of health promotion in generic health services has been somewhat ad hoc. It has been claimed that “very little is yet known about the way to implement effectively a comprehensive, integrated approach” (Deschesnes et al., 2003, p.389) in some settings and, given how recently health promoting palliative care has been proposed, this viewpoint is a consideration in this study. Whitelaw et al. (2006) point out that new approaches to integrating health promotion and the complexity of the contexts in which these take place contribute to limitations in evaluating the implementation process. The evaluation of health promotion has focused primarily upon program evaluation and outcome measurement (Hawe, Degeling & Hall, 1990) and, historically, has put less emphasis upon whole system approaches (Dooris, 2006). This may be due, at least in part, to a perceived tension between theory and practice in health promotion:
Whilst the theoretical framework guiding the work may be rooted in systems thinking and organizational development, the practice is often constrained to smaller-scale project-focus work around particular issues.

(Dooris, 2004, p.44)

This is in spite of the increasing emphasis from WHO upon the global agenda for health promotion, most recently illustrated in the Bangkok Charter. Ironically, it is a whole systems approach that has been recently reiterated as essential to effectiveness of health promotion implementation (Jackson et al., 2006). This deficit is one that informs any attempt to explore the integration of health promotion principles and practice into palliative care organisations. In this context, what responses to health promoting palliative care are evident in the strategic documentation of government or peak bodies in palliative care?

2.4.1.1 Strategic responses to HPPC

In their document Service Provision in Australia: a Planning Guide, PCA (2003) provided population-based guidelines for palliative care service development, asserting the importance of health promotion principles and strategies to improve health and lessen disease. Certainly, there is some evidence of health promoting approaches to palliative care in the agenda for the strategic development of palliative care in Australia, as expressed in the National Palliative Care Strategic Plan (Commonwealth of Australia, 2000). The Australian Government’s Department of Health and Ageing [DoHA] identified three priorities in the organisation of palliative care services. Firstly, it promotes community and professional awareness and understanding of the role of palliative care services. Secondly, it supports continuous improvement in the quality and
effectiveness of palliative care service delivery across Australia. Finally, it promotes partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings. Priorities relating to improved community awareness, and the development of partnerships across sectors are shared by both palliative care and health promotion. However, no explicit statement regarding a health promoting approach was made, a situation replicated in other Australian jurisdictions. In the state of Queensland, the health department’s Strategic Directions for Palliative Care Services 2000-2005 (Queensland Health, 2000) implied principles and strategies that are congruent with health promotion, without overtly naming the approach and remaining within existing biomedical approaches. A social model of health is not evident per se and this represents a wider challenge to the integration of health promoting palliative care – whilst elements of social models of care are detectable in the current policy and practice environment, biomedical frameworks continue to dominate the conceptualising of palliative care.

Nevertheless, a health promoting approach to palliative care was explicitly described by Palliative Care Queensland [PCQ], the state-based counterpart of PCA. Through the National Palliative Care Program, PCQ has implemented a community development program which unambiguously named health promoting palliative care as a key activity (Palliative Care Queensland, 2004). However, whilst a brief project was conducted, no enduring health promoting palliative care programs with the peak body are apparent. In a public consultation paper, the Victorian State Government (Laverick, 2004) acknowledged the benefits of
understanding palliative care with reference to “the prevention and relief of suffering” (p.41) and the organisation of services to achieve this health promoting outcome. Palliative care providers and affiliated professional groups are marketing their services with clear reference to the promotion of quality of life and comfort, choice in the setting of care, supporting the entire family network, and giving attention to the emotional and spiritual experience of dying (Palliative Care Association of Queensland, 1997). Despite these initiatives, the impact of health promotion on palliative care services remains unmeasured in Queensland. Doing so could make a valuable contribution towards understanding the impact upon organisations in implementing the principles and practice of health promotion in palliative care services.

2.4.1.2  Health promoting palliative care as a ‘model’ of care

As noted, descriptions of models of palliative care demonstrate little definitional consistency in the use of the term for the varied approaches to palliative care provision. A ‘model’ has been defined as “a functioning or proposed system of organisation for the provision of palliative care” (Salisbury, 1999, p.57), and this definition has been applied to both organisational and governmental levels. Yet it contributes to a lack of clarity in failing to capture the conceptual elements of models of care. Moreover, the term has been used to portray national health care systems and palliative care programs (Bruera & Sweeney, 2002), settings of care (e.g.: hospital, home, or hospice) and service structure (Salisbury, 1999), the transition from curative to palliative intent along the trajectory of illness (Ahmedzai, 1996), and even WHO’s description of
palliative care (Clark & Seymour, 1999). Collectively, these uses of the term ‘model’ allude to three key elements of a model of care, comprising:

- A particular conceptual or philosophical perspective, which is expressed through the mission and values of an organisation.

- This mission and these values are made concrete through strategic planning and organisational goals and objectives.

- Organisational structures and processes provide the mechanisms by which a program of service delivery is planned, delivered and evaluated in ways consistent with the underpinning conceptual base.

This perception of models of care is evident in PCA’s (2004) policy consultation paper, which demonstrated the conceptual and practical domains of service models in palliative care in their descriptions of patient-focused, specialist and generalist models. Notably, models of palliative care, including health promoting palliative care, are not mutually exclusive and may contain elements in common. These models, therefore, can be understood to overlap rather than run parallel to each other. However, health promoting palliative care differs from the models described above inasmuch as it is both accommodating of common elements and critical of other models of care (Rumbold, 2004). For example, whilst acknowledging the competence of the biomedical model in palliating many physical manifestations of advancing disease, health promoting palliative care is equally critical of the neglect of psychological, spiritual and social domains of human experience, in spite of biomedicine’s predominance in the health care professions generally, and its adoption by the palliative care profession.
Subsequently, health promoting palliative care can be understood to be a model of care insofar as it originates in a conceptual perspective that promotes optimal health even in the presence of incurable disease. It utilises palliative care philosophy to inform the development of organisational mission, values, and strategic directions, and the Ottawa Charter to supply parameters for determining the scope of goals and objectives. Finally, a health promoting palliative care organisation might apply specific performance indicators which target these elements, such as those proposed by Eagar et al. (2004). This particular evaluation framework currently shapes a great deal of the evaluation of palliative care services in Australia although it would require amendment to accommodate a social model of care such as health promoting palliative care. Collectively, these conceptual and practical elements describe the health promoting palliative care model of care. It is not, Kellehear (1999b) states, simply “an additional thing to do” (p.23), an added burden in an already busy organisation.

2.4.2 Studying paradigmatic shifts in organisations

How would a palliative care organisation demonstrate the impact of the integration of health promotion principles and practice into palliative care services? When health promotion has been introduced in other environments where, like palliative care, its compatibility is not immediately obvious, researchers have reported an array of organisational impacts. In their study of health promoting hospital emergency departments, Bensberg and colleagues (2003) reported the suitability of these environments for health promotion practices, noting that such a paradigm shift required the efforts of both the individuals in, and the infrastructure of, the organisation. Staff education and the
support for health promotion at the program level were found to be key components in effecting this change. Similar requirements have been identified elsewhere, where the need to establish both conceptual compatibility and policy support was fundamental to an organisational commitment to a changed perspective (Aujoulat, Le Faou, Sandrin-Berthon, Martin, & Deccache, 2001). Indeed, organisational change of this nature was noted to be complex, gradual and cyclical (Elwyn & Rhydderch, 2002). Further, it has been suggested that organisational change is only effective when it is a highly facilitated process (Moullin, 2002).

2.4.2.1 “The constant challenge of change”

The recent history of palliative care shows that health care organisations in the developed world have undergone a period of fundamental reform over the past few decades. The redefining of the relationships between services and governments, the establishment of benchmarks for performance, and the implementation of quality management systems have characterised health care reform in a political climate where cost-effectiveness has dominated and the influence of health care consumers is growing ever greater. Indeed, “a hallmark of the modern health care enterprise is the constant challenge of change” (Mickan & Boyce, 2002, p.49). For many decades, health care services have incorporated organisational structures and processes that address the constant changes they experience. This attempt to accommodate – and indeed, promote – organisational change is underpinned by various theoretical perspectives.

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6 (Mickan & Boyce, 2002, p.49)
2.4.2.2 Organisational metaphors: machine or organism?

Whilst it is important to do so, any attempt to describe the nature of organisations is only ever an approximation (Begun et al., 2003). In refining the foundations of organisational theory, theorists have utilised metaphors to assist understanding in how organisations work. Whilst a number of these exist, two in particular have influenced health care service organisations over the past 50 years or so (Morgan, 1998). In viewing organisations as ‘machines’, systems theory has been proposed as a means to understand how organisations function and demonstrate their capacity to adapt to change (Mickan & Boyce, 2002; Shortell & Kaluzny, 1997). An important distinction between closed and open systems is made; closed systems assume that an organisation can function independently of the external environment, and emphasises the participation of individuals in organisational behaviour (Mickan & Boyce, 2002). Conversely, open systems are fundamentally linked to the socio-political contexts within which they exist, and their capacity to innovate and adapt is central to their attainment of organisational goals (Shortell & Kaluzny, 1997). Whilst in the past, health care organisations have tended towards the closed system design, increasingly open systems theory has been seen as suitable to apply to contemporary health care organisations, given the embedded nature of health care in modern societies (Scott, 2003). This theory permits the scrutiny of change across a broad range of organisations and the field that they comprise. Specifically, Scott suggested an examination of the belief systems and assumptions that underpin the behaviour of an organisation’s participants, and the practices that constitute a field’s organising principles; individuals and collectives; and practices which support regulation. In acknowledging the necessity to address the influence of external environments
upon organisations, support for an open systems theory is found elsewhere (Begun et al., 2003).

However, health care services are complex organisations and intensely engaged with the broader socio-political contexts in which they exist, particularly given their accountability for the use of public funds and links with medical insurance. It has been suggested that systems theory is an inadequate descriptor of how organisations function, as the machine metaphor fails to capture the complex, interactive and organic nature of organisations (Morgan, 1998). Indeed, it could be suggested that the values evident in the history of the modern hospice movement, and its subsequent behaviour, represent a rejection of the machine metaphor.

An alternative to open systems theory has been developed using a related metaphor that views organisations as organisms. That is to say, organisations demonstrate a complex interrelatedness between their human, business, and technical components and are geared towards modifying themselves in light of the influences exerted by these components and other contextual factors (Begun et al., 2003). This metaphor is founded in complexity theory, and views organisations as complex adaptive systems. In defining complex adaptive systems, Begun, Zimmerman and Dooley (2003) described the fundamental nature of organisations as made up of multiple and diverse elements, with the capacity to modify themselves as needed, and profoundly interconnected with its context. These elements are in a constant state of change, highly interconnected with each other, capable of ordering themselves according to shifting priorities, and able to modify themselves in response to feedback (Kaluzny & Hernandez, 1988). In applying
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this complexity theory to health care organisations, it has emerged as a less mechanistic approach than open systems theory, and can be conceptually linked to a holistic and non-linear approach to relationships between components of organisations (Sauerborn, Nitayarumphong, & Gerhardus, 1999). The capacity to adapt to change is a core – and essential – attribute of modern organisations that meet their targets (Begun et al., 2003) and is fundamentally linked to the implementation of new models of service delivery, such as that which health promoting palliative care represents to palliative care organisations.

2.4.2.3 Evaluating organisational change

The assessment of organisational change has been linked to the evaluation of quality in organisations by the late Armenian-American health researcher and educator, Avedis Donabedian, who led the development of theory, concepts and measurement of quality in health care. Attempts to define the characteristics of organisational change refer to any modification in process, structure or outcomes within an organisation (Breedlove, 1994). Donabedian developed a triad approach to the assessment of the quality of care which is known as the structure-process-outcome framework [SPO] (Ader, Berensson, Carlsson, Granath, & Urwitz, 2001; Gagnon & Grenier, 2004). This framework has been noted in both health promotion (Aspinal, Addington-Hall, Hughes, & Higginson, 2003; de Wit, van Dam, Vielvoye-Kerkmeer, Mattern, & Abu-Saad, 1999), and palliative care (Kaluzny & Hernandez, 1988). Whilst conceptual difficulties in the definitions of SPO elements have long been a feature of the framework (Closs & Tierney, 1993), these definitions are proposed and utilised in the conceptualising of this thesis:
**Structure**

‘Structure’ refers to the configuration of organisational elements designed to facilitate achievement of the organisation’s goals, regulate the influence of individual variations on the organisation, and facilitate the exercise of responsibilities related to roles (Donabedian, 1980). Organisational structure is the arena for organisational action. Examples of structural elements include the setting; the articulation of organisational mission, goals, and objectives; dynamics within setting (eg: policy and procedure, documentation systems); provision for risk management (eg: staffing); and interactions between members of the organisation (eg: lines of accountability) (Ader et al., 2001; Closs & Tierney, 1993).

**Process**

‘Process’ refers to the operationalisation of these structures to achieve organisational goals. Examples of process elements may include implementation of documentation, the exercise of decision making, leadership style, communication style, community needs analysis and the nature of consumer and stakeholder involvement (Ader et al., 2001; Closs & Tierney, 1993; Kayrooz & Trevitt, 2005).

**Outcomes**

The term ‘outcomes’ refers to the products of these organisational elements as a result of their configuration and operationalisation. These outcomes may be fulfilment of organisational goals or, indeed, the failure to do so. Outcome measurement in palliative care is challenging – for the most part, it has not found relevance in the standard epidemiological measurements of morbidity and mortality (Closs & Tierney, 1993), focussing instead upon quality of life,
symptom control, and patient/caregiver satisfaction. More recently, it has been proposed that palliative care services must identify outcomes relevant to individuals, families and whole communities (Byock et al., 2001). In Australia, Eagar, Cranny & Fildes (2004) released an evaluation guide for palliative care services and programs that similarly contains elements of health promotion and public health, embracing consumer, organisational and systemic outcomes. In another Australian program, the Palliative Care Outcomes Collaborative [PCOC] represents a contemporary attempt to “develop and support a national benchmarking system that will contribute to improved palliative care outcomes (University of Wollongong, 2007, ¶3). Linked to the Standards for Providing Quality Palliative Care for All Australians (Palliative Care Australia, 2005a), PCOC demonstrates an approach to continuous quality improvement in end of life care in Australia.

Consequently, organisational impact can be understood to refer to alterations in the structures, processes, and outcomes that explicitly demonstrate the principles and practices of health promoting palliative care. This profile illustrates the integration of health promotion principles and practice as it provides a framework through which the elements of health promotion can be detected. In their discussion of community organisational culture, Koch and Kralik (2001) have constructed a checklist based on the SPO framework, for the mapping of community health care organisations, which is utilised in the following chapter.

2.4.2.4 Utilisation of quality improvement strategies

One approach to the planning, implementation and evaluation of organisational change is the quality improvement approach, such as Total Quality
Chapter 2: Literature Review

Management [TQM]. Linked to the SPO framework, TQM is a term used to describe an organisation-wide approach to a continuous process, involving all members of an organisation, to fulfil the organisational goals, meet the requirements of service users and other stakeholders, and act within the fiscal constraints of the organisation’s means (Moullin, 2002).

However, the difficulty in obtaining consensus for a definition of quality in health care is long acknowledged, particularly as the perspectives of health care consumers are likely to differ from those of providers (Moullin, 2002), service administrators or financers (Ader et al., 2001; Donabedian, 1980; Gagnon & Grenier, 2004; Tasso et al., 2002), or clinicians, including nurses (Donabedian, 2003). The process of TQM is a circular one, wherein a dynamic progression through assessment, action, evaluation and monitoring permits the continual evaluation of the structure, processes and outcomes of organisations and their activities (Australian Council on Healthcare Standards, 2006). TQM is widely adopted in organisational practice (Eagar, Garrett, & Lin, 2001). In Australia, this is evident in the Australian Council of Healthcare Standards’ [ACHS] (2006) EQuIP Standards program of accreditation that has been widely implemented in the assessment of health care services.

However, the application of TQM to palliative care has a somewhat chequered history. Whilst some palliative care services have been assessed by ACHS, overall they have been slow to incorporate TQM. It has been suggested that quality is an integral component in the philosophy, configuration and provision of palliative care (Higginson, 1993), yet ironically this has led to a disinclination to utilise quality management processes (Palliative Care Australia,
2003). For the most part, early consideration of the successes of palliative care centred around quality of life, particularly symptom control. The bulk of earlier investigations had been focussed upon clinical outcomes for the recipients of palliative care (Dangel, Fowler-Kerry, Karwacki, & Bereda, 2000; Douglas, Higginson, Myers, & Normand, 2000; Gazelle, Buxbaum, & Daniels, 2001; Patrick, Engelberg, & Curtis, 2001), and certainly this remains a necessary component of the evaluation of palliative care services.

A core concept in understanding the issue of quality in palliative care is that the experience of incurable illness and dying, taking on a caregiver’s role, grieving and death itself cannot be fully understood solely within a medical context (Byock et al., 2001; Palliative Care Australia, 2003; Howarth, 2007). The perspective of palliative care services is deeply founded upon notions of holistic care, which is informed by the context of the patient’s social world, hence the usefulness of health promotion concepts in end of life service provision. It is proposed that the benchmark for the measurement of good quality dying and death is “the degree to which a person’s preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others” (Patrick et al., 2001, p.724). Whilst this operational definition is indeed patient-centred and consumer-driven, its primary application seems to be to facilitate a post-mortem evaluation of the organisation’s contribution to an individual’s good death. There is growing attention being given to the evaluation of palliative care service provision, including public health components.

TQM components can be applied to the implementation of the health promoting palliative care model in an adapted form. The elements of TQM
described above are expressed in a more evolved form in an alternative evaluation hierarchy for palliative care services and projects recently proposed by Eager, Cranny and Fildes (2004). In it, the authors put forward evaluation of palliative care organisations’ impact on, and outcomes for, consumers, providers, and the care delivery system as a valid and valuable measure of these services. Interestingly, this hierarchy demonstrates elements that represent several health promoting principles, such as sustainability, dissemination of information, and community capacity building. Similarly, Byock, Norris, Curtis, & Patrick (2001) have developed a conceptual framework for facilitating TQM in community palliative care, illustrated in Figure 2.2 below. This framework takes a whole community approach to end of life care, with the endorsement of the USA national government and integrating elements of both palliative care and health promotion. By attending to end of life needs at both individual and community levels, a health promoting approach to palliative care becomes evident, facilitating highly contextualised and holistic care.

According to its authors, the framework is applied as follows:

- Identify existing reliable instruments that assess relevant characteristics of end of life care; for example, those found in health promotion to assess community capacity.
- Define the structures and processes of the organisation which facilitate the desired outcomes of end of life care.
- In order to plan, implement and evaluate end of life interventions, and build the evidence base, the TQM cycle is applied.
Once evaluated, the intervention can be retested and applied across systems both within and outside of the organisation.

FIGURE 2.2: OPERATIONAL MODEL FOR COMMUNITY BASED QUALITY IMPROVEMENT

Like the examples described elsewhere in this review, this framework demonstrates another attempt to evaluate palliative care services utilising both quality improvement techniques and the principles of health promotion, whilst integrating the core values of palliative care. It provides further valuable conceptual information for the development of this study.

2.5 Chapter Summary

This literature review has examined the published and grey literature regarding palliative care and health promotion, and the organisational issues that may arise from their integration. Palliative care services in the developed world, including Australia, have developed primarily through localised community
action, with the impetus for their development often led by individual clinicians and *ad hoc* funding decisions. In an attempt to resolve these disparate models of palliative care, it has been suggested that the principles and practices of health promotion are not only theoretically congruent, but have the potential to positively influence the ways in which care is provided to dying people and the communities to which they belong. Underpinned by the *Ottawa Charter for Health Promotion* (World Health Organization, 1986), Kellehear (1999b) proposed a health promoting palliative care model, in an endeavour to support people at the end of life in ways that promote their optimal health and attempts to prevent avoidable morbidity in individuals, families, communities and societies. These strategies include an overt engagement with the wider community and governments in an endeavour to promote health amongst dying people and the communities to which they belong.

Whilst approaches to program planning and evaluation have been explored extensively in health promotion generally (Egger, Spark, Lawson, & Donovan, 1999; Hawe, Degeling, & Hall, 1990; McMurray, 2003; Wass, 2000) and in palliative care specifically (Tierney et al., 1994), there remains no standardised approach in Australia to the appraisal of a paradigmatic shift to health promoting palliative care in existing palliative care services. Nevertheless, PCA’s (2003) planning guide for palliative care organisations includes health promoting strategies as essential components of the professional support of dying people and their families. Consequently, it can be concluded that there is a current impetus for the consideration of how health promoting palliative care might influence existing palliative care services.
CHAPTER 3:
METHODOLOGY, DESIGN AND METHODS

3.1 Introduction

This chapter’s purpose is to explain the methodology, research design and methods selected to address the research questions of this study:

◦ What impact does the implementation of health promotion principles and practice have upon palliative care organisations?

◦ What factors advance or impede integration of health promotion principles and practice to palliative care service provision?

To answer these questions, this study was undertaken in a community based specialist palliative care service and applied a single-site, instrumental case study design, utilising mixed data collection and analysis methods.

This chapter is presented in three sections. Firstly, it considers the theoretical assumptions of the research methodology. Secondly, it provides description of, and rationale for the study design, including the schematic illustration of the conceptual framework for this study and the strategies employed to establish and maintain the rigour of the research. Finally, it gives detailed descriptions of the methods utilised, including sampling techniques, data collection and management methods, and data analysis strategies.

3.2 Methodology

This study is guided by a constructionist-interpretivist paradigm. The concept of constructionism was introduced by Blumer (1938, in Crotty, 1998) and
focused upon the construction of meaning by people within the context of human interaction (Schwandt, 1998). The emergence of interpretivism is usually attributed to the work of Weber (1947/1964) and evolved under the influence of phenomenological sociologists. However, interpretivism cannot be solely identified with a single theoretical origin, as it has been broadly influenced by many theoretical positions (Sandberg, 2005). The common thread in these positions, however, is phenomenology, which builds upon the work of Heidegger (1927/1981), Husserl (1931/1962) and others, in claiming that the “human world is…an experienced world” (Sandberg, 2005, p.43) and that knowing relies upon interpretation of lived and contextualised experience. Further, Denzin and Lincoln (1994) have proposed that “all research is interpretive [insofar as] it is guided by a set of beliefs about the world and how it [can] be understood and studied” (p.33). In this study, these beliefs – or theoretical assumptions – are:

- **Relativist ontology**: in attempting to understand the nature of reality, this paradigm assumes that there are multiple, constructed realities known relatively by the observer (Denzin & Lincoln, 1994). In this study, relativist ontology underscores the notion that the reality of organisational transition is “represented through the eyes of the participants” (Robson, 2002, p.17).

- **Intersubjectivist epistemology**: to understand the relationship between constructed reality and the observer, this paradigm assumes that reality is interpreted subjectively from the perspective of the observer, but that this knowing is informed and changed by the knowing of other observers; indeed, it proposes a collectively constructed reality (Denzin & Lincoln, 2005; Sandberg, 2005). Perälkylä (in Denzin & Lincoln, 2005) emphasised the
contextual nature of intersubjectivity. Noting that is especially useful in the study of institutional settings, Peräläkylä asserts that an intersubjective epistemology enables the investigator to obtain insight into institutional contexts through the participants’ understanding of and interaction within such settings.

- **Naturalistic methodological procedures**: the process of enquiry into these realities utilises procedures that are contextualised in the natural world; importantly, this does not constrain it solely to the use of qualitative methods and in this study, mixed methods are utilised in the single-site, instrumental case study design (Denzin & Lincoln, 1994; Tashakkori & Teddlie, 2003).

Where quantitative and qualitative methods are combined in mixed method research, as they are in this study, it is appropriate to address the question of these apparently ontologically opposed positions. Central to resolving this dilemma in mixed method research is giving brief attention to a longstanding debate about the nature of ‘truth’.

### 3.2.1 The nature of ‘truth’

The nature of truth and the paths to its knowing have been the subject of Western philosophical debate for many centuries (Roberts & Taylor, 2002). The positivist paradigm has dominated research enquiry since the 19th Century, founded on the assumption that an objective reality exists outside of human observation that is knowable and measurable (Polit & Beck, 2004). Put simply, it contends that an objective truth exists and that ordered and highly systematic examination is necessary to test and know the ‘truth’ about the subject under enquiry. ‘Reality’ is viewed as independent of human perception. Positivism also
claims to be able to identify causality, a thesis first proposed by the philosopher Hume (1888). Qualitative enquiry has been criticised as subjective and insufficiently systematic to objectively identify causality within phenomena (Couchman & Dawson, 1990), suggesting that qualitative research methodologies lack rigour because they fail to systematically address issues of validity and reliability.

Conversely, protagonists of naturalistic enquiry reject the positivist notion of an objective truth. As noted above, the constructionist-interpretivist paradigm, which underpins the methodology of this study, proposes that ‘truth’ is a construction of human meaning-making and does not exist independently of human interpretation. In the researched environment, therefore, participants construct reality “…not [as] a fixed entity but rather a construction of the individuals participating in the research; reality exists within a context, and many constructions are possible” (Polit & Beck, 2004, p.15). Consequently, quantitative enquiry has been criticised as reductionist and disconnected from lived human experience (Robson, 2002). Some have asserted that objectivity itself is impossible, given the complex social contexts of phenomena, subjects and researchers (Sandberg, 2005; Streubert Speziale & Carpenter, 2003).

This apparent incompatibility of the positivist and naturalistic paradigms and the quantitative and qualitative methodologies assigned to them has been discussed at length in the published literature, particularly where attempts to combine them within studies have been made. Mixed method research has been criticised for assuming to reconcile ontologically opposed positions, although attempts to do so have been in evidence from the 1930s (Tashakkori & Teddlie,
2003). More recently, Denzin and Lincoln (2005) were highly critical of the use of mixed methods within experimental research designs as it “presumes a methodological hierarchy in which quantitative methods are at the top and qualitative methods are relegated to an auxiliary role” (p.9). This concern was not shared by Robson (2002) who saw their use as complementary and enhancing interpretation. Indeed, the emergence of the “pragmatism and compatibility thesis” (Tashakkori & Teddlie, 2003, p.7) been an attempt to answer concerns about the both the theoretical and practical foundations of mixed method research. Interpretation of reality is, it is argued, a multifaceted process best served by multifaceted research design.

Underscoring the relativist ontology of this study is the assumption that to understand reality, there is a need for various types of knowing and that each be given equal consideration, rather than relegated to irreconcilability – that they be seen as “different positions on a continuum of knowledge” (Foss & Ellefsen, 2002, p.244). Begley (1996) added that, as the assumptions underpinning each end of this continuum are simply different from each other, one cannot be considered superior to the other. Others seek to clarify that the intention of combining both the positivist and naturalistic research traditions in mixed method research is not to achieve positivist goals:

...combining them can add range and depth, but not accuracy...we should combine theories and methods carefully and purposefully with the intention of adding breadth or depth to our analysis, but not for the purpose of pursuing objective truth. (Sim & Sharp, 1998, p.27)
Dootson (1995) concurs, having argued that any attempt to reconcile these positions is futile; the challenge instead being to ‘know’ data in a new way. Naturalistic research maintains the position that people’s perceptions of reality are profoundly holistic and contextualised, and subsequently, individual elements of human experience cannot be separated either from the whole or from the social contexts in which they are situated. In this study, this perspective is reflected in the primacy placed upon knowing the real-world context of the research enquiry.

3.2.2 Intersubjective knowing

Given this study’s ontological view of multiple, constructed realities, an intersubjective epistemology was an appropriate means to understand the context in which relationships between the knower and the known take place. Building on the work of phenomenology, Sandberg (2005) rejected the notion that the knower and the known are two separate entities, independent of each other. Instead, he asserted the subject and object exist as such because of their interrelatedness. Whilst Husserl and Heidegger ultimately differed on how constructed reality is established, Sandberg (2005) argued reality is always understood through contextual lenses, such as history, culture, ideology, gender, and language and that the relative knowing of reality is “socially constructed by continuous negotiation between people about the very nature of that reality” (p.45). This intersubjectivity embraces both the lived reality of individuals and the shared knowing by the collective.

Therefore, in this study, this epistemological position compelled the researcher to inquire not only about the perceived nature of the phenomena of interest, but to understand the multifaceted context in which these phenomena
take place. It is theoretically consistent that this study utilised methodological pluralism to select a mixed method design to address the research questions.

3.2.3 Methodological pluralism

The utilisation of methodological pluralism in this study is congruent with the ontological and epistemological positions described. This study is based on the assumption that combining of methodologies promotes holistic knowing of the phenomena of interest in their real-world context, as promoted by a number of authors. Morse and Chung (2003) have argued strongly in its favour as a pathway to the holistic understanding of the multidimensional and complex nature of human experience, which demands a more diverse means of enquiry that neither quantitative nor qualitative approaches can fulfil alone. Indeed, Cowman (1993) asserted the inadequacy of single methodology research in addressing whole person experience and its complexity. Tashakkori & Teddlie (2003) acknowledged that combining these disparate paradigms is not without its perils; whilst identifying difficulties in nomenclature, rigour and design, they also argue that mixed method research possesses a utility in the lived world that offers insight into the complexity of human knowing of phenomena. Foss and Ellefsen (2002) agreed that the complex nature of knowing endorses a multimethod approach in order to obtain a more complete picture. This study adopts the “complementary strengths thesis” (Tashakkori & Teddlie, 2003, p.19), where the combining of the positivist and naturalistic paradigms retains the assumptions of each in order to add interpretive strength to the study.

Two distinct outcomes of combining epistemological paradigms and the use of multiple sources of data have been identified as confirmation and
completeness (Begley, 1996; Shih, 1998). Confirmation refers to the establishment of accuracy or trustworthiness of the multiple observations of the complex phenomena under study, which represents an attempt to identify the validity of the findings. It has been suggested that confirmation allows for a reduction in the margin of error by offsetting the weaknesses of one method by the strengths of another (Jick, 1979; Shih, 1998), although others have warned that this counterbalance is not automatically corrective (Begley, 1996; Shih, 1998). However, Sim and Sharp (1998) questioned the assumption that the validity of research enquiry is improved through the combination of multiple sources of data, as the notion of validation itself relies upon a positivist assumption that an objective reality can be identified and confirmed. This concern is allayed somewhat in the context of this study when viewed as an act of verification of the data’s accuracy rather than attempting to promote a claim of objective truth.

Combining data may assist the researcher to attain an answer to the research question that demonstrates completeness (Rice & Ezzy, 1999). Sim and Sharp (1998) viewed completeness as a more realistic goal when combining data, referring to the attainment of findings that demonstrate the complexity of the phenomena under examination, best described metaphorically as ‘putting together the pieces of the puzzle’. In this study, both confirmation and completeness were sought from the multiple sources of data.

### 3.2.4 Summary of methodology

This examination of methodology explains the theoretical assumptions that underpin this study. These assumptions are summarised in Table 3.1 and provide
the justification that the selection of case study design was a theoretically sound response to the research questions and the complex multifaceted context in which these questions were addressed. This research design is described in detail below.

### TABLE 3.1: SUMMARY OF THEORETICAL ASSUMPTIONS

<table>
<thead>
<tr>
<th>Theoretical Assumption</th>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality is a human, social construct known and shaped by its collective knowing</td>
<td>Heidegger (1927/1981), Husserl (1931/1962), Sandberg (2005)</td>
</tr>
<tr>
<td>Reality is optimally known from multiple perspectives</td>
<td>Foss &amp; Ellefsen (2002), Morse &amp; Chung (2003), Rice &amp; Ezzy (1999)</td>
</tr>
<tr>
<td>The positivist and naturalistic paradigms are compatible and provide information about phenomena of interest from “different positions on the continuum of knowledge”</td>
<td>Foss &amp; Ellefsen (2002, p.244), Morse &amp; Chung (2003)</td>
</tr>
<tr>
<td>The contexts of phenomena of interest are essential components of understanding those phenomena</td>
<td>Yin (2003), Stake (1995)</td>
</tr>
<tr>
<td>Paths of research enquiry utilising multiple perspectives can permit completeness of understanding of complex phenomena and a holistic understanding of multidimensional contexts</td>
<td>Begley (1996), Morse &amp; Chung (2003)</td>
</tr>
</tbody>
</table>

### 3.3 Research Design

Having established the methodological foundations of this study, this section now provides description of, and rationale for, the selection of a single-site, instrumental case study design. This includes the schematic illustration of the conceptual framework for this study and the strategies employed to establish and maintain the rigour of the research.

#### 3.3.1 Conceptual framework

The conceptual framework for this study incorporates the methodological underpinnings, key conceptual issues and the research procedures, to demonstrate the links between theory and methods. A structural hierarchy suggested by Silverman (2000) was adapted to provide a scaffold for illustration of the
Figure 3.1: Conceptual Framework and Research Plan

What impact does the integration of health promotion principles and practices have upon the structures, processes and outcomes of a palliative care organisation? What factors advance or impede this integration?

**Palliative Care**
- Affirms life, regards dying as normal
- Neither hastens nor postpones death
- Provides relief from distressing symptoms
- Views care on physical, psychological, social and spiritual realms
- Offers support to live as actively as possible until death
- Offers support to families during the patient’s life and in bereavement

**Kellehear’s Health Promoting Palliative Care**
- Provide education and information for health, death and dying
- Provide social support at both personal and community levels
- Encourage interpersonal reorientation
- Encourage reorientation of palliative care services
- Combat death-denying health policies and attitudes

**Health Promotion**
- Builds public policy
- Creates supportive environments
- Strengthens community action
- Develops personal skills
- Reorients health services

**CONTEXT – PALLIATIVE CARE ORGANISATION**

Phenomenon – Integration of HPPC

**Instrumental Case Study Design**

- Documentation review
- In-depth interviews
- Questionnaire
- Focus groups

Data reduction and display
- Descriptive matrices
- Interpretive matrices

Drawing and verifying conclusions
- Case description
conceptual framework in a complex schema of interrelated elements that were selected to address the research questions. This schematic is shown in Figure 3.1.

Examining the schematic in detail, the conceptual framework illustrates the key components of palliative care and health promotion, discussed in detail in the literature review in the previous chapter. Whilst Kellehear’s (1999b) model presented five goals of health promoting palliative care and provided pertinent examples of its application, these goals were assumed to be neither prescriptive nor exhaustive. Consequently, this study utilised the five key action areas of the Ottawa Charter for Health Promotion (World Health Organization, 1986) to conceptually define the principles of health promotion, whilst drawing on Kellehear’s five goals of health promoting palliative care to assist in the identification of health promotion practices in the palliative care setting. The structural, process and outcome elements of the palliative care organisation In applying an instrumental case study design, this study utilised multiple sources of data to address the research questions regarding the phenomena of interest. Each of the five key action areas of the Ottawa Charter represented a subunit of analysis and was investigated utilising a subset of research questions. These questions provided a starting point for enquiry and were etic in nature – that is, they were brought into the process of investigation rather than generated by the process of enquiry (Stake, 2000). In concrete terms, the etic research question was the same for each of the five key action areas: what structural, process and outcome elements demonstrate the integration of health promoting palliative care into the case study organisation? For each of the subunits of analysis, the following questions were asked:
How are these elements integrated into the structures and processes of the organisation?

What factors enable these elements to become part of the organisational structures and processes?

What factors represent a barrier to these elements becoming part of the organisational structures and processes? constituted the phenomena of interest in this study.

It is acknowledged that *emic* questions emerged from data collected in the course of the investigation (Stake, 2000). For example, in exploring the organisational processes that support the strengthening of community action, the path of enquiry pursued an early theme about the core business of the case study site; transcripts demonstrate emic questions in response to this.

Four data collection methods are illustrated in the conceptual framework – document review, in-depth interviews, focus groups and questionnaires – and each required different data management processes and analysis strategies. The units of analysis provided the analytical filter through which data reduction utilising a descriptive matrix, and data analysis utilising an interpretive matrix were undertaken, allowed for conclusions to be drawn. These methods are described in detail below.

The conceptual framework schematic demonstrates the centrality of the case study research design to this study and its pivotal place in linking theory to methods. The selection of case study research design in this study enabled a diverse path of inquiry into highly contextualised phenomena of interest, and is examined in detail below.
3.3.2 Case study research design: the “study of the particular”

Case study research design is being increasingly selected as an appropriate and flexible approach to research in nursing and the social sciences. Its use in the latter is well established (Yin, 2003) and its utility in nursing has been recently demonstrated (Luck, Jackson, & Usher, 2006; Walshe, Caress, Chew-Graham, & Todd, 2004). Case study research permits the “detailed, extensive study of a particular contextual and bounded phenomenon that is undertaken in real life situations” (Luck et al., 2006): 104). It is known as the “study of the particular” (Stake, 2000, p.xi) and is most commonly applied where the phenomenon of interest is complex and highly contextualised, with multiple variables unsuitable for control (Stake, 1995; Yin, 2003). This was a key consideration in its selection as the design for this study.

This focus upon real-life context provides methodological flexibility to the case study researcher – approaches to research design can be selected on pragmatic, as well as philosophical grounds. Building on the theoretical foundations described above, the selection of case study research design permitted enormous methodological flexibility. However, this paradigmatic flexibility can baffle when it is considered that it:

…can use either qualitative and quantitative methods, can be prospective or retrospective, can have an inductive or deductive approach to theory, can focus on one case or many, can describe, explain or evaluate…

(Walshe et al., 2004, p.677)

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1 (Stake, 2000, p.xi)
In order to clarify the nature of case study research, it is important to conceptualise it as an approach to research design, rather than a methodology in its own right. Case study research has been viewed as a ‘paradigmatic bridge’ because it is not assigned to a fixed ontological, epistemological or methodological position (Luck et al., 2006). Further, case study designs may have explanatory, exploratory or descriptive functions and are acknowledged to have multiple applications to evaluation research (Yin, 2003). Whilst more recently case study design has undergone refinements and intensive promotion of its application (Stake, 1995, 2000; Yin, 2003), many of the features of case study research are drawn from a broad range of research paradigms and usually utilise multiple methods (Walshe et al., 2004).

Stake (2000) has provided three definitional categories of case studies, each with a discrete purpose:

- The *intrinsic* case study is applied to better understand a particular case for its own sake.
- The *instrumental* case study utilises the case to examine particular issues foreshadowed in the phenomenon of interest.
- The *collective* case study is an extension of the instrumental case study to several sites in order to promote better understanding and, perhaps, contribute to theoretical development.

This study was an instrumental case study as it defined the ‘case’ as the palliative care service in order to examine the phenomenon of the integration of health promotion principles and practice into a palliative care organisation.
Chapter 3: Methodology, Design and Methods

An examination of the rationale for the use of case study research design further demonstrates its suitability for selection in this study. The selected palliative care organisation demonstrated a number of characteristics that confirm the selection of case study research design to address the research questions. These are summarised in Table 3.2 below.

### Table 3.2: Rationale for Case Study Research Design

<table>
<thead>
<tr>
<th>Rationale</th>
<th>Source</th>
<th>Site Characteristics / Other Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where the phenomenon of interest is complex, multivariate and multifaceted.</td>
<td>(Stake, 1995; Yin, 2003)</td>
<td>Organisation is a complex adaptive system; organisational variables are numerous.</td>
</tr>
<tr>
<td>Where the phenomenon of interest cannot be understood apart from its context.</td>
<td>(Bergen &amp; While, 2000; Cowley, Bergen, Young, &amp; Kavanagh, 2000; Lee, 2003; Yin, 2003)</td>
<td>Integration of health promoting palliative care is a contextualised phenomenon. Integration is contextualised by organisation internal and external environments.</td>
</tr>
<tr>
<td>Where the phenomenon of interest is more completely understood through examining it from multiple perspectives.</td>
<td>(Walshe et al., 2004)</td>
<td>Integration of health promoting palliative care occurs at organisational and individual levels and warrants investigation across viewpoints.</td>
</tr>
<tr>
<td>Where flexibility in research design is required and other designs have limited capacity to answer the research questions.</td>
<td>(Walshe et al., 2004)</td>
<td>Incremental integration by site disallows experiment and control design.</td>
</tr>
<tr>
<td>Where theory is underdeveloped or absent.</td>
<td>(Walshe et al., 2004; Yin, 2003)</td>
<td>Palliative care theory underdeveloped. Contended theoretical foundations of health promotion. Health promoting palliative care a new field with limited theory development.</td>
</tr>
</tbody>
</table>

### 3.3.3 Rigour in mixed method case study research

The assertion of compatibility of the naturalistic and positivist paradigms argued earlier in this chapter, along with the selection of a mixed method, instrumental case study research design, necessitated a precise approach to maintaining rigour in this study.

The establishment and maintenance of rigour in mixed method research such as this study requires an understanding of the interface between the
qualitative and quantitative methodologies. As debate about the rigour of both qualitative and mixed method research has evolved over the past 30 years or so, the navigational terminology of triangulation had been applied to the social sciences and was considered a key strategy in achieving rigour (Denzin, 1978). The use of this approach to the merging of methods is broadly evident in the nursing research literature and elsewhere (Begley, 1996; Dootson, 1995; Foss & Ellefsen, 2002; Jick, 1979; Shih, 1998; Sim & Sharp, 1998). However, critiques of this nomenclature, such as those provided by Erzberger and Kelle (2003) and Morse (2003), have asserted that, as a metaphor for the integration of data from multiple sources, triangulation is an inadequate descriptor for the complexity of establishing rigour in mixed method studies.

Morse (2003), Tashakkori & Teddlie (2003) and others have proposed a system of categorisation of mixed method research that superseded the language of triangulation and addressed this complexity. A notational system to denote the configuration of mixed method design has been in use for over a decade and provides an important foundation in this study for understanding rigour (Morse, 2003). Illustrated below in Figure 3.2, this system denotes the methodological paradigms, the primary and supplementary status of each of these paradigms in any particular study, and the scheduling of this integration (ie: whether simultaneous or sequential collection of data), in a methodological ‘equation’.
Chapter 3: Methodology, Design and Methods

FIGURE 3.2: NOTATIONAL SYSTEM FOR MIXED METHOD RESEARCH

<table>
<thead>
<tr>
<th>QUAN or quan</th>
<th>QUAL or qual</th>
</tr>
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<tbody>
<tr>
<td>= quantitative</td>
<td>= qualitative</td>
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<table>
<thead>
<tr>
<th>UPPER CASE</th>
<th>lower case</th>
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<tbody>
<tr>
<td>= primary paradigm</td>
<td>= supplementary paradigm</td>
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</table>

+ indicates simultaneous collection of data  → indicates sequential collection of data

Equation configuration: [PRIMARY PARADIGM] then [timing symbol] then [supplementary paradigm]

EXAMPLE: QUANT→qual denotes a mixed method study with dominant quantitative methods followed by supplementary qualitative data (eg: questionnaire followed by in-depth interviews).

(From Morse in Tashakkori & Teddlie, 2003)

Utilising this system, the equation describing the design of this mixed method study was denoted as QUAL+quant; that is to say, qualitative and quantitative data were collected simultaneously with the qualitative data being the primary source of information, supplemented by the quantitative data. This is an important consideration in this discussion of rigour as it points to a concern for the achievement of the rigour of this study’s qualitative data and quantitative data as a supplementary source. Strategies to promote the establishment and maintenance of rigour in both methodologies are discussed below.

3.3.3.1 Rigour of primary qualitative methods

With this study’s QUAL+quant configuration, consideration of rigour within the qualitative methods is foremost. In a research climate where naturalistic enquiry has been viewed as inferior to the prevailing positivist paradigm, qualitative methods have been criticised for lacking rigour (Baum, 1995; Denzin & Lincoln, 1994). Whilst the measurement of validity and reliability is unanimously advocated by adherents of quantitative methodology, the place of validity and reliability as gauges of rigour in qualitative methodologies is debated. Qualitative methodologies underwent a period of
reassessment during the past two decades (Morse, Barrett, Mayan, Olson, & Spiers, 2002) in which parallel criteria were proposed as corresponding measures of rigour in qualitative methods in response to criticisms of poor rigour (Miles & Huberman, 1994). These are noted below in Table 3.3.

**TABLE 3.3: RIGOUR CRITERIA ACROSS PARADIGMS**

<table>
<thead>
<tr>
<th>Positivist paradigm</th>
<th>Naturalistic paradigm</th>
<th>Checklist</th>
</tr>
</thead>
</table>
| Internal validity   | Credibility / Authenticity | ◦ Is the researcher a credible enquirer?  
◦ Is the path of enquiry consistent with the underlying ontological and epistemological views?  
◦ Does the research demonstrate adherence to the proposed data collection and analysis? |
| External validity   | Transferability / Fittingness | ◦ Do the conclusions drawn “fit” the experiences of the participants?  
◦ Has an attempt to verify these conclusions with participants been made?  
◦ Are alternative explanations for divergent data provided? |
| Reliability         | Dependability / Auditability | ◦ Does the study demonstrate how analytical decisions have been made?  
◦ Is an audit trail evident? |

(Adapted from Miles & Huberman, 1994; Morse et al., 2002)

However, Morse et al., (2002) have latterly asserted that validity and reliability are appropriate criteria for attaining rigour in qualitative research and that each criterion possesses attributes in common across these paradigms. Further, the use of positivist criteria by one key proponent of case study research (Yin, 2003) and naturalistic criteria by another (Stake, 1995) have added to this debate. It has been necessary in this study to clarify the intent of each criterion as an important measure of rigour. This is provided in the summary below at the end of this section.

**3.3.3.2 Rigour of supplementary quantitative methods**

As the dominant methodology, naturalistic enquiry provides the theoretical drive of this study. In the QUAL+quant configuration, the quantitative portion of
this study took a supplementary role to the dominant qualitative methodology. Notably, the supplementary method had insufficient statistical power to permit generalisation to populations but, importantly, the role of the supplementary method in this study was to augment the findings obtained through the dominant qualitative methodology rather than generate statistically generalisable results (Morse, Wolfe, & Niehaus, 2005).

Nevertheless, the quantitative portion of this study demonstrated internal validity by appropriately addressing one specific aspect of the phenomena of interest; its external validity was demonstrated in its use of tested instruments (eg: by Kristjanson, 1993, and Sherbourne & Stewart, 1991) and its reliability was established by the instruments’ previous use in the field of palliative care (eg: by Kristjanson, 1993). To ensure reliability and validity were maintained in the collection of data for this study, the instruments remained unchanged other than to include the name of the organisation under study.

3.3.3.3 Reflexivity

A final consideration in the maintenance of rigour in this study was that of the role of the researcher within the researched environment and acknowledgement of possible “biases, values and interests” (Creswell, 2003, p.182). A tension exists between the acknowledgement of pre-existing opinions and the recognition that the presence of the researcher in the processes of enquiry is itself an influence on the conduct of the study. Bracketing has been proposed as a strategy to distance the researcher from the researched by identifying and holding off any preconceived notions about the phenomena of interest and has foundations in both phenomenology and ethnography (Streubert Speziale &
Carpenter, 2003). However, bracketing was not attempted in this study, based upon the view that it is founded upon positivist notions of an objective ‘truth’ being “somehow already lodged within the data” (Rolfe, 2006, p.307) awaiting discovery, and represents a view inconsistent with the interpretivist paradigm underpinning this study. Rather, to minimise bias, the researcher undertook to acknowledge his individual perspectives taken into the research process and their potential impact upon the collection and analysis of data.

As a community-based palliative care nurse of more than 15 years’ experience, the researcher acknowledged his longstanding interest in social models of end of life care including, more recently, Kellehear’s work on health promoting palliative care. The researcher also recognized his pre-existing perspectives of the case study site were informed by the core values of the palliative care profession embraced by the case study site. Given the case study site’s philosophical foundation in Tibetan Buddhism, it is also relevant to declare that the researcher is not Buddhist, although shares many of the humanistic values inherent in Buddhism. He has never been employed by the case study site as a clinician or any other capacity, although he has collaborated in joint clinical care in the past. Conversely, the researcher is professionally known to many within the researched environment, and this experience may add to the credibility of naturalistic researchers to undertake such highly contextualised enquiry.

Three features of reflexivity are evident in this study. Firstly, the inclusion of the “many-voiced” account (Koch & Harrington, 1998, p.888) is a key characteristic, where the research text demonstrates more than the researcher’s interpretation. Secondly, reflexivity is evident in the awareness of the researcher
of the contextual locations of the phenomena of interest, informed by his professional experience and his familiarity with contemporary issues in both palliative care and health promoting palliative care. This broader contextual knowledge evolved throughout the course of the study through (a) an ongoing dialogue between the researcher and the principal supervisor, herself a leader in the field of palliative care, and (b) the researcher’s participation in a number of national committees that addressed issues relevant to the study, such as community capacity building. Finally, the deliberate embedding of the researcher in the organisation during the data collection period acknowledged that the researcher was not separate from the process of enquiry but was indeed an instrument of qualitative enquiry. The implications of these features are discussed further in the following section.

3.3.3.4 Summary of rigour strategies in this study

This discussion demonstrates four important considerations in the establishment and maintenance of rigour in this study. Firstly, sound theoretical reasoning informed the selection of appropriate methods. Secondly, methodological rigour was observable in the maintenance of a detailed account of procedural and analytic decisions to demonstrate how the study was undertaken. Thirdly, the combining of multiple data sources, whether the data were convergent or divergent, facilitated a more complete picture of the complex phenomenon under investigation (Rice & Ezzy, 1999). Finally, interpretive rigour was attained when the researcher’s interpretation of the findings was shown to validly reflect those of the people under study.
These factors were evident in this study in the following criteria for rigour in case study design that must be evident throughout the process of enquiry (Barbour & Barbour, 2003; Morse et al., 2002):

- **Construct validity**: underpinned by sound theoretical reasoning and obtained through demonstration that the phenomena being studied were measured by the methods employed, through clear identification of the type of organisational changes being studied, and provision of a clear rationale for the selection of methods (Yin, 2003). Both of these were addressed in this study and more detailed descriptions are provided below.

- **Internal validity**: whilst more of a concern where the establishment of causality is sought, internal validity in this case study design was attained through the application of pattern matching to build themes during analysis, wherein a pattern of outcomes was anticipated and verified by the case study data. Importantly, it included identifying the predicted pattern of contextualised phenomena of interest prior to data collection (Stake, 1995; Yin, 2003). These foreshadowed issues are identified in Table 3.4 in the next section of this chapter. This represents one means of attaining methodological rigour and supports reflexive processes by substantiating pre-existing, contextual issues through the critique of contemporary literature.

- **External validity**: case study design sets out to facilitate theoretical, rather than statistical, generalisation. That is to say, external validity was achieved in this case study where the findings verify the theoretical propositions of the study (Yin, 2003) and may be replicated when repeated elsewhere. This is evidence of interpretive rigour. For example, a foreshadowed issue was that
of the use of death education programs in order to develop the personal skills of individuals relating to issues of death and dying was a key structural and process element of health promoting palliative care. In this study, this proposition was verified by the case study site clearly demonstrating the development and implementation of death education programs with this explicit intent.

- **Reliability**: strongly linked to external validity, reliability in this case study was concerned with the transferability of theoretically verified and procedurally robust case study protocols (Yin, 2003) promoted by provision of a clear record of the operational steps undertaken in the course of the case study in the form of an audit trail. Again, this contributed to methodological rigour. An example of this is demonstrated in the Transcript Summary Form shown in Appendix 1 which illustrates one step in the audit trail during data analysis. The measured, reflexive engagement of the researcher with the subject under study also promoted external validity in this primarily qualitative research study (Carr, 1994).

### 3.4 Research Methods and Procedures

The conceptual framework/research plan illustrated previously in Figure 3.1 shows the conceptual underpinnings derived from the literature review and describes the methods used in the collection, management and analysis of data in this study. In this section, detailed descriptions are given of the defining and bounding of the case, ethical issues, sampling techniques, data collection and management methods, and data analysis strategies for this multiple method research study.
3.4.1 Defining the case

In this instrumental case study, the case study site was a community-based, palliative care service located in metropolitan Brisbane, Australia, recruited to participate as the site for this study. This hospice began integrating health promotion principles and practice in an incremental way into their organisational structures and processes. This service was studied in order to increase understanding of the phenomenon of the integration of health promotion principles and practices; the organisational represents the unit of analysis for this research study. Utilising the five key action areas of the Ottawa Charter to frame their implementation, the service’s governing body altered the case study site’s organisational structure to facilitate the implementation of the health promoting palliative care approach, and had appointed a senior member of management to identify and roll out other changes over their three year strategic cycle. These included, but were not limited to the activities listed in Figure 3.3.

**Figure 3.3: Planned Activities at Case Study Site**

- Review of existing organisational policies and documentation, with development of health promoting policies in identified gaps.
- Update webpage to reflect HPPC approach.
- Promotion of community engagement through a number of public activities, such as the annual Art Show and the Christmas program.
- Provision of consumer and community education activities.
- Implementation of a client spiritual support program.
- Development of caregiver information resources.
- Liaison with government and peak bodies regarding palliative care policy and public health, including but not limited to state and national health departments.
- Participation, where possible, in social research.
- Publication, where possible, of articles promoting HPPC.
- Implementation of a staff support and education programs, including death education for staff and volunteers.
- Inclusion of HPPC concepts in volunteer training programs.
Following Figure 3.1, the subunits of analysis are listed in Table 3.4, which provides a descriptive statement and a set of structural, process and outcome elements that are conceptually consistent with health promoting palliative care, as explored in the literature (Kellehear, 1999b; Kellehear et al., 2003). Although again neither prescriptive nor exhaustive, their inclusion here as cues is supported by Stake’s (2000) description of the foreshadowed problem in the evolution of issues in a case study. Further, Table 3.4 lists the potential data sources for this information identified prior to the commencement of data collection and includes documentarial and human data sources consistent with the mixed methods proposed.
## Table 3.4: Subunits of Analysis – Descriptions, Cues and Potential Data Sources

<table>
<thead>
<tr>
<th><strong>Key Action Areas</strong></th>
<th><strong>Descriptions</strong></th>
<th><strong>Cues</strong> (Not Prescriptive or Exhaustive)</th>
<th><strong>Outcomes</strong> (Products of Organisational Elements)</th>
<th><strong>Data Sources</strong> (Where Could This Information Be Found?)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building public policy</td>
<td>Concerned with the participation of the case study site in the development and/or uptake of public policy relating to palliative care and the support of dying people.</td>
<td>◦ External committee memberships&lt;br&gt; ◦ Social research projects&lt;br&gt; ◦ Alliances between organisation and associations&lt;br&gt; ◦ Internal policy review committee&lt;br&gt; ◦ Internal committee identifies public policies for adoption&lt;br&gt; ◦ Lobbying activities&lt;br&gt; ◦ Contribution to research projects</td>
<td>◦ Evidence in policy of contributions by organisation&lt;br&gt; ◦ Organisation adopts and reviews public policy&lt;br&gt; ◦ Publications promoting social change</td>
<td>◦ Organisational chart&lt;br&gt; ◦ Annual reports&lt;br&gt; ◦ Strategic plans&lt;br&gt; ◦ Policy/procedure documents&lt;br&gt; ◦ Minutes&lt;br&gt; ◦ In-depth interviews with key informants</td>
</tr>
<tr>
<td>Creating supportive environments</td>
<td>Concerned with the ways in which the case study site contributes to the creation of supportive environments to enhance well-being for consumers and employees of the palliative care service.</td>
<td>◦ Psychosocial support roles&lt;br&gt; ◦ Support groups&lt;br&gt; ◦ Staff support programs&lt;br&gt; ◦ Psychological and social support activities&lt;br&gt; ◦ Model of care reflects HPPC elements&lt;br&gt; ◦ Participation in spiritual program&lt;br&gt; ◦ Participation in staff support programs&lt;br&gt; ◦ Identification of outcomes relevant to pts/carers&lt;br&gt; ◦ Pt/carer satisfaction with / feedback about social support by organisation&lt;br&gt; ◦ Staff / volunteers report health and well being supported by physical environment of workplace</td>
<td></td>
<td>◦ Previous organisational patient satisfaction surveys&lt;br&gt; ◦ Purposive sample of carers (n=40) for survey&lt;br&gt; ◦ Convenience self-nominated sample of patients (n=10) and carers (n=6) for in-depth interview.&lt;br&gt; ◦ In-depth interviews with key informants</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th><strong>Key Action Areas</strong></th>
<th><strong>Descriptions</strong></th>
<th><strong>Cues (not prescriptive or exhaustive)</strong></th>
<th><strong>Data Sources (where could this information be found?)</strong></th>
</tr>
</thead>
</table>
| **Strengthening community action** | Related to the nature of the engagement of the case study site with the wider community, beyond the recipients of palliative care services, to promote community action towards improved support of people at the end of life. | - User participation in governance  
- Public awareness programs in various locations  
- Death education programs | - Needs analysis results  
- Minutes of governance bodies  
- In-depth interviews with key informants  
- Webpage, publicly released brochures  
- News media articles |
| **Developing personal skills** | Concerned with the case study site’s participation in the development of personal skills to assist individuals to deal with issues around death and dying. Includes both health care professionals and primary caregivers. | - Death education programs  
- Staff professional development program  
- HR – appraisal mechanisms in place  
- Caregiver education resources | - Increased skill levels measurable in staff/volunteers following organisational input  
- Carers report increased skill levels in providing care through organisational input |
<table>
<thead>
<tr>
<th>KEY ACTION AREAS</th>
<th>DESCRIPTIONS</th>
<th>CUES (NOT PRESCRIPTIVE OR EXHAUSTIVE)</th>
<th>DATA SOURCES (WHERE COULD THIS INFORMATION BE FOUND?)</th>
</tr>
</thead>
</table>
| Reorienting health services | Related to the activities of the case study site in reorienting its members to a health promoting approach, and has a particular focus on the holistic needs of its client population, and changes in organisation attitudes. | ◦ Mission, values, objectives, and policies and procedures reflect organisational orientation  
  ◦ Governance  
  ◦ Recording systems (patient records inc. assessment tools)  
  ◦ HR – recruitment criteria, position descriptions, staffing profile | ◦ In-depth interviews with key informants  
  ◦ In-depth interviews and focus groups with staff and volunteers  
  ◦ Webpage  
  ◦ Mission/values/ objectives  
  ◦ Policy/procedure documents  
  ◦ Organisational chart  
  ◦ Annual Reports  
  ◦ Corporate Plans  
  ◦ Strategic Plans |

- QI cycle planned and/or implemented against HPPC goals  
- Audits undertaken  
- HPPC education for staff / volunteer  
- Leadership style reflects HPPC  
- HPPC orientation of organisation evident in organisational documents  
- Members report and demonstrate orientation to health promotion principles and practices
3.4.2 Field procedures

Two key procedural activities took place prior to the commencement of data collection that were essential to the implementation of the study. Firstly, this study obtained full ethical clearance from the Queensland University of Technology [QUT] Human Research Ethics Committee (see Correspondence re Ethics Clearance in Appendix 2) and in the absence of their own constituted Ethics Committee, the case study site provided in writing letters of acceptance of QUT’s clearance (see Case Study Site Correspondence in Appendix 3). The issues particular to research with vulnerable groups were of paramount importance and are discussed below. Secondly, the establishment of a relationship between the researcher and the case study site was an early research procedure in this study. The case study site has a history of encouraging social research relating to issues around death, dying and bereavement, and has accommodated a number of students undertaking postgraduate studies in past years. Indeed, in preparing for ethical clearance to conduct this study, a number of strategies to deidentify data sources were established to protect the confidentiality of respondents. For example, transcripts were coded rather than named, all references to individuals’ names were deleted, and as an organisation, the case study site requested anonymity to be maintained in the reporting of the research study (see Appendix 3). Moreover, it was appropriate to clarify with the organisation a number of logistical issues facilitating the conduct of this research.

3.4.2.1 Research with vulnerable groups

It is acknowledged that the palliative care patients and carers targeted in this study comprised a vulnerable group. However, the participation of palliative
care consumers in research was not automatically assumed to be unreasonably burdensome. Whilst it was acknowledged that complex and sensitive issues may arise that could represent risk to participants, the compelling argument for palliative care consumers’ inclusion in research suggests that it is desirable to place these risks within an “acceptable range” (Truog, 2003, p.3). This argument finds its basis in the origins of modern palliative care described in the previous chapter. Hospice pioneers changed the care of dying people by listening to the dying recipients of health care (Bradburn & Maher, 2005; Kübler-Ross, 1969). The exclusion of consumers by professionals from participation in shaping the form of palliative care services has been viewed by some as perpetuating the paternalism so reminiscent of the health care environment against which modern hospice movement rebelled (Barnett, 2001). Indeed, consumer participation has been linked to “ensuring quality in supportive care services” (Small, 2003, p.29). This increasingly consumerist approach is evident in cancer and HIV, both of which can lead to a transition into palliative care services; it cannot be assumed that [in] “…crossing a line between active treatment and palliative care, [patients] are not well enough to take an active part in user involvement” (Bradburn & Maher, 2005, p.92). Participation in research enables consumers of palliative care services to have a forum where their voice is heard – indeed, participation rates of 66% have been reported (Ross & Cornbleet, 2003). Some relevant examples include Stajduhar’s (2003) interviews of family carers at home, whilst Jarrett, Payne & Wiles (1999) investigated patients’ and carers’ perceptions of home services.
Specifically, there was a risk in this study that consumers may have incorrectly perceived an obligation to participate in questionnaires and in-depth interviews in order to maintain the provision of services by the organisation. However this was not anecdotally reported in the course of the data collection. Similarly, there was a risk that the process of reflection asked of them in completing the questionnaire, and in undertaking in-depth interviews, may have been the source of psychological distress to some participants. Bearing in mind that the questionnaires were sent a fortnight after admission and the interviews (where consent was granted by participants) followed a week or two after that, the subject matter of this study relating to service consumers represented no increased levels of risk for psychological distress than in their day-to-day living as palliative care consumers.

To minimise the risk of psychological distress to consumers through their participation in questionnaires or in-depth interviews, an information sheet was provided indicating the intended subject matter, voluntary participation, the right of each person to withdraw their participation at any time, and assurances that any information provided will be deidentified and kept confidential (the consent packages are provided in full in Appendix 4). Given the imperative to seek the participation of consumers of palliative care services in research, the need for skilled, sensitive engagement with consumers by researchers who are alert to problems of fatigue and distress was particularly pertinent (Wright & Flemons, 2002). In-depth interviews were conducted by the researcher whose experience as a palliative care nurse enabled him to be alert to issues for patients and their carers in the palliative care setting, such as negotiating an appropriate time for the
interview, pacing the interview around the participant’s energy, and being sensitive to the participant’s body language and other cues to suggest temporary or permanent cessation of the interview. On only one occasion was it necessary to temporarily suspend the interview recording at the request of the consumer participant.

Consumers who experienced psychological distress were offered, in the first instance, appropriate support by the researcher. Consumers were encouraged to contact the organisation’s counsellors, whose contact details were provided to all patients and their carers on admission to the palliative care service. However, to the researcher’s knowledge, these support services were not required by any consumer participants in this study.

3.4.2.2 Access

Permission was given in writing for the conduct of this study in this organisation by its Executive Director, on behalf of its Board of Directors (see Appendix 3). Whilst negotiations were primarily undertaken with the site’s Service Manager who was responsible for the development and implementation of health promoting palliative care, preparatory discussions included the Executive Director, the Director of Programs, and the Board of Directors, so that the project could proceed should the Service Manager have become unavailable for any length of time or even discontinued employment with the service. Prior to commencing fieldwork, the researcher addressed a meeting of the Board to describe further the details of the study to the Directors.

Further, to enter this site with transparency and minimal disruption to staff and services, two strategies were employed to introduce both the researcher and
the research project. Firstly, the researcher attended staff meetings throughout the period of data collection. Secondly, a public information sheet was made available to all staff (see Appendix 5). These strategies were employed to build rapport, provide clear information about the research study and give opportunities for questions to be addressed to the researcher. The researcher attended the site on average three days per week, usually for the duration of the normal working day of employees. From time to time, it was essential to be flexible, as opportunities arose to study organisational activities outside of these hours and to participate in other data collection strategies, such as focus groups.

3.4.2.3 Role description of researcher

Further to the discussion above of reflexivity, a role description was assigned to the researcher. Given the organisation’s familiarity with the presence of researchers on-site, the researcher’s role was referred to as a ‘PhD student’ and the information provided in the strategies described above informed staff and volunteers of specific activities undertaken in the course of the research project.

3.4.3 Data collection and initial analysis methods

Data collection was operationalised by method, in order to facilitate concurrent investigation of multiple subunits of analysis, each represented by the five key action areas of the Ottawa Charter. As noted previously, four data collection methods were planned – document review, questionnaires, in-depth interviews and focus groups. Each of these data collection methods is described in detail below and, as each data collection method required different data management processes to be applied at the time of their collection, these are
described here also. Data collection and management strategies are illustrated in the conceptual framework in Figure 3.1.

3.4.3.1 Review of organisational documentation

Document analysis is acknowledged as the source of rich data when researching organisations (Kayrooz & Trevitt, 2005). Documents should be understood not merely to mean written texts – rather, documents express their contents in multimodal forms, such as diagrams, photographs, organisational frameworks and electronic documents, wherein text is the primary – but not sole – method of communication (Prior, 2003). In this study, the main sources of documentary data were:

- **Printed data**: comprised of hard copy documents such as annual reports, strategic plans, organisational survey instruments, policy and procedure manuals, brochures and pamphlets, advertising leaflets and newsletters, and including non-textual data such as schematic diagrams and press photographs. These were stored electronically but were distinct from web-based data inasmuch as their primary form for use was paper-based.

- **Web-based data**: comprised of the website pages of the home hospice, the bookstore, and the call centre. These included downloadable, printable documents but were distinct from printed data inasmuch as their primary form for use was electronic and internet-based. Each website is described below and was open to the public domain at the time of commencement of data collection in August 2005.
The primary website was that of the case study site. At the time of data collection the site was comprised of 21 separate pages describing the organisation’s beginnings, vision/mission/values, broad services, recruitment information and links to other sites.

The second website of interest was that of a bookstore run on-site, a subsidiary company run by the case study site. At the time of data collection, it was comprised of twelve separate web pages, describing its purpose, purchasing processes and catalogues, most with rapid turnover of content as merchandise becomes available. A detailed explanation of the place of the bookstore in the work of the case study site is provided in Chapter 4.

Finally, the third website relevant to this study was that of an on-site call centre. As an information provider, the call centre website was comprised of eleven separate pages providing information about palliative care to the general public and health care professionals.

Visual data: were included where relevant elements of the case study site or participants’ perspectives were represented in photographs or artworks that were subsequently scanned electronically for inclusion in this paper-based dissertation. In a few instances, the path of inquiry was augmented by data from visual sources. In particular, the completeness of the description of the case study site was aided by the use of photographs of its key temporal elements. These are utilised in Chapter 4 and show the building and its grounds, and spiritual objects that illustrate the strong link between the philosophy of the organisation and its provision of palliative care services.
An orientation for the research to both the hard copy documents and the websites was provided by personnel from the case study site. A voluminous quantity of organisational documents was identified in the case study site as relevant to this study. Following an initial screening of their content, a total of 127 sources from these broad sources were identified as being of direct or indirect relevance to the research questions. A full synopsis of documentary data sources and their coding is attached as Appendix 6 and represents a strategy promoting methodological rigour.

- **Targeted subunits of analysis:** in this study, document review was employed to target all five subunits of analysis and inform the development of the case description.

- **Rationale/purpose:** over the data collection period, organisational documents were monitored to detect evidence of health promoting principles and practices, of those factors that advance or impede their integration, and of their impact as noted in the formal records of the organisation.

- **Data sources:** an examination of the site’s webpage initiated the process of document enquiry. Documents were identified through this examination and in discussion with its personnel. As anticipated, they included documents such as the Mission Statement, statement of objectives, policy/procedures, Annual Reports, Corporate and Strategic Plans, brochures and newsletters. Permission for access to specified documents out of the public domain was sought from the organisation’s Executive Director or her delegate and recorded in writing.
• **Time points**: as past and contemporary documents were relevant to this study, the review of organisational documentation took place throughout the data collection period.

• **Data collection strategies**: record of organisational documentation was kept on the *Document Summary Form* (see Appendix 7).

• **Data management strategies**: for data management and later analysis, data were coded and transferred to the *descriptive matrix* (see Table 3.6).

• **Data analysis approach**: thematic analysis of document content for key evidence of subunits of analysis and identification of emergent issues was undertaken. All documents were subject to critical reading to identify the data relevant to the case description, and organisational structures, processes and outcomes that indicated the site’s participation in the five key action areas of the *Ottawa Charter*. Potential or actual enablers and barriers to the implementation of health promotion principles and practices were identified.

• **Particular issues**: personnel files of staff and volunteers were not accessed in this study.

### 3.4.3.2 In-depth interviews

In-depth interviews are a popular research method commonly used in organisational research (Kayrooz & Trevitt, 2005; Minichiello, Aroni, Timewell, & Alexander, 1990). Their key function in this study, as with most social science research, was to “give access to knowledge…of meanings and interpretations that individuals give to their lives and events” (Minichiello et al., 1990, p.1). To achieve this, a semi-structured approached was taken which enabled interview
participants to disclose their interpretations of events directly relevant to the elements of health promotion that constituted the phenomena of interest.

- **Targeted subunits of analysis:** in this study, in-depth interviews were used to target all subunits of analysis by conducting interviews with three distinct groups: key informants, consumers, and staff/volunteers. Interviews for key informants targeted all subunits, whilst those for staff and consumers targeted the subunits of analysis of *developing personal skills* and *creating supportive environments*.

- **Rationale/purpose:**
  - **Key informants:** to detect actual evidence of, or plans for, health promoting palliative care in the SPO activities of the organisation.
  - **Consumers:** to explore in depth the experience of consumers in receiving palliative care support, the personal skills required for caregiving, and the role of the organisation in facilitating these.
  - **Staff/Volunteers:** to explore in depth the support of staff and volunteers in the workplace and the personal skills required for palliative care work. In each group, evidence was sought that demonstrated the impact of targeted health promotion components and identified the factors that advanced or impeded their integration.

- **Data sources:** the three groups of people were targeted for interview – purposive samples of senior personnel (as key informants), staff, and consumers (patients and caregivers) were obtained. Thirteen interviews were conducted with key informants; six interviews with seven consumers were
conducted (one interview was conducted with two carers of the same patient); eight general staff members and four volunteers were interviewed.

- **Time points:**
  - **Key informants:** key informants were identified and interviewed early in the data collection period to establish key issues and sources of other information. Further interviews of key informants were sought throughout the course of the data collection period; to augment early data and verify early findings, some key informants were reinterviewed.
  - **Consumers:** it was anticipated that staggered time points could allow for comparisons between consumers’ perceptions in each half of the data collection period to detect any changes as a result of the organisation’s implementation of the health promoting palliative care model. However, recruitment of consumers for interview was below expected numbers and interviews occurred across the entire data collection period.
  - **Staff/Volunteers:** these interviews were scheduled to optimise the subjects’ exposure to the organisation’s implementation of health promotion principles and practice. Researcher flexibility in scheduling interviews with staff and volunteers enabled optimal opportunities for data collection by this method, with some interviews conducted off-site and after normal working hours.

- **Data collection strategies:** to reflect this study’s conceptual boundaries, a semi-structured format was utilised in order to identify key issues and themes
relevant to the targeted subunits of analysis. Etic prompt questions were developed for each group according to the targeted units of analysis (see Appendix 8), but were refined as data from other methods were collected and informed the path of inquiry. In particular, the Carer Questionnaire provided a number of cues for patient and carer interviews.

- **Data management strategies:** the Contact Summary Form (attached as Appendix 9) provided a record of the interview schedule. These interviews were audiotaped and transcribed for coding, with key quotes and emergent themes recorded on the descriptive matrix.

- **Particular issues:** consumers were recruited through exposure to the carer questionnaire and via clinician input applying the exclusion criteria, then directly contacted by phone by the researcher to request their participation. If verbal consent was given, they were visited by the researcher at an arranged time convenient to them. Clinicians were not informed which consumers agreed to be interviewed. In conducting interviews, it is noted that the researcher is an experienced community palliative care nurse with previous experience in conducting research interviews. Other strategies employed to protect the vulnerability of the palliative care patient and caregiver populations in this research are detailed above.

### 3.4.3.3 Focus groups

Focus groups are an effective method of providing diverse insight into complex phenomena (Kayrooz & Trevitt, 2005), such as organisational change. For the purposes of this study, focus groups were defined as “…a semi-structured group session, moderated by a group leader, held in an informal setting, with the
purpose of collecting information on a designated topic” (Carey in Morse, 1994, p.226). The content validity of focus groups as a data collection method was strengthened by the consistent use of a single moderator for each group, known as equivalence, and their use in conjunction with other methods (Streubert Speziale & Carpenter, 2003). Whilst interviewing allows for in-depth exploration of individual perspectives, focus groups offer an opportunity for such perspectives to be challenged by other group participants and explored in greater depth; as such they can contribute to validity of data (Kayrooz & Trevitt, 2005).

There is a risk in focus groups of participants becoming distracted and drifting from the topic (Kayrooz & Trevitt, 2005) and a balance must be struck by the researcher to maintain a balance between preserving the boundaries around the case being discussed whilst allowing an inductive approach to be maintained. Similarly, it is the responsibility of the researcher to ensure that the focus group in not dominated by one or more participants, and that all members have an opportunity to participate; this was achieved in this study by the researcher asking for comment from each participant throughout the course of each focus group.

- **Targeted subunits of analysis:** in this study, focus groups were utilised specifically to target two subunits of analysis, those of developing personal skills and strengthening community action, and finally as a verification strategy where early findings were presented back to participants for their consideration at the end of the data collection period.

- **Rationale/purpose:** to determine staff and volunteers’ perceptions of the personal skills needed for palliative care work and the nature of the engagement of the organisation with the wider community. This method
investigated the collective experience of staff and volunteers of the integration of health promotion principles and practice in the organisation and asked them to identify the factors that advance or impede their integration.

- **Data sources:** at the time of commencement of data collection, the case study organisation employed 16 direct-care staff (registered nurses and counselors) and had approximately 40 family-support volunteers. The participation in focus groups of all direct-care staff and approximately 50% of volunteers was sought. A total of four focus groups were conducted – two groups of five clinicians each, and two groups of six volunteers. A fifth focus group was held at the conclusion of the data collection period as a verification strategy and comprised of 21 participants made up of key informants, staff and volunteers. These were divided into small groups of three or four, each addressing a component of health promotion.

- **Time points:** focus groups with clinical staff and volunteers were held at the beginning and conclusion of the data collection period. As with consumer interviews, these focus groups were scheduled to optimise the subjects’ exposure to the organisation’s implementation of health promotion principles and practice. Moreover, the groups were seen as an opportunity to recruit members of staff and volunteers for one-on-one interview and were scheduled to facilitate this.

- **Data collection strategies:** in this study, focus groups explored the interpersonal skills required by palliative care workers and volunteers and the nature of the organisation’s engagement with the wider community. The
groups explored possibilities in relation to the integration of health promotion principles and practice. This approach explicitly facilitated identification and exploration of the enablers and barriers. As was described for in-depth interviews, etic prompt questions and guidelines were developed for each focus group according to the targeted units of analysis (see Appendix 10).

- **Data management strategies:** Data were collected through use of a professional stenographer/court reporter with substantial experience in focus group transcribing. These data were refined for coding, with key quotes and emergent themes recorded on the *descriptive matrix.*

- **Particular issues:** participation in focus groups was voluntary and non-prejudicial to employment or tenure, with informed written consent obtained from each participant.

### 3.4.3.4 Questionnaires

The use of questionnaires in this study represents a supplementary method to the qualitative methods described above. Whilst questionnaires are amongst the most common data collection methods used in social sciences, their careful preparation and administration is essential to their rigour (Daly, Kellehear, & Gliksman, 1997; de Vaus, 2002). Their application in the measurement of consumer satisfaction with services has been examined and compared with other strategies (Aspinal et al., 2003; McGrath, 2001; Tasso et al., 2002) and, whilst demonstrating some limitations, are viewed as a valid and cost-effective data collection strategy (Lecouturier, Jacoby, Bradshaw, Lovel, & Eccles, 2003). In the selected instruments, issues of satisfaction have been addressed concurrently with perceived levels of social support (Sherbourne & Stewart, 1991) and are
viewed as key elements of the experiences of the consumers of supportive palliative care services (Burns, Dixon, Smith, & Craft, 2004; Lecouturier et al., 2003).

◦ **Targeted subunit of analysis:** in this study, questionnaires were used to target the subunit of analysis creating supportive environments.

◦ **Rationale/purpose:** to determine whether the case study organisation’s attempts to create supportive environments were verified by carers. This supplementary method (QUAL+quant) assisted in identifying the current impact of this core element of health promotion already evident in the activities of the case study organisation on its recipients. Moreover, it enabled identification of specific factors noted by respondents to be relevant to the provision of support in the home setting by the organisation, both in terms of the advancement or impediment of this health promoting component.

◦ **Data sources:** in consultation with the clinical staff, exclusion criteria were developed when screening carers for participation in the questionnaire. Carers of patients who had been admitted to the hospice service for at least a fortnight were excluded if they were under 18 years of age, where death of the patient was imminent (ie: within approximately four days), or where it was believed that the psychosocial dynamics in the family or setting of care were such that the arrival of a posted questionnaire could present a risk to the stability of the situation. A total of 106 questionnaires were posted over a nine month period; 25 were returned; of these, 24 were valid, with one excluded that had been completed by a patient rather than their carer. This
represents a response rate of 23%, which was sufficient to generate supplementary data in the form of descriptive statistics (Morse, 2003).

- **Time points:** taking into consideration the average number of carers of current clients in the case study organisation, it was anticipated that the data collection period would yield the targeted enrolment levels. Whilst this target was not achieved, sufficient data were collected to provide supplementary information.

- **Data collection strategies:** a validated instrument [FAMCARE] sensitive to the carers of those with life-limiting illness had been developed and tested by others (Kristjanson, 1993; Ringdal, Jørdhøy, & Kaasa, 2002). It was applied here in conjunction with a validated instrument *[MOS Social Support Inventory: MOS-SSI]* designed for the measurement of levels of, and satisfaction with, social support in the chronically ill (Sherbourne & Stewart, 1991). These instruments were chosen as they address elements of service provision that are relevant to the creation of supportive environments, such as the provision of support across emotional, tangible, affectionate and social interaction domains. They were slightly reworded to accommodate the carers within this study, and are contained in full in Appendix 11. As a brief, self-administered instrument, this questionnaire was posted to all new carers two weeks following client admission for completion, containing a reply-paid envelope for return of completed surveys. If consent to conduct a follow-up interview was given by a respondent, contact to arrange this followed promptly.
Data analysis strategies: these data were scored to establish mean scores and standard deviations within subscales and for total scores. These findings were added to the descriptive matrix.

Particular issues: return of completed surveys was considered to constitute implied consent to participate in data collection by these questionnaires. The administration of these instruments to carers also provided an opportunity to recruit participants for in-depth interviews with minimal disruption of patients and their caregivers. It is suggested that, whilst questionnaires are commonly used in health care research, interviews are a strategy for obtaining “more in-depth information and exploration of factors that influence [patient] satisfaction” (Tasso et al., 2002, p.5), therefore interviews were conducted to augment the findings of the questionnaire.

3.4.4 Data sources

Data relevant to each subunit of analysis were identified from these four sources. As anticipated, particular data collection methods enabled targeting of discrete health promotion components, however, there were areas of considerable overlap and data relevant to each component were drawn from multiple sources. These are summarised in Table 3.5 below.

3.4.5 Mixed method data analysis

As the collection of data by multiple methods and initial data management occurred, mixed method data analysis strategies were applied, which have been previously illustrated in the conceptual framework in Figure 3.1. As discussed, the analytical goals in this study were completeness and confirmation. The
analysis was highly focused on describing and interpreting the particular phenomena of interest with full acknowledgement of the context in which they had taken place.

The use of multiple sources of data necessitated the application of the multifaceted process of analysis illustrated in the conceptual framework, wherein the data analysis methods demonstrated paradigmatic congruence with each of the data collection methods. To efficiently manage the analysis of voluminous raw data, and to enable the transition from the initial analysis to the mixed method analysis, this study applied three analytical phases, described as data reduction, data display, and drawing/verifying conclusions (Miles & Huberman, 1994). Whilst described here in phases, the analytical process was not sequential, as overlap between these phases is commonplace in studies of this nature and occurred in the course of this study.
### Table 3.5: Subunits of Analysis – Actual Data Sources

<table>
<thead>
<tr>
<th>Key Action Areas</th>
<th>Documentary Data Sources</th>
<th>In-Depth Interviews</th>
<th>Questionnaires</th>
<th>Focus Groups</th>
<th>Verification Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total retrieved: 127</td>
<td>Key Informants: n=13</td>
<td>24 returned valid</td>
<td>Staff: x2 each with n=5</td>
<td>n=21 comprising key informants, staff and volunteers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Staff: n=8</td>
<td></td>
<td>Volunteers: x2 each with n=6</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Volunteers: n=4</td>
<td></td>
<td>Consumers: n=7</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Building public policy</td>
<td>16</td>
<td>Ki: n=4</td>
<td>0</td>
<td>S: x2</td>
<td>n=4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>S: n=3</td>
<td></td>
<td>V: x2</td>
<td></td>
</tr>
<tr>
<td>Creating supportive environments for staff and volunteers</td>
<td>14</td>
<td>Ki: n=7</td>
<td>0</td>
<td>S: x1</td>
<td>n=4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>S: n=7</td>
<td></td>
<td>V: x2</td>
<td></td>
</tr>
<tr>
<td>Creating supportive environments for consumers</td>
<td>56</td>
<td>C: n=8</td>
<td>24</td>
<td>V: x1</td>
<td>n=3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ki: n=4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>S: n=4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>V: n=2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strengthening community action</td>
<td>82</td>
<td>Ki: n=10</td>
<td>0</td>
<td>S: x2</td>
<td>n=4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>S: n=4</td>
<td></td>
<td>V: x1</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>V: n=2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing personal skills</td>
<td>49</td>
<td>Ki: n=7</td>
<td>0</td>
<td>S: x1</td>
<td>n=4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>S: n=8</td>
<td></td>
<td>V: x2</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>V: n=4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reorienting health services</td>
<td>85</td>
<td>Ki: n=11</td>
<td>0</td>
<td>S: x2</td>
<td>N=3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>S: n=2</td>
<td></td>
<td>V: x2</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>V: n=3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.4.5.1 **Data reduction and display**

As noted above, data were initially analysed in ways consistent with the underlying methodologies. Having been collected from multiple sources, specific strategies for data reduction included thematic analysis of transcribed data and organisational documents, and statistical analysis of questionnaires. All data were coded\(^2\) and then conceptually grouped for ongoing reference utilising descriptive matrices, to assist their later use in data display and conclusion-drawing and verification. In anticipation of the use of descriptive matrices in the data display phase, these data were managed mindful that the subunits of analysis correspond to the key action areas of the **Ottawa Charter**. In the first instance, the four data collection methods had appropriate analytical methods aligned:

- **Thematic analysis of organisational documentation:** given the highly contextual nature of organisational documents (Miller, 1997), documentary evidence was methodologically important to this case study research and can be analysed using both qualitative and quantitative methodologies (Dew, 2005). Due to the underdeveloped theoretical base of health promoting palliative care, an inductive approach was used in this study, where documents were read and reread for evidence of both convergence and divergence.\(^2\)

---

\(^2\) Data sources were coded thus:
- First letter indicates method – ie: I=interview, F=focus group, D=documentation
- Documents have second letter denoting their type – ie: P=printed data (hardcopy/paper or electronically stored), V=visual data, W=web-based data
- Two digit number indicates numerical order of activity by subcategory. eg: **01**
- Next letter indicates category of I or F source: K=key informant, S=staff, V=volunteer, P=patient, C=carer.
- Digits following colon denote page of data in text or lines in transcript where direct quotation of raw data occurs. eg: :**15-17**
- Eg: **I03C:12-20** denotes that the third interview undertaken was with a carer and lines 12-20 of the transcript are directly quoted.
divergence with the foreshadowed issues, and emergent themes were identified. Key portions of evidence were recorded on the descriptive matrix, which is described in detail in below. Hodder (2003) proposed that confirmation of findings from documentary data occurs when there is internal consistency of elements within the document and external consistency with the foreshadowed issues. Initial critical reading of the organisational documents was undertaken to identify the organisational structures, processes and outcomes recorded that indicate the site’s participation in the five key action areas of the Ottawa Charter and to identify potential or actual enablers and barriers to the implementation of health promotion principles and practices.

- **Thematic analysis of in-depth interviews and focus groups:** thematic analysis used in this case study research demonstrated the underlying intersubjectivist epistemology in its attempt to capture the lived experience of participants in the context under examination. The initial analyses of interview and focus group data were undertaken following their transcription in a first reading of the transcript. This reading was done with consideration of the phenomenon of interest and its elements but was inductive in nature as the foreshadowed issues did not represent a formed theory and were utilised subsequently in further analysis. A written summary of each transcript was completed; an example is shown in Appendix 1. Data segments were coded, transferred from the transcript document and inserted into the descriptive matrix in which other data relevant to specific categories were placed. Other
data informing the research question but not assigned to specific categories within the matrix were recorded separately for later consideration.

- **Statistical analysis of questionnaires:** descriptive statistics grouped within questionnaire sections were generated to determine the sources and extent of support and levels of satisfaction with service provision elements. These quantifications were interpreted according to the scoring hierarchy and added to the descriptive matrix.

Effective data display facilitates “careful comparisons, detection of differences, noting of patterns and themes, seeing trends and so on” (Miles & Huberman, 1994, p.92). A descriptive matrix is a flexible format for the simultaneous display of data from multiple sources. In this study, a descriptive matrix was formed for each subunit of analysis, initially with the elements of the vertical axis displaying structure-process-outcome components and the elements of the horizontal axis displaying columns for data indicative of factors, enablers and barriers. The descriptive matrix framework is illustrated in Table 3.6, and coded data were inserted in the matrix grid to illustrate and verify the theoretical relationship between axial elements. A sample of the descriptive matrix with data inserted is provided as Appendix 12.

This first level of interpretation facilitated the development of a case description (Yin, 2003). The case description presents data that contextualise the integration of health promotion principles and practice in the palliative care organisation, assisting in identifying enablers and barriers to their integration. It is presented as Chapter 4. Further, this initial analysis enabled a transition to interpretation of greater depth, by enabling an examination of congruence with the
theoretical propositions derived from the literature review and through consideration of convergent data.

**Table 3.6: Descriptive Matrix Grid**

<table>
<thead>
<tr>
<th>SUBUNIT OF ANALYSIS: [EG: DEVELOPING PUBLIC POLICY]</th>
<th>FACTORS</th>
<th>ENABLERS</th>
<th>BARRIERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structures</td>
<td>Insert data</td>
<td>Insert data</td>
<td>Insert data</td>
</tr>
<tr>
<td>Processes</td>
<td>Insert data</td>
<td>Insert data</td>
<td>Insert data</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Insert data</td>
<td>Insert data</td>
<td>Insert data</td>
</tr>
</tbody>
</table>

**3.4.5.2 Drawing and verifying conclusions**

An *interpretive matrix* is a mechanism that moves descriptive data towards conclusion-drawing by allowing the data to be considered with reference to an analytical framework (Miles & Huberman, 1994). In this study, the interpretive matrix was developed to consider the data to determine the qualitative impact of health promotion principles and practice upon the organisation. Analytic text accompanied the matrices to elaborate upon the key issues recorded, noting patterns and themes, and overlapping with the third phase of analysis. The interpretive matrix is illustrated in Table 3.7 below.
The interpretive matrix was developed as the data collection proceeded to enable the further identification of patterns/themes, and the identification of data that are conceptually consistent with (convergent) or contradictory to (divergent) the foreshadowed issues. To interpret these data with reference to the study aims and objectives, an examination of congruence with the theoretical propositions and consideration of rival explanations underpinned the analytical process (Yin, 2003) and moved the data beyond mere description of the case, to meaningful analysis.

**Table 3.7: Interpretive Matrix Grid**

<table>
<thead>
<tr>
<th>Building public policy</th>
<th>THEME #1</th>
<th>THEME #2</th>
<th>(etc)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creating supportive environments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strengthening community action</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing personal skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reorienting health services</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
and verifiable conclusions regarding the research questions. The operational steps corresponded with these components and applied in this phase to facilitate the drawing of conclusions were noting patterns and themes (pattern matching) and making contrasts and comparisons (rival explanations) (Miles & Huberman, 1994). These processes permitted consideration of convergence and divergence in the data.

In this study, two strategies promoted validity and assisted in the completeness of findings. Firstly, these conclusion-drawing processes were recorded on a record of analysis form (see Appendix 13) to promote validity of findings and to contribute to the audit trail. Secondly, the conclusions drawn through this analysis were presented to purposive sample of participants representing, wherever possible, the participants in data collection, the ‘players’ in the context, in a focus group forum. These conclusions were offered for verification and modification where required to establish completeness of findings.

### 3.5 Chapter Summary

This chapter has provided a detailed description of the research methodology, design and methods selected to address the research questions. These strategies includes discussion of the theoretical drive for the research methodology, description of the mixed-method case study design, including selected data collection and analysis procedures, and the strategies employed to establish and maintain the rigour of the research. The following chapters present the data collected and analysed utilising these methodological features.
CHAPTER 4:

CASE DESCRIPTION

4.1 Introduction

In keeping with the methodology described in the previous chapter, this chapter contains contextual information about the case study site, known as the case description. Generation of this description was an early strategy in the conduct of this research in order to contextualise the nature of, and boundaries around, the case (Streubert Speziale & Carpenter, 2003). As its name suggests, this case description primarily contains descriptive data, with some evaluative statements, and sets the scene for the presentation of data analysis in the chapters that follow.

Data were primarily obtained via the case study site’s webpage and organisational documentation, although data from a number of in-depth interviews and focus groups augment this description. Data sources were individually coded. A coded list of documents (including web-based and visual data) is attached as Appendix 6. A checklist based upon Donabedian’s (2003) SPO framework with elements of health promotion was modified and utilised in this study, wherein a general outline was followed by specific factual information about organisational elements (Koch & Kralik, 2001). This checklist has been discussed previously in this dissertation and is recorded in Table 4.1.

1 At their request, the case study site and their programs are not identified by name in this dissertation (see Appendix 3). Instead, the terms “the case study site” or “the organisation” or “the hospice” are used variably throughout. Identifying data elsewhere, such as websites or letterheads, have been blacked out.
### Table 4.1: Organisational Checklist for Generation of Case Description

<table>
<thead>
<tr>
<th>Outline of a community organisation/service/program</th>
<th>Structures</th>
<th>Processes</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ Physical location</td>
<td>◦ Organisational structures</td>
<td>◦ Communication lines</td>
<td>◦ Professional measurable outcomes</td>
</tr>
<tr>
<td>◦ Purpose</td>
<td>◦ Organisational governance</td>
<td>◦ Client-centred service</td>
<td>◦ Client-directed measurable outcomes</td>
</tr>
<tr>
<td>◦ Philosophy</td>
<td>◦ Policies and Procedures</td>
<td>◦ Consumer participation</td>
<td>◦ Community action</td>
</tr>
<tr>
<td>◦ Mission, vision, values</td>
<td>◦ Committees</td>
<td></td>
<td></td>
</tr>
<tr>
<td>◦ Client populations</td>
<td>◦ Legislative governance (the Act and rules by which an organisation is managed)</td>
<td>◦ Quality improvement</td>
<td>◦ Client/consumer group satisfaction</td>
</tr>
<tr>
<td></td>
<td>◦ Strategic and operational plans</td>
<td>◦ Research utilisation</td>
<td>◦ Service/program evaluation</td>
</tr>
<tr>
<td></td>
<td>◦ Funding</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(From Koch & Kralik, 2001, p.47)

### 4.2 Outline of Case Study Site

The case study site in this research study is a palliative care service provider based on Buddhist principles of compassion and the relief of human suffering. This organisation has provided specialist palliative care to people in their homes (ie ‘home hospice’) since 1992. More recently, it began a process of incremental integration of health promoting principles and practices primarily following the influence of the writings of Kellehear and his colleagues (1999a; 1999b; 2003).

The real-life context of the case study site is dynamic and complex, intersubjectively interacting with time, place, its players and the perspectives of the researcher. Therefore, whilst these case description data were current at the time of collection and are reported in the present tense, it is acknowledged that continuous organisational change at the case study site may have resulted in some
factual information being superseded between data collection and submission of this thesis.

4.2.1 Physical location

The headquarters of the case study site are housed in a heritage-listed building dating back to the 1880s. Its premises have functioned over the course of its history as a private residence and a military hospital (DP57:1) and are located close to the central business district on land owned by the state health department. Whilst the building had been derelict for much of the past 20 years, the state health department offered the hospice a 30-year peppercorn lease in exchange for the building’s restoration through funds raised by the case study organisation. This restoration was completed in December 2004 and the building was occupied from January, 2005.

Photographic data of the premises are shown in Figure 4.1. Prior to its relocation, the case study organisation was housed in bungalow accommodation on the same site. This physical relocation elicited a strong sense of place and belonging amongst staff and volunteers, and is specifically addressed in the reporting of the health promotion component of creating supportive environments in Chapter 5.
4.2.2 Purpose

The organisational purpose of the case study site is able to be easily identified, being clearly stated in a number of organisational documents and on their website:

[This organisation’s] goal is to provide comfort and quality of life for people who are dying and their families, and relieve fear and suffering associated with loss. [It] exists to relieve the physical, emotional and spiritual suffering many people experience as they face death and to help them to die in peace and with dignity. (DW02:1)

The explicit use of the words ‘dying’ and ‘death’ in this statement is a deliberate action by the hospice in response to the perceived fear of death in general society discussed in the literature review (Ariès, 1976; Kübler-Ross, 1969) and the disagreement experienced amongst health care professionals – including some palliative care practitioners – regarding the use of language to describe the work of palliative care (Clark & Seymour, 1999). The case study site’s official position, stated in the website and reiterated in interview with a key informant who participated in the development of the hospice’s philosophy, is that this...
confusion is symptomatic of a death-denying society and the deliberate use of these words represents a calculated strategy in their attempts to counter it (I10K).

### 4.2.3 Philosophy

The link between Buddhist philosophy and the provision of palliative care as an act of compassion is a prevalent feature of the hospice’s integration of health promoting palliative care and is discussed throughout this chapter. With strong Judeo-Christian origins, the exercise of compassion in care of the dying has been ranked as an important moral notion amongst European palliative care workers (Janssens et al., 2002). In a similar fashion, the philosophy of the organisation is clearly identified in its documentation and on its website as being based on a Buddhist philosophy of love and compassion (DW04:1). The provision of home based palliative care services by the case study site is underpinned by the Buddhist beliefs of impermanence and compassion, and is an activity of the international Buddhist organisation titled the *Foundation for the Preservation of the Mahayana Tradition* [FPMT]. Under the spiritual direction of Tibetan Buddhist teacher Lama Zopa Rinpoche, the hospice was established to “help remove the physical, emotional and spiritual suffering people experience as they face death” (DW03:1).

This connection is represented in Buddhist iconography by the figure of *Avalokiteshvara* or the *Chenrezig Buddha* (see Figure 4.2), who embodies the “thousand hands of compassion” (DV03:1) required to ease the suffering in the world, particularly, in the case of hospice palliative care services, the suffering experienced in dying. This philosophical basis for the socially-active nature of Buddhist practice is known as a ‘embedded Buddhism’ and the hospice’s
activities have been specifically addressed in a number of contemporary commentaries about Buddhism in Australia (Bucknell, 2000; McGrath, 1998; Sherwood, 2003). Web links to Buddhist perspectives on death and dying on the website of the FPMT are available on the organisation’s website, further detailing Buddhist philosophical foundations (DW17:1-2).

During the data collection period, Lama Zopa Rinpoche toured Australia and visited the case study site, providing teachings to the staff, volunteers, supporters, and patients and their families of the organisation on the value of the preparation for death and the work of the hospice in this process. On 17 June 2006, Rinpoche also consecrated the newly-erected stupa (Figure 4.3) in the grounds of the hospice’s headquarters; a stupa is “a symbolic representation of the enlightened mind and of the path leading to that state of perfection” (DP45:1). The researcher attended this ceremony as an observer, as it was
an open function that non-Buddhists were welcome to attend. It was observed that this event was attended by many members of the wider community who would not necessarily have had any direct contact as service recipients with the hospice. As such, it was viewed by one key informant as a strategy in strengthening community action towards the support of people at the end of life (I10K). Moreover, the presence of the stupa in the grounds of the hospice is considered by Buddhists to be of tremendous spiritual benefit to the organisation’s work and is regarded as a “very precious and holy object” (DP45:2). Such is its significance in Australian Buddhism that His Holiness, the 14\textsuperscript{th} Dalai Lama Tenzin Gyatso will include a private visit to the hospice during his visit to Australia in July, 2007.

4.2.4 Mission/vision/values

In response to the death-fearing society described above, the vision statement of the case study site includes an intentional acknowledgment of its health promoting agenda; notably, this passage demonstrates a link between their broader, community-focused goal and the provision of services to dying people:

\[
\text{...the creation of a healthy community attitude in relation to death and dying and its mission is to promote hospice philosophy and provide hospice services to the members of our community who are affected by death and dying. (DW04:1)}
\]

Its values are similarly spelled out as being “preciousness of life, respect for the individual, compassionate service, empowerment and universal responsibility” (DW04:1). These values are expressed in slightly different language in the strategic plan, where the values of the hospice are listed as:
Chapter 4: Case Description

- The preciousness of life
- The contribution and worth of the individual
- Compassionate service
- Empowerment of the individual and community, and
- Shared responsibility for each other’s wellbeing.

(DP04:1)

Despite significant changes in organisational language and amendments to the operationalisation of its strategic direction, the intent of these original values has remained unchanged since the organisation’s inception (I22K). These stated values are conceptually compatible with the core values of palliative care put forward in the Standards for Providing Quality Palliative Care for All Australians (Palliative Care Australia, 2005a) and noted in Figure 3.1. Interestingly, they demonstrate congruence between the case study site’s Buddhist philosophy and the values held by the wider palliative care profession which, as mentioned above, have Judeo-Christian origins.

4.2.5 Client populations

In the 2001 national census, the catchment area of the case study site showed an average demographic profile for age, gender, ethnicity and dwelling status in the general population, with 19% aged 55 years or over, 51.1% female, 21% born overseas, 1.7% indigenous and 70% in ‘family households’. Significantly for home based palliative care and its reliance upon family caregivers, 22% of the population resided in ‘lone person households’ (Commonwealth of Australia, 2001). In numerical terms, in the financial year 2003-2004 the organisation made 454 admissions to its home hospice program, with a further 656 families receiving bereavement support (DP34). Clients can
self-refer, or be referred by a member of their family, the on-site call centre, or a
health care professional such as their general medical practitioner [GP]. Where
the referrer is not the client’s GP, the hospice’s practice is to contact the GP as a
courtesy, prior to assessment of the client. The amount of time spent with clients
was not reported.

Further to the explicit use of the words ‘death’ and ‘dying’ noted above,
there is some variance in the nomenclature used to describe the clientele of
palliative care services, including the case study site. It deliberately describes its
service as being for “those who are dying” (DW01:1). The use of these terms is a
contested practice within the palliative care profession. By contrast, peak bodies
such as Palliative Care Australia [PCA] use terms such as those with ‘life-limiting
illness’ (Palliative Care Australia, 2005a), whilst others, such as authors of
palliative care textbooks, have used descriptors such as “patients with incurable,
life-threatening diseases” (Doyle & Jeffrey, 2000, p.1). Notably, however, the
hospice’s Information Booklet for patients and their families defers to a
contemporary definition, referring to palliative care as being provided for
“patients whose disease is not responsive to curative treatment” (DP44:2), whilst
referring elsewhere to “the terminally ill” (DW02:2). This varied use of language
in the case study site reflects a debated and unresolved issue which may have an
impact upon public perceptions of the organisation’s potential for involvement,
and is discussed further below.

In a manner consistent with the wider view in palliative care that the
families (however defined) of patients are also the recipients of care, the hospice
repeatedly refers to the “family as client” and its supportive role with the families and carers of its patients (DW01:1; DW02:1-2; DW03:1).

4.2.6 Legislative governance

Like all health care providers in the Australian state of Queensland, the case study site is subject to governance by state legislation. Key legislation is listed in Table 4.2; each of these pieces of legislation is found on the Queensland government website at [http://www.legislation.qld.gov.au/OQPChome.htm](http://www.legislation.qld.gov.au/OQPChome.htm) and is available in the public domain. The legislation governs numerous issues regarding the regulation of palliative care services, including the governance and operation of private and non-government health care organisations, professional standards of health care practitioners including nurses, the use of scheduled medications, and the role of the State Coroner. There is some reference made to this legislation in the hospice’s Policy and Procedure manuals (DP1-32) although the links are not explicitly made in every case.

Notably, in a social model of health, legislative governance is not constrained to health policy, as has been demonstrated widely in the generic health promotion literature (Talbot & Verrinder, 2005). The presence of health promoting policies applied to the end of life would be evident where the integration of health promoting palliative care had been successful. Whilst the health promoting palliative care has reached some Australian state governments’ broader policy agenda, this is not so in Queensland and this legislation shows no evidence of the application of health promotion in the provision of palliative care services. For example, in the Australian state of Victoria, *Strengthening palliative care: a policy for health and community care providers 2004-09* (Laverick, 2004)
is a key policy document of the state health department that includes references to enhancing the health of palliative care consumers, the role of the community in the support of people with life-threatening illnesses, and the development of clear directions for public policy relating to issues of death, dying and loss.

**TABLE 4.2: KEY GOVERNING LEGISLATION OF PALLIATIVE CARE SERVICES IN QLD**

<table>
<thead>
<tr>
<th>Health Act 1937</th>
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<tbody>
<tr>
<td>Health Regulation 1996</td>
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<tr>
<td>Health (Drugs and Poisons) Regulation 1996</td>
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<td>Health Practitioners (Professional Standards) Act 1999</td>
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<td>Health Services Regulation 2002</td>
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<td>Nursing Act 1992</td>
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<td>Nursing By-law 1993</td>
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<td>Coroners Act 2003</td>
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<td>Coroners Regulation 2003</td>
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<tr>
<td>Private Health Facilities Act 1999</td>
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<td>Private Health Facilities (Standards) Notice 2000</td>
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<td>Private Health Facilities Regulation 2000</td>
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**4.2.7 Strategic and operational plans**

The strategic plan of the case study site is subject to review on an annual basis by a leadership group, in collaboration with the Board of Directors (described below) and was reported against during the data collection period. It identifies crucial issues and associated goals for the organisation which both explicitly and implicitly demonstrate consideration of health promotion principles (DP36). However, it also demonstrates some of the features of an operational plan, such as specific operational actions, their timeframes and the persons responsible, rather than broad statements of strategic goals. It was reported by
one member of the leadership group that this lack of clarity in the naming of these key documents appeared to cause some confusion amongst others in the leadership group regarding the documents’ function (I20K). For example, the respondent reported that ongoing changes to strategic goals were necessary when operational issues were constantly re-evaluated, despite establishing the strategic goals for a specified period of time.

Nevertheless, the strategic plan specifically identifies three health promotion elements as major strategic goals and further demonstrates evidence of health promotion principles in its mention of prevention of harm:

**Goal 3b:** To prevent and alleviate harm associated with dying and related loss through building supportive communities, strengthening community action and developing personal skills in line with Health Promoting Palliative Care principals [sic]. (DP36:4)

Moreover, the participation of the hospice in the building of public policy is also identified by respondents as a strategic goal, and the plan allocates time frames, persons responsible, and concrete strategies to achieve these goals (DP36).

### 4.2.8 Funding

Like a number of its counterparts in the state, the hospice provides its service through funds provided by the Commonwealth Government’s Department of Health and Ageing, [DoHA] which are, in turn, administered by Queensland Health. In what is viewed as an important strategy in *creating supportive environments*, the hospice provides home based palliative care without charge to its users. As a registered charity, the organisation describes its funding sources on its website home page in its call for donations:
[The hospice] does not charge clients a fee for providing our home based palliative care. The considerable monetary costs involved are met from government funding augmented by many private donations and bequests from generous people like you. (DW01:1)

The organisation’s website publicly asserts that the average cost for supporting each client and their family averages out at $4000 and that government funds only cover half this amount (DW02). Consequently, it places a strong emphasis in its web-based and printed documentation upon individual donations and corporate sponsorship.

4.3 Structures of Case Study Site

4.3.1 Organisational structures

On its website, the hospice indicates that, in keeping with its philosophy and values described above, it provides:

- Hospice-at-home program focusing on holistic client-centred care
- Community and professional education programs on end of life issues
- Community participation
- Hospital/general practitioner/community services collaboration. (DW04:1)

However, a distinguishing feature of the case study site is the fluidity of its structural configuration and the roles within it. During the period of data collection for this study, the configuration of organisational structures, and the communication lines that accompany them were amended several times. Consequently, whilst the organisational chart shown in Figure 4.4 below was current at the time of the conclusion of data collection, an earlier organisational
Figure 4.4: Organisational Chart

The organisational chart is shown in Appendix 14 which contains many of the same elements as Figure 4.4 but in a different configuration. Moreover, the chart shown in Figure 4.4 is expected to evolve further upon conclusion of this study. The organisational chart also illustrates the structural link between the FPMT and the case study site. This link serves as a means of preserving the Mahayana Buddhist tradition, sustaining its philosophy and providing spiritual – moreso than temporal – guidance in FPMT organisations, including the hospice (I10K).
4.3.2 Organisational governance

The case study site is governed by a Board of Directors that is linked with the work of the organisation through the Executive Director. At the time of data collection, the Board was comprised of nine individuals drawn from the business, academic and legal professions; office bearers include the Chairperson, Deputy Chairperson and Honorary Treasurer, with the remaining six members named as directors (DP34). Membership of the Board of Directors is for an unspecified term. The Board takes responsibility for consideration of the strategic direction of the organisation and has been provided with detailed information about the health promoting palliative care approach (DP34).

4.3.3 Policies and procedures

Policy and procedure manuals are easily accessible to all members of staff including volunteers, in both printed and electronic formats. Each manual is divided into five subsections based upon the assessment framework of the Australian Council on Healthcare Standards [ACHS] (Australian Council on Healthcare Standards, 2006). The policy manual (DP01-15) is concerned with the following issues with direct relevance to the key elements of health promoting palliative care:

- **Continuity of Care**: clinical issues such as admission, care planning and discharge, medication management.

- **Human Resource Management**: code of conduct, recruitment, orientation, professional development, performance appraisal, grievance mechanisms, leave of absence, dismissal.
Chapter 4: Case Description

- **Information Management**: documentation, email use, record keeping.
- **Leadership and Management**: policy development, rights and responsibilities, euthanasia, complaints, external presentations, privacy.
- **Safe Practice and Environment**: workplace health and safety, workplace rehabilitation, waste management.

In the same way, the procedure manual (DP:16-32) is divided into the same five subsections, and includes the issues listed below that also have direct relevance to the key elements of health promoting palliative care:

- **Continuity of Care**: access to and entry into the hospice’s programs, admission into inpatient facilities, liaison with the Department of Veteran Affairs [DVA], management of client equipment, review of client outcomes, provision and use of on-call service, and clinical procedures.
- **Human Resource Management**: implementing disciplinary action, compliance with the code of conduct, rostering, staff satisfaction.
- **Information Management**: management of computer records, management of hard copy records, reporting of quality activities.
- **Leadership and Management**: obtaining informed consent for treatment, use of financial systems, providing external presentations.
- **Safe Practice and Environment**: maintaining after-hours safety; fire and evacuation procedures, manual handling.

A schedule for review and renewal of policies and procedures is included in these documents.
4.3.4 Committees

There is a fluid and somewhat informal committee structure within the case study site. The leadership group make up a key committee, comprising the Executive Director and the five managers – the home hospice service (ie: the clinical services), an on-site call centre, the death education program, business programs and administration. In such a small organisation, this group is responsible for most of the decision making and other activities often allocated to separate committees in larger organisations such as strategic planning, operational planning, and outcome evaluation (I13K). From time to time, a number of standing committees have been formed to deal with specific issues, such as policy and procedure reviews, although none were operating during the data collection period of this study (I13K).

Notably, on an informal level, a core group of senior personnel, which include some members of the leadership team but not others, was reported by other staff and volunteer respondents to meet and influence strategic decisions (I09K; I29V) although its placement within the organisational structure is not clear. Concerns were raised by some respondents about the activities of this informal group in light of their influence upon the organisation, and this is discussed in detail in the following chapter.

4.3.5 Programs

The organisational chart shown in Figure 4.4 shows five program streams within the case study site. These are:
4.3.5.1 The home hospice service

This is the central activity of the case study site, its original service and, in the view of many respondents, its core business. The home hospice service notes that its “specialist palliative care team provides a free at-home service” (DW06:1). This description includes references to home care as the setting of care, pain and symptom management, the 24 hour on-call services, liaison with general medical practitioners and other health services, counselling and spiritual care, family support by trained volunteers, the loan of home nursing equipment and a bereavement support program. The provision of interdisciplinary palliative care to persons with life-limiting illnesses, their families and carers, comprises eight full-time equivalent specialist palliative care nursing positions, three full-time equivalent counsellors, two spiritual care personnel (usually Buddhist nuns), and approximately 65 family support volunteers (DW02:2). Notably, whilst the team does not include a medical officer, the home hospice service undertakes to establish and maintain working partnerships with existing GPs and medical specialists of those referred to their care (DW06:1). The provision of care prior to death includes nursing, counselling, spiritual care, volunteers and respite care, and the bereavement support provided after death including counselling and spiritual care (DP44).

The integration of health promoting palliative care has sparked a debate within the case study site, which is evident in the data of this study, regarding the identity of the core business of the organisation. This question emerged as a key theme in this study and is discussed at length later in this dissertation.
4.3.5.2  **The call centre**  
An on-site call centre is a Queensland Health funded program run by the case study site (DW34). Its aim is:

…to improve quality of life for people who have a terminal illness and provide links to carer support. [It] is operated by counsellors and registered nurses who provide information and links for regional and remote areas of Queensland, as well as metropolitan areas. (DW35:1)

The call centre provides information for both the wider community and the professions involved in the provision of palliative care (DW34). In the financial year 2005-2006, the call centre received over 1500 calls, with just over 600 of these from family members of palliative care patients seeking home based palliative care services (DP76). This represents an increase of 50% in the total number of calls to PCIS from the previous financial year (DP34).

In addition to its telephone service, the call centre website contains links to disease-specific websites, including Queensland AIDS Council, the National Heart Foundation, and Lifeline (DW43:2). It also provides resource materials in PDF format for carers and health professionals (DW41) that are shown in summary form in Appendix 15 and demonstrate information for the general public, consumers, carers, bereaved persons and health care professionals.

4.3.5.3  **The death education program**  
During the data collection period, the case study site developed and began marketing public education programs that address issues regarding life and death, living and dying (DW02:2). Details of its death education program are distributed amongst community and corporate groups with current program schedules
Chapter 4: Case Description

(DP52). These programs are provided in a fee-for-service fashion. Its goals are directed at potential participants, and aim to assist them to:

- Become better equipped to deal with everyday stresses and important issues in your life, teaching you how to work with them.
- Gain insights into the effects your thoughts have on your general happiness, wellbeing and your interactions with others.
- Apply self awareness in transforming your thoughts using guided visualisation, breathing techniques and different forms of meditation.
- Establish a daily meditation practice.
- Strengthen your personal capacity to manage physical and/or emotional pain.
- Develop a greater capacity for happiness and love, for self and others. (DP52:1)

Further, the organisation indicates that “emotional and spiritual support and information related to loss is available to the wider community” (DW02:2). The provision of such services beyond the recipients of the hospice’s clinical services and their families is viewed by its personnel as demonstrating their goal to create “a healthy community attitude in relation to death and dying” noted in their vision statement earlier (DW04:1). This overlaps with its activities promoting community participation noted above, and includes ‘closure ceremonies’ such as funerals and memorial services, and personal development programs that have the stated aim of “empowering people to find meaning in their experiences of life’s transitions” (DW02:2).

4.3.5.4 Administration

The presence of infrastructure support is regarded as an integral part of any organisation. However, in a health promoting palliative care organisation,
such support is considered as a strategy for the integration of the health promotion component of creating supportive environments for staff (Kellehear, 1999b). This is provided by the case study site for quality management, information services, and human resources, as illustrated in Figure 4.4.

4.3.5.5 Business management

Further infrastructure support for the business management of the organisation is provided, with finance, promotion, fundraising, and office-based volunteer services (see Figure 4.4). The organisational chart also indicates the presence of a bookstore, which “distributes and specialises in books on Buddhism, meditation, the Tibetan language, as well as travel and culture within Tibet” (DW22:1). The case study site took over the running of the bookstore in early 2005 and is a major distributor in its field in Australasia (I08K). Whilst its offices are located within the case study site’s premises, it does not offer a shopfront to the general public. Its function is twofold – firstly to provide an income source for the home hospice service – hence its placement under the business management stream – and secondly, as an extension of the philosophy described above. In this study, it was described as “a living example of compassion in action” (I08K:9), with its activities understood as a means of strengthening community action towards acts of compassion to the dying.

4.4 Processes of Case Study Site

4.4.1 Organisational communication lines

Organisational communication lines correspond with the case study site’s structural configuration and formal reporting responsibilities followed this
configuration; an ‘open door policy’ is commonplace for staff and volunteers to verbally communicate with their managers (I10K). The fluid committee structure within the organisation corresponds to similarly fluid lines of communication and, as mentioned above, this was the source of instability for some personnel, particularly volunteers, whose coordinator role changed three times during the data collection period with the appointment of new individuals to the role (F01V; F02V; I29V). For some, this was seen to impact directly upon their sense of the hospice as a workplace that created a supportive working environment.

4.4.2 Client centred service

The centrality of the client in a partnership of care is an accepted and longstanding core tenet of palliative care (Doyle & Jeffrey, 2000). In a number of locations in its documentation, the organisation states the client – including family and friends of the patient – is central to their provision of home-based palliative care (DW01; DW02). Indeed, they describe their support as “holistic, client-centred care” (DW04:1). In examining the organisational processes of the case study site, client centredness is reported in the manner of engagement by clinical staff with clients and the promotion of the client and their family as partners in care, both of which are discussed in more detail below.

4.4.3 Consumer participation

The participation of consumers in the activities of palliative care organisations is an emerging, but complex, issue in the field (Monroe & Oliviere, 2003; Small & Rhodes, 2000). As discussed above, palliative care has historically placed the patient, their family and carers at the centre of care, and the case study
site ascribes to this view. However, in the integration of the health promoting palliative care approach, consumer participation is sought not only in this sense of their primacy, but in diverse ways, from consultative processes to their presence in organisational governance and decision making (Kellehear, 1999b).

Clearly the presence of clinically unstable recipients of palliative care services in organisational governance processes has pragmatic, as well as ethical, constraints. Therefore, palliative care organisations seeking to integrate a health promoting approach are obliged to create innovative, appropriate mechanisms for consumer participation. During the data collection period of this study the organisation appointed a consumer representative to the Board of Directors as an integration strategy towards a health promoting palliative care approach (I14K). However, this appointee was an exiting member of the senior staff of the hospice whose continued involvement at the level of strategic governance was sought. The selection of health care professionals – let alone a former staff member – as a consumer representative has been questioned by Ahmedzai and Hunt (2003). User participation in the governance of palliative care organisations, they have suggested, could utilise both the presence of community members in decision making groups and mechanisms for the voice of consumers of the organisation’s clinical services to be heard in the measurement of quality. In this sense, the cases study site’s appointment may function adequately to address the latter criterion but falls short of fulfilling the former. Whilst as a transitional arrangement this appointment may prove to be sufficient, the implementation of a health promoting palliative care model would be characterised by community members representing the views of consumers. This would be more consistent with generic health
promotion practice (Talbot & Verrinder, 2005), changes within mainstream palliative care generally (Small & Rhodes, 2000) and health promoting palliative care specifically (Kellehear, 1999a, 1999b, 2005).

4.4.4 Quality improvement

At the time of data collection for this study, the case study site was undergoing a service improvement process to fully implement a TQM framework. In the context of integrating a health promoting palliative care approach, organisational changes were being incrementally implemented using the plan-do-study-act sequencing, such as that described by Lynn, Schuster and Kabcenell (2000) in their discussion of quality care for people at the end of life. Whilst the organisational leadership team effected organisational changes, some informants described this as an incremental, rather than organisation-wide, implementation. Some respondents reported that it was not always apparent that this process of change was strongly linked to a quality improvement cycle (I16K; I29V). This contextual issue is an important consideration in the integration of health promoting palliative care by the organisation.

Despite these concerns, the case study site’s processes demonstrate many of the minutiae that characterise robust quality improvement. For example, client satisfaction surveys are regularly distributed by the hospice and their analysis integrated into organisational decision making (DP23). The hospice also conducts annual staff and volunteer satisfaction surveys.²

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²Multiple sources of data: (DP08; DP11; DP17; I13K).
4.4.5 Research activity

Participation in social research has been identified by Kellehear and colleagues (2003) as a feature of health promoting palliative care organisations and is noted as a foreshadowed issue in Table 3.4. As a small organisation, the case study site’s participation in research has been noteworthy; in addition to this study, the hospice has hosted post-doctoral study by an Australian social scientist (McGrath, 1998) and numerous post-graduate studies, including an honours study in psychology and a masters level study in nursing by a visiting Chinese Buddhist. Moreover, the case study site is a consortium member of the Centre for Palliative Care Research and Education [CPCRE], a state health department funded centre “developed to provide a framework to enhance palliative care education and research throughout the State” (Centre for Palliative Care Research and Education, 2005, ‘About Us’ ¶1). In this role, the case study site has a representative on the CPCRE Board of Advice and contributes to decision making through provision of guidance and advice on strategic and operational matters.

4.5 Outcomes of Case Study Site

4.5.1 Measurable professional outcomes

Like many of its counterparts, the case study site voluntarily undertakes four-yearly accreditation with the ACHS. Indeed, it successfully underwent this external assessment during the data collection period of this study. As reflected in the Policy and Procedure manuals described above, the ACHS evaluates outcomes for the five areas of:
Continuity of Care.

Human Resource Management.

Information Management.

Leadership and Management.

Safe Practice and Environment.

(from Australian Council on Healthcare Standards, 2006)

It is therefore directly concerned with aspects of the hospice’s activities that represent their strategies to integrate health promoting palliative care, which are discussed in detail in the following chapters.

During the data collection period, PCA released a framework for service development (Palliative Care Australia, 2005b). The case study site began mapping itself against the criteria for a Level 1 Specialist Palliative Care Service following the PCA framework; these are illustrated in Table 4.3 below. At the conclusion of the data collection period for this study, this activity was still very much in a developmental state, but is viewed by the leadership team as an important step in the organisation’s strategic development and a highly relevant means by which its professional outcomes can be measured. This includes those organisational elements representing health promoting palliative care (I16K).

On a more micro-organisational level, the case study site conducts performance management activities designed to evaluate the outcomes of professional conduct amongst its staff (DP05; DP19), although one informant noted that this was inconsistently applied due to resource constraints (I13K).
4.5.2 Measurable client outcomes

Optimal quality of life and client satisfaction are prominently featured in the measurement of client outcomes in palliative care (Ahmedzai & Hunt, 2003). A range of validated instruments are in use to measure aspects of these outcomes; some are generic to health care (Padilla, Frank-Stromberg & Koresawa, 2004; Omery & Dean, 2004) whilst others are specific to pain (McGuire, Kim, & Lang, 2004) or the end of life issues (Lynn, Schuster & Kabcenell, 2000; Mistakidou et al., 2004). The identification of qualitative outcomes for clients has been advocated also (McGrath, 2001). Within the case study site, evidence of validated tools for measuring quality of life could not be located, however the measurement of patient and carer satisfaction is routinely undertaken and a summary of results made publicly available – not surprisingly, client satisfaction levels are usually high (DP23).

4.5.3 Community action

Health promoting palliative care is viewed by many in the organisation as an appropriate means by which their long record of community action can be
formalised. The hospice’s engagement with the wider community has a high profile. Each year, it conducts a second-hand art market and a Christmas market (see Appendix 16). Each event is well attended by members of the public and, in addition to raising funds, they offer opportunities for individuals to become active in the work of the hospice as volunteers or fundraisers. Moreover, since relocating into its new premises, the organisation is able to offer meeting rooms and a large room for small functions. It is also in the context of community action that the hospice has embarked on the death education project, offered educational programs addressing issues of living and dying.

4.5.4 Service/program evaluation

In light of the concerns identified with the quality improvement processes discussed above, it is notable that the organisation’s self-evaluation is primarily limited to a measurement of satisfaction only (DP01). In addition to measuring satisfaction levels amongst consumers discussed above, the staff and volunteers working for the hospice are surveyed annually or upon cessation of employment/volunteering, and levels are typically high.

Individual activities such as education programs are routinely evaluated by participants and again, feedback is usually positive. As noted, the case study site undergoes ACHS accreditation and is also required by Queensland Health to report upon their performance. There is no evidence of a formal organisation-wide service evaluation having been undertaken relating to their attempts to integrate a health promoting palliative care model.
4.6 Chapter Summary

The case study site’s leadership team was first exposed to health promoting palliative care through the lecture tour of Professor Allan Kellehear in 2000 to promote his textbook *Health Promoting Palliative Care* (Kellehear, 1999b). In the time since, a member of staff in a leadership role was allocated responsibility for its consideration and implementation within the organisation. The hospice’s leadership team elected to integrate a health promoting palliative care approach incrementally over a period of some years, a process which will be discussed at greater depth in the following chapters.

This chapter has provided a case description of the case study site to provide a real-life context for this research study. The palliative care organisation under study was a small non-government organisation providing community based palliative care to people with life-limiting illnesses in their own homes. Underpinned by a Buddhist philosophy, the organisation had undertaken to implement the health promoting palliative care approach championed by Kellehear (1999b) to address the social nature of the experience of dying for individuals and the wider community. This site description provides the context within which the analysis case study data will be reported in the following chapters.
CHAPTER 5:

FINDINGS – IMPACT, ENABLERS AND BARRIERS

5.1 Introduction

This chapter reports the findings of the first level data analysis. Its purpose is to deepen the understanding of the case study site by exploring the key issues pertinent to the implementation of health promoting palliative care and identifying the factors that advance or impede this implementation. As described in the methodology, design and methods chapter, confirmation was a key analytical goal.

The structure of this chapter is based upon the analytical filter described in the previous chapter, comprising the five key components of health promotion of the Ottawa Charter for Health Promotion (World Health Organization, 1986), with subsections for each component detailing the issues related to that component’s implementation and identifying the enablers of and barriers to its integration. The use of multiple sources of data – documentation review, carer questionnaires, in-depth interviews, and focus groups – necessitated the application of the multifaceted process of analysis illustrated in the conceptual framework (see Figure 3.1), wherein the data analysis methods demonstrated paradigmatic congruence with each of the data collection methods. These first level findings have been drawn from the preliminary analyses of data utilising the descriptive matrix (see Table 3.6 and Appendix 12).
Chapter 5: Findings – Impact, Enablers and Barriers

Further analysis and discussion is provided in Chapter 6, utilising the emergent themes from this first level analysis and the literature review to explore the major themes of the study.

5.2 Building Public Policy

The first health promotion component of the Ottawa Charter to be considered is that of building public policy. In health promotion practice, this has included consideration of all public policies impacting upon health, and has not constrained itself to health policy alone, as “all public policies, not just those labeled as health policies, have health consequences” (Wass, 2000, p.18). In this study, it refers to building public policy as a fundamental component of integrating health promoting principles and practice, and relates to the case study site’s participation in the development and/or uptake of healthy public policy relating to palliative care and the support of dying people. Specifically, as noted in Figure 3.3, the organisation planned to liaise with government and peak bodies regarding palliative care policy and public health as part of implementing this component of health promotion. It was anticipated by the case study site that this liaison primarily targeted state and national health departments. However, there was also recognition that the brief of health promoting palliative care extended to other departments.

This is underpinned by Kellehear’s assertion that public policy is a reflection of a wider vision for social action in the provision of care and support at the end of life and that the involvement of palliative care services in policy development is congruent with their social goals (Kellehear, 2005). Indeed, this implies that to address public policy around end of life issues is itself healthy.
Others have agreed that, given their proximity to death and dying and their professional expertise, the participation of palliative care services in public policy and planning processes relevant to end of life issues is a concern for all of society (Rao et al., 2005). This is despite the historical reluctance in the early modern hospice movement to be aligned with the mainstream health care systems of the day (Clark & Seymour, 1999). Further, when the public policy platform for health promoting palliative care proposed by Kellehear (2005) is considered, it is clear that the operationalisation of these policies includes a broad range of strategies that include, but are not limited to, conventional understandings of health.

5.2.1 Implementation of building public policy

Analysis of the data has highlighted that the case study site’s implementation of health promoting palliative care included a number of initiatives towards the integration of building public policy. In this first level analysis, two themes emerged.

5.2.1.1 Conceptual link between palliative care and public policy

In a manner consistent with the proposals of Kellehear (1999a, 1999b, 2005), study participants readily identified a conceptual link between the provision of palliative care and participation in the development of public policy, particularly where service provision was concerned. Consistent with the literature, palliative care was identified in this study as a concern for the whole community, not just for people who are dying and their families, and that health care services should reflect that (Kellehear, 1999a, 1999b, 2005; Rao et al., 2005; Salau, 2006). The view of Rao and colleagues (2002) that the end of life is a
public health issue given the “universal incidence” (p.215) of death is supported by this key informant, who saw a link between the collective ownership of palliative care and the provision of nursing care:

Palliative care belongs to everybody…we’re all going to die, so whether we have a generalist nurse or whatever, you should be given palliative care… (I02K:62-64)

This respondent linked the public health imperative to provide palliative care services with policy positions that enabled those services to be supplied. Not surprisingly then, public policies that impact upon the community’s experiences of issues of death and dying – including service provision – were viewed as being a concern for health promoting palliative care organisations.

However, the operationalisation of the case study site’s contribution to building public policy was not necessarily an automatic corollary of this recognition of conceptual congruence. One key informant with direct involvement in the external strategic activities of the case study site questioned whether the organisation had begun to integrate this element of health promotion into its practice (I02K). Participants of another study (Rao et al., 2005) into public health priorities for end of life initiatives provided detailed descriptions of policy development activities, including the assessment of existing legislation, liaison with the state legislature, and participation in expert panels relating to palliative care. However, in this study, most participants associated the hospice’s involvement in public policy development with the strategic activities of senior personnel of the organisation, who were seen to be more appropriate participants in such activities than clinical staff or volunteers. That is to say, there was a perception amongst some staff and volunteer respondents that activities relating to
public policy, governance of palliative care and organisational planning could be generically described as ‘strategic’.

A value was seen by many respondents, though, in having those involved at a clinical level involved in formulating public policy. This was a link viewed in pragmatic terms by one staff member, who speculated that effective policy planning resulted from strong links between strategic and operational activities:

…you need to have specific clinical knowledge but then you also need to have that strategic view and everything that underpins that…awareness of government policies. But you can’t have that in isolation. (I23S:134-137)

At first glance, this may seem a somewhat passive participation with the development of public policy – an awareness of government policies that underpin organisational strategy, rather than active participation in its development. However, this issue was teased out further at the verification workshop, whose participants described the integration of this component in more detail. Its value lay, they asserted, in keeping a strong and reciprocal link between the ‘coalface’ and the strategic level:

FACILITATOR: Part of what I have been told by some of you is that when a person who is involved at the strategic policy making level really gets what the day-to-day service provision is about, then better policy is developed.

GROUP 2: We feel that is happening from both sides. Coalface people are understanding strategic development and the strategic developers are understanding what the coalface people are doing. (F05:51-56)

A divergent view was taken by a staff member who saw the need for a person in leadership to oversee the integration of the function of building public policy:
It really needs people...who are open enough to see the benefits of all the other areas [brought in by health promoting palliative care] then pulling the team together. Not that people in those high levels need to be embedded in the operational stuff, but they need to be open to the impact of the operational stuff. (I23S:139-140; 142-143)

Hence, study participants showed little resistance to the idea of building public policy as a legitimate concern of the case study site. This ready recognition of conceptual congruence between palliative care and public policy development was clearly reiterated later at the verification workshop; however some ambivalence was shown by participants about the value of the hospice’s involvement in building public policy beyond the organisation’s position on euthanasia (F05; DP12). Nevertheless, whilst they were less clear about its scope and boundaries and who was responsible for it, they were able to identify their involvement in a number of public policy development activities.

5.2.1.2 Existing involvement in public policy development

In in-depth interviews some respondents provided examples that they perceived demonstrated the case study site’s past or existing influence upon public policy, with particular reference to clinical issues of death and dying. One clinical staff member was involved with a working group of palliative care health professionals who liaised with the State Coroner and the Australian Funeral Directors’ Association to clarify the policies regarding removal of deceased persons from private dwellings when death had been expected (I15S). This was a problem unique to community palliative care practice, with previous requirements impacting upon families by necessitating the attendance of the state Police Service to every home death. This staff member perceived that these requirements created
unnecessary anxiety for newly bereaved families, presented difficulties for community palliative care nurses, and unnecessarily increased demand upon the resources of the police service. Policies and practices were developed to streamline these procedures. Respondents reported a direct impact upon the home-based care provided by many palliative care services in the state, including the case study site. It provided clarity for services and an approach to this sensitive situation that was felt to be more sympathetic towards newly-bereaved families (I15S). The longer term impact of this action has not been determined although it could be hypothesised that this change in practice could contribute to better bereavement outcomes for family members and carers.

Similarly, the staff member also identified a second practical issue unique to community based palliative care that was influenced by public policy. Whilst the administration of scheduled medication (such as subcutaneous morphine) by family carers is commonplace in the home-based palliative care setting, the legal parameters around this practice are unclear. The staff member (I15S) was involved in the authorship of guidelines for the administration of medication by carers in the community setting that meet both the patients’ needs and satisfies the requirements of the state Health (Drugs and Poisons) Regulations 1996. This process was facilitated by Queensland Health and was ongoing at the conclusion of the data collection period of this study. Whilst Kellehear, Bateman and Rumbold’s (2003) guidelines emphasised the social, moreso than clinical, activities of health promoting palliative care, Rao and colleagues (2005) reported the review of clinical guidelines as a policy development priority in palliative
care, demonstrating a link between policy and practice. This respondent verified these priorities were being addressed at the case study site.

A gap in public policy specific to the issue of grief and bereavement was identified by a key informant (I02K) who observed that, despite the substantial evidence that early intervention in bereavement is beneficial in the workplace, it remains the case that a total of only three working days is permitted for bereavement leave. This respondent believed that a health promoting palliative care organisation should not only lobby for this to be reconsidered but should lead by example and individualise bereavement leave entitlements for its own staff, and, to this end, implemented this approach at the hospice as an organisational policy. Whilst not directly impacting upon other palliative care organisations, it was viewed by this respondent as an important example to set in the professional community and, to some extent, drive the policy agenda. In this sense, this is a strategy towards reorienting health services also.

5.2.2 Enablers of building public policy

Having described conceptual congruence and existing activities in building public policy, respondents identified a number of structures, processes and outcome factors that they believed enabled the integration of this component of health promotion.

5.2.2.1 Integration of public policy documents

The uptake of public policy documents by the case study site is regarded as an indicator of their participation in building public policy and represents a foreshadowed issue described in Table 3.4. The case study site’s strategic plan (DP:35) demonstrated the organisation’s endeavours to integrate the public policy
agenda relating to palliative care into its organisational structures. These key policy documents included Queensland Health’s Strategic Plan 2000-2005 (Queensland Health, 2000) and Health 2020 (Queensland Health, 2002), and PCA’s Palliative Care: Service Provision in Australia – A Planning Guide (Palliative Care Australia, 2003), Standards for Providing Quality Palliative Care for All Australians (Palliative Care Australia, 2005a) and A Guide to Palliative Care Service Development: A Population Based Approach (Palliative Care Australia, 2005b). Notably, there was not strong evidence of generic policy documents beyond the legislative requirements listed in Table 4.2 – the organisational focus seemed to rest upon explicit palliative care policy documents.

Nevertheless, these policy documents provided a foundation for the hospice’s strategic goal to become eligible as a Level 1: Specialist Palliative Care Service as described by PCA (Palliative Care Australia, 2005b) and illustrated in Table 4.3 in the previous chapter. Despite earlier uncertainty, the subgroup addressing these issues in the verification workshop acknowledged that this structural enabler was evident in organisational documentation (F05) and that its value lay in its provision of nationally available policy guidelines for service development (Palliative Care Australia, 2003), including the case study site’s transition to a health promoting palliative care approach.

5.2.2.2 Ongoing review of participation in public policy development

The internal review of organisational policy was anticipated by Kellehear et al. (2003) as a process enabler for the integration of public policy (see Table 3.4) and was evident as an established process within the case study site. The inclusion of public policy elements as a reflection of the strategic position of the
hospice as a health promoting palliative care organisation was the responsibility of the leadership team who, in a small organisation like this, fulfilled this function in lieu of a policy review committee. A schedule for the review of organisational policy documents to evaluate their integration of health promoting public policy was noted on each policy document including those selected for this study (DP1-DP15).

One key informant (I02K) queried whether it is the responsibility of service providers to participate directly in developing public policy or whether it is more appropriately the remit of peak bodies for palliative care, such as Palliative Care Queensland [PCQ]. This key informant’s view was that the participation of the hospice’s personnel in these bodies – rather than directly as representative of the organisation – is more fitting and denotes a key process enabler for it to influence public policy around issues of death and dying, grief and bereavement (I02K; I15S). Examination of the work of Kellehear (1999a, 1999b, 2005) and Rao et al. (2005) suggests that a health promoting palliative care organisation would participate in both activities. Indeed, during the data collection period of this study, two key informants were elected to the State Council of PCQ. The outcome of their contribution to building public policy as representatives of PCQ was beyond the scope of this study due to time constraints, although the need for a unified voice representing palliative care services was held as a key characteristic of this body’s lobbying (I02K; I15S).

This example of establishing partnerships between personnel, service providers and peak bodies to address concerns about the development of healthy public policies for the end of life alludes to a range of approaches to participation
to effect such change (Kellehear, 2005; Talbot & Verrinder, 2005). In their discussion of approaches to participation, Talbot and Verrinder (2005) describe a continuum from manipulation to participant control, moving from complete passivity to full, active control. On this continuum, partnership is seen as an empowered arrangement wherein power is shared between participants and those holding knowledge and resources. In this sense, the health promoting palliative care service provider is the participant, seeking a partnership with government wherein genuine contributions to the development of health public policy for the end of life are made. Importantly, the capacity of organisations to contribute in this way is an important consideration and is discussed further below.

The presence of these established structural and process elements within the case study site is understood to demonstrate some attempts towards the integration of building public policy, although a systematic strategy was not evident. Further, the data from this study also demonstrated that significant barriers remain to its full integration.

### 5.2.3 Barriers to building public policy

I find changing public policy one of the...most challenging things to do with health promoting palliative care because there’s so many variables, and the external factors, we’re governed by external factors, and the organisations by internal factors...internally we can do things...like belong to associations, we can lobby, we can do all those sort of things, but the other variable is where politically...it’s too long term for politics to bring it up and have some really touched by it. (I02K:156-161)
This quotation illustrates this key informant’s sense of the complicated challenge inherent in building public policy that supports a healthier approach to death and dying. Three emergent themes, where the relationship between organisations and the systemic governance of health care were the key factors, were identified in these descriptions of the barriers to the integration of building public policy.

5.2.3.1 Systemic barriers in government

The need for palliative care organisations like the case study site to influence public policy was identified in these data when the direct impact of various public policies was considered. In addition to the perceived absence of health promoting palliative care awareness within Queensland Health mentioned previously, many study participants singled out government funding policies and practices as the foremost barrier, further complicated by the Australian triple-tiered government structure. For example, the apparent synchronising of public policy development with the electoral cycle was seen as a fundamental barrier to effective planning by governments and the participation of stakeholders (I02K).

Further, the limit placed upon funding for community care on the basis of patients’ prognoses being six months or less directly and negatively impacted on the organisation’s capacity to provide key activities in health promoting palliative care; for example, early intervention strategies which would be operationalised in programs providing community awareness or bereavement support (I07S; I17K).

Public policies regarding private health insurance were also seen as presenting significant impediments to clients of the hospice who were usually unable to claim home-based palliative care services or receive financial remuneration for the high cost of pharmaceutical products in this setting (I02K).
This was seen to be exacerbated by an inactive public who seem to be reluctant, unable or disempowered to lobby private health funds for support of their palliative care; as one key informant put it, “Until they need it, they don’t look for it” (I02K:165). Given the link between public awareness and creating pressure for public policy reform by government, this presents a barrier to gathering public support for such a reform agenda influenced by palliative care organisations (I02K). It is also a consideration in *strengthening community action*.

These examples from the case study site demonstrated particular barriers resulting from specific policies of contemporary government upon the practice of health promoting palliative care by the organisation. There was no evidence of the kind of policy reform agenda proposed by Kellehear (2005) that proposes a set of strategies for a whole of government approach to promoting healthy public policies around issues of death and dying.

### 5.2.3.2 Systemic barriers in other stakeholders

The participation of palliative care organisations with representative peak bodies is acknowledged as a key strategy in influencing public policy in the context of integrating a health promoting palliative care approach (Kellehear, 1999a, 2005; Kellehear et al., 2003; Rao et al., 2005; Rao et al., 2002). Outside of the relationship between palliative care services and government, participation in peak bodies such as PCQ and PCA was identified by respondents as an important strategy in addressing the gaps in public policy.

However, it was the source of some concern to respondents that the relationship between these organisations did not seem beneficial, with a key informant suggesting this was a fundamental barrier in optimising the influence of
these bodies on public policy (I02K). Participation in the work of PCQ was acknowledged as desirable, but the nature of the relationship between PCQ and PCA was brought into question. The key informant perceived the incapacity or unwillingness of PCQ’s governing body to look beyond state-based concerns to the national policy agenda in palliative care (I02K) and felt that participation in the governance of PCQ was an appropriate response.

Further, this key informant saw a gap in the hospice’s current structure that whilst links were made with academic institutions, these were generally not schools of public health or social sciences, which were viewed as more appropriate to health promoting palliative care than schools of nursing or those concerned with the allied health disciplines (I02K). The case study site had previously invited Prof. Kellehear to speak about health promoting palliative care at in-house, but no formal links with an Australian academic institution with expertise in health promoting palliative care were established at that time or at the time of this study. This was seen as a desirable destination for the organisation although there was no evidence of attempts having been made at this time.

5.2.3.3 Limited organisational capacity

Despite a sense of urgency for public policy change felt with palliative care organisations, the hospice’s staff saw themselves to be greatly constrained to effect such change (I23S). In a focus group discussion, participants identified industrial action as a strategy for influencing public policy. Two participants asserted that the difficulty for the hospice lay in part in the nursing subculture in the state, suggesting:
PARTICIPANT 1: I think we have to influence government. We have to. Nursing has taken a long time to realise that.

PARTICIPANT 2: In this state… I have noticed nursing within this state is not nearly as political as in other states.

(F04S:349-352)

Interestingly, this view was not upheld by some other members of the focus group who had themselves participated in industrial action by nurses in Queensland in the 1970s (F04S).

Ironically, given the perceived inadequacy of funding for direct care noted above, respondents proposed that funding constraints also limited the capacity of the organisation to contribute to the building of public policy (I07S; I15S). Their view was that this may indeed impede the organisation’s capacity to operationalise the health promoting palliative care approach, although it need not stand in the way of lobbying for, and implementing, systematic reform towards integration of health promoting palliative care as suggested by Kellehear (2003; 2005; Kellehear et al., 2003) and Rao et al. (2005). The government allocation of resources was driven by a multitude of factors and impacted directly on the case study site’s capacity to obtain inpatient care for those of its clients who required it. Reports of financial constraints placed on a nearby palliative care unit as a result of competing priorities for resources caught the attention of one key informant, who remarked that:

… what’s happened at [major hospital PCU] … they’re going to have to close the unit for a few weeks and that’s largely because of budget and … the reason given from some of the people from [this hospital] are [sic] that a lot of the money is given to medical interventions, tests, while people are in the unit, and then there’s very little money for actually caring for
people once they get back out into the community. Or even for them staying in hospital.

(I10K:20-26)

This quotation itself raises a significant outcome barrier for the integration of building public policy – these sorts of experiences are not recorded, as outcome measurement in palliative care is still in its nascent state and misses those who are either turned away or never referred to palliative care services despite an identified need for them (I02K).

However, these difficulties raised a larger question being considered by staff about what constitutes the hospice’s core business (F04S). A tension was seen to exist between the imperative to provide the home-based palliative care services and participating in those activities that were outside of direct client care:

Our ability in palliative care to influence policy makers at the high [level] is the hard part. That is really the hard part because the reality for most of us is doing the grunge work down the bottom. We are helping people stay in their daily lives. That is not perceived well in the higher level. That is not perceived well at higher government or policy makers’ levels. You and I have had the discussions on which politician needs to get a life-limiting illness to make the best public input on health care. Until we get somebody really high profile, palliative care won't get the media on it.

(F04S:272-278)

These concerns are significant, given that they go beyond merely identifying a resource limitation. Respondents’ ambivalence towards non-clinical components of palliative care that are integral to health promotion challenge the conceptual congruence is evidenced elsewhere and underpin the question about what constitutes the hospice’s core business. Moreover, a number of respondents
appeared to perceive limited organisational capacity to participate in developing public policy on the basis of a limited understanding of what it entails. That is to say, many of the examples given demonstrate participation within the constraints of the existing Australian health system and are yet to move beyond this to the broader social agenda inherent in the health promoting palliative care model. To extrapolate the description in the literature review of complex adaptive systems (Begun, et al., 2003), the case study organisation can be understood to be deeply engaged with the broader socio-political contexts in which it exists. Its capacity to participate in the development of public policy relating to issues of death and dying would therefore relate to the political and policy development agenda at state, national and international levels. In the absence of comprehensive support for health promoting palliative care policies from governments, most respondents from the case study site demonstrated an apparently limited understanding of participation in policy development; importantly, those few respondents who showed awareness also identified a role for the organisation in advocacy for consideration of public health perspectives by governments.

The question of core business is reiterated elsewhere in the data, expressing a key theme of this study, and is discussed at length later in this dissertation. However, an alternative view was considered by verification workshop participants in their discussion about the place of power in these issues. Small group members were not convinced that the relationship between funding constraints and limited power was entirely causal:
GROUP 2: Limited funding equals limited power to influence public policy. Influences but not equals.

FACILITATOR: Explain that to me. The question of power is a really important one.

GROUP 2: Limited funding equals limited power to influence public policy. It's not limited funding that stops us influencing public policy. It is probably time. We could get a group of high profile volunteers together. We could possibly influence public policy. It's not just funding. It's about the drive and direction in which to gather that in a group. (F05:73-79)

This identification of ‘drive and direction’ reinforces the need for a strategic, systematic approach to health promoting palliative care, which was not entirely evident in this case study and perhaps represents a substantial risk to the success of its integration. In identifying potential threats to a public health approach to the end of life in his text Compassionate Cities, Kellehear (2005) flagged related issues such as professional and medical dominance, corporate managerialism, and economic rationalism as creating a culture of discouragement of community development.

5.3 Creating Supportive Environments

The second key action area in the Ottawa Charter is that of creating supportive environments. In health promotion practice, this has been seen as the need for “living, work and leisure environments organised in ways that do not create or contribute to poor health” (Wass, 2000, p.18) and is viewed as being optimised when built upon robust public policy. In this study, it relates to the ways in which the case study site contributes to the creation of supportive
environments to enhance well-being for consumers and employees (including volunteers) of the palliative care service. Given arguments for holism in the provision of palliative care (Kearney, 1992) and Kellehear’s (1999a) assertion that health promoting palliative care addresses the underdeveloped social areas of palliative care that have diminished at the expense of medico-nursing interventions, it is clear that this subunit of analysis is not merely concerned with a checklist of discipline-based interventions but with the nature of these interventions in promoting well-being.

As this section deals specifically with these two discrete groups – staff/volunteers and consumers – they are addressed separately.

5.3.1 Implementation of creating supportive environments for staff and volunteers

The case study site’s implementation of health promoting palliative care included a number of initiatives towards the integration of creating supportive environments for staff and volunteers. In this first level analysis, two themes emerged, noted below.

5.3.1.1 Support of staff/volunteers is fundamental to palliative care

Support of health care professionals, including volunteers, is a central tenet in palliative care, found in national standards for palliative care services (Palliative Care Australia, 2005a) and utilised in discipline specific competency standards (Canning, Yates, & Rosenberg, 2005). It was not surprising to see, therefore, that this component was a familiar one to the study participants, where the risks and burden of supporting dying people have long been recognised as inherent consequences of this work.
Whilst many organisations provide a range of strategies to support its staff and volunteers, self care is seen as an essential practice in palliative care; this is well-demonstrated in the following two examples drawn from the Australian context. Firstly, the *Standards for Providing Quality Palliative Care for All Australians* state in Standard 13 that “staff and volunteers reflect on practice and initiate and maintain effective self-care strategies” (Palliative Care Australia, 2005a, p.40). Secondly, building on this standard, and drawing upon the first-hand experiences of Australian specialist palliative care nurses, the recently developed *Competency Standards for Specialist Palliative Care Nursing Practice* states in Competency Standard 4 that the specialist palliative care nurse “recognises the effects of the intimate and intense nature of caring for individuals with a life limiting disease, their caregivers and family has on the self and other members of the team, and responds effectively” (Canning et al., 2005, p.110).

Respondents in this study drawn from staff and volunteers of the hospice saw few conceptual hurdles in this key area of health promoting palliative care; indeed, the data indicate there is no apparent difference identified between mainstream models of palliative care and health promoting palliative care in this regard. Both approaches have the care and support of individuals and their families and carers as central tenets (Palliative Care Australia, 2004a). Its integration subsequently has not presented the challenges of a substantive paradigm shift. Rather than focussing upon the concept of building supportive organisational components per se, respondents were concerned with the minutiae of this support, and these are discussed below.
5.3.1.2 Support strategies must be concrete

A number of structural, process and outcome elements were foreshadowed (see Table 3.4) as features of creating supportive environments for staff and volunteers. Firstly, the provision of psychological support and other staff support programs was evident and these have been discussed in the Case Description above; participation in psychological support programs by staff and volunteers was widespread amongst respondents, although for some, this was not always seen to be beneficial (I07S; I13K; I15S). For example, formalised debriefing had been introduced but this was only scheduled three times a year and, for one respondent, the utilisation of an ‘outsider’ was a disincentive to participate (I15S). Conversely, another respondent felt uneasy about the hospice’s counsellors being the source of this form of formalised support and sought private – and self-funded – counselling (I07S). These examples suggest that the provision of psychological support by a health promoting organisation to its staff requires highly individualised and flexible strategies to meet varied needs (Kellehear, 1999b).

Secondly, the case study site provided a monthly educational and clinical supervision program for staff and volunteers, comprising a mixture of information sharing, educational activities, and social events (I13K). It is viewed broadly as a highly beneficial strategy for creating a supportive environment within the organisation for staff and volunteers, particularly adding to a “sense of community and family” (I19K:102). However, despite its relevant content and valuable teambuilding opportunities, the program had little impact for a number of the nursing staff whose workloads (F04S) or geographical location (I13K) prevented their attendance. In particular, the issue of clinical workload was a significant
5.3.2 Enablers of creating supportive environments for staff and volunteers

Conceptual congruence and existing activities were again identified in this subunit of analysis. Respondents further described a number of structures, processes and outcome factors that they believed enabled the integration of this component of health promotion.

5.3.2.1 Alignment of personal and organisational values

A recurring theme in the data in relation to the enablement of supportive environments for staff and volunteers was that working at the hospice provided many with an opportunity to work in an environment that aligned closely to their values. Whilst this was especially true for Buddhist practitioners (I28S; I29V), it was also the case for others (I26K). This adds to the sense of congruence that emerged from this first level analysis in the previous section, where the conceptual link between palliative care and public policy was evident to respondents. Such congruence of values – particularly those based upon Buddhist practice – was viewed as a foundational issue upon which other considerations about the working environment were built, which is well demonstrated in the staff and volunteer satisfaction surveys for 2005 that shows 85% satisfaction levels in their identification with the organisation (DP71:5). This high degree of congruence may well minimise the impact of a transition to health promoting palliative care.
5.3.2.2 Organisational stability

As discussed in the literature review, change is a normative feature of organisations, particularly those that are viewed by their members as organic, rather than mechanistic (Mickan & Boyce, 2002). In an organisation where change was identified as a constant feature, the relocation into their new premises (see Figure 4.1) represented a significant improvement in the physical environment (I06V). Previously, the organisation’s headquarters had been housed in two bungalow-style buildings on the same site that were in a state of moderate disrepair. This relocation impacted directly upon volunteers, whose sense of being “very much adrift” (I19K:205) was replaced by a strong sense of belonging.

This period of enormous change in the physical environment coincided with a number of changes in the coordination of the volunteer program and consequently a feeling of great instability amongst volunteers (F02V; F03V; I26K). The provision of the volunteering program was understood both as requiring particular forms of support and as an agent of support (for consumers and for office-based tasks). Previously, two staff members had been responsible for the coordination of the volunteer corps – one for the office-based volunteers and the other for the family-support volunteers. This negative impact was resolved with the appointment of a single coordinator:

We did go through a little stage where we had a changeover, a bit of lack of communication between the volunteers. We have a lot of changes of people in charge of the volunteers and, for a year or so, I started to think I don’t know why I bother to do this because nobody cares that the volunteers are here. We had about a year. We had a few changes. You felt you went out to the client, there was no one to speak to that cared that you had been. We lost a little bit of touch. Since
Volunteers reported that the appointment of a single coordinator made them feel more supported, more aware of their role, and better informed (F03V). Significantly, however, in the short period of time since the conclusion of formal data collection activities, this appointee also resigned and once again, a change of personnel was undertaken. Whilst staff turnover is a feature of any organisation, the difficulty encountered by these volunteers was the reconfiguration of roles that accompanied each of these changes in personnel. The data suggest that when organisational stability was evident, the capacity of volunteers to create supportive environments was enhanced.

5.3.2.3 Provision of formalised support

Structural and process elements of the volunteer program, such as the initial training program and ongoing monthly support meetings, were key enablers of creating supportive environments for volunteers (F02V; F03V). This is consistent with the national standards in Australia for the provision of palliative care services (Palliative Care Australia, 2005a) and a common feature of most of the larger palliative care programs in this country. The hospice’s volunteer newsletter was identified by respondents as a key communication process that enabled this support (I19K) and volunteers appreciated gestures of support by the hospice, such as a social function at Government House as guests of the Queensland State Governor (I29V).

Team leaders have formal responsibility for watching for stress amongst volunteers and staff relating to organisational change; in real terms a great deal of support occurs informally. For example, respondents reported strong
interpersonal networks within the volunteer groups that were usually the first source of support for debriefing (F02V; F03V). Whilst this support tended to be reactive, it was acknowledged by the case study site’s leaders that it should be anticipated whenever change is planned (I13K), a key consideration in the communication of impending organisational change that the transition to health promoting palliative care represents.

5.3.2.4 Effective communication of organisational change

As is the case in many organisations (Moullin, 2002), well-communicated information about organisational changes made change easier to cope with in this case study (F04S). The timing of this communication was a matter of some dispute; this respondent describes communication in way that reflects the case study site’s organic organisational nature:

So talking about it early has an advantage, it has a disadvantage in the fact that people then feel like the sand’s being shifted all the time, and in actual fact, what's happening is an idea is being developed and developed up and developed up and it changes shape and morphs around a bit, you know, before it actually becomes what it's going to become.

(I19K:95-99)

This process enabled staff to view their contribution to the change as being valued by the organisational leaders:

…[clinical service manager] has been [here] a while now and she had a different attitude and certainly she can bond with the girls and change takes a lot longer. So instead of - it will be lodged at a nurses’ meeting. They’ll be given information and then a couple of weeks later, then we'll get the feedback. And so it's a slower process, but it's - but I think it's a better process because then they feel that they've been consulted at that time and that's not imposed upon them. (I13K:75-80)
Staff in one focus group reported that this process of consultation created a strong sense of ownership of the organisation amongst its employees and volunteers and was seen to contribute to the creation of a supportive work environment (F04S).

Another example of the way in which well-facilitated change has created support for staff is found in one interview with a staff member, who felt reassured that should her personal circumstances change, the organisation shows enough flexibility in the allocation of roles to accommodate these changes (I26K). Indeed, one new member of staff reported a sense of being supported by her manager and others in the organisation when challenged by transitions into a new role, stating: “I have felt supported by [the hospice] all the way through” (I31S:138). A key informant from the management team offered these reflections in interview:

I think, with change with anybody, it really needs to be - people need to be told about it, have time to absorb it, have their say as we bring the change in, rather than boom, boom, boom. Because people naturally don't have time for that sort of change at any time…quickly. (I13K:47-50)

5.3.3 Barriers to creating supportive environments for staff and volunteers

While the effective management of constant organisational change has been reported as a key enabler in the integration of this area of health promotion, the converse was also evident. This was encountered by respondents in two ways; firstly, where organisational change was not perceived to be strategically made, and secondly where there was insufficient consultation with those impacted upon by the change or where change had not been communicated adequately. These presented serious and sometimes overwhelming barriers to the creation of
supportive environments for staff and volunteers, who reported feeling unsettled and insecure when rapid change was not communicated clearly and accurately (I01V; I13K). This was not unique to the case study site, having been experienced by other respondents in this study who had come from the public sector (F04S).

5.3.3.1 Perceptions of business practices

The leadership practices of the core management group were perceived by one interviewee as inconsistent and not based in sound business principles. This former volunteer was particularly disparaging, as it presented to her an insurmountable barrier to the hospice creating a supportive working environment for her. The respondent was especially critical of the manner in which she perceived the organisation was run:

:::what it looks like is the core group of women are running it and the impression I get is that they sit around and yack about this or that, or this person or that person, and make these decisions in this subjective way and it appears to be haphazard, in the things I heard and seen, that they do something and not long after, it changes, it returns back to what somebody suggested in the first place, that they poo-pooed possibly because they had some subjective impression of what that person was like. And so it’s very much that personality based stuff, instead of like we’re all adults here and we’re in business, and looking at the facts, and nothing subjective in looking at okay, what have we got now, is it working well, why isn’t it working well, and what is it we’re trying to head towards in the long term, midterm, short term? So it just strikes me that the planning cycle and the decision making cycle doesn’t happen like a normal business.

(I29V:468-478)
However, whilst some other respondents conveyed their disapproval of how changes had been communicated, this specific criticism was not repeated elsewhere in the data. Indeed, when this question of whether ‘normal’ business practices were lacking in the hospice’s leadership was put to the verification group, it was resoundingly rejected:

**FACILITATOR:** Were there particular points that you disagreed with?

**GROUP 1:** Yes. One here that the perception is that normal business processes are not in place and *ad hoc* decision making happens. We…believe that there are business processes in place, that often it is time and laziness to access them that stops it. We disagree strongly with that. (F05:27-31)

Subsequently, the criticism has been interpreted to represent the experience of one respondent’s reflections upon the constant state of change within the case study site. This criticism demonstrates the respondent’s perceptions of subjective, personality-driven and unsystematic decision making:

**INTERVIEWER:**…what you’re describing is the need to think and behave strategically rather than reactively?

**RESPONDENT:** Absolutely, that’s exactly it, what I’m saying. It’s subjective and reactive and I hate to say it because it’s so anti-female to say now, but it is like this sort of old woman knitting circle type atmosphere. (I29V:323-327)

The respondent’s own reservations at her harsh descriptions were also evident here. One key informant, a member of the management team, anticipated these sorts of difficulties:
...it's that feeling of insecurity. That we don't know where we're going or maybe three of us will know where it's going in their minds, you know, because it's a feeling of just chopping and changing their mind all the time. (I13K:109-111)

This concern for the apparent lack of a systematic approach to the implementation of health promotion principles and practice in the case study site represents another key consideration in this study and is discussed at length in the following chapter.

5.3.3.2 Ineffective communication of organisational change

The second matter where the management of constant organisational change presented barriers to the creation of supportive environments was where change had been made without ample consultation or not been adequately communicated. It was acknowledged by a key informant from the leadership team that a number of significant changes had been poorly handled through releasing information too soon, before it was “bedded down” (I19K:127). This problem was noted by another member of the leadership team:

I think it's keeping people informed, but one of the problems that comes out of that is that what is talked about today has changed by tomorrow and by the next day. So if you talk to someone today, that - and in their mind, they sort of think that's the way it's going to go. And then to discover next week, someone's talking a different story - hang on a minute, I thought it was going to be such and such? Oh, no. That was three things ago…

(I13K:91-95)
This process barrier brought about negative outcomes for staff and volunteers, who felt devalued by poor consultation, which was described by another member of the leadership team in this way:

[This change] affected them in…how they felt being valued. They didn't feel valued...They didn't feel that they were consulted very much on the changes that were going to happen and...they felt imposed upon...even though the change wasn't hard for them to make… (I13K:40-44)

There was divergence in the data regarding the quality of the communication of organisational changes, with some staff viewing it as getting worse and others as getting better (F04S; F05). Those respondents who perceived a decline in the quality of communication pinpointed a specific reason – the impact of workload was raised frequently in this study as a barrier to effective communication and the creation of supportive working environments. An increasing workload for clinical staff, especially nurses, limited their availability to attend monthly support meetings (F04S), particularly those working in the northern catchment and located furtherest from the headquarters (I13K). Whilst information was provided by email, this was criticised as inadequate, especially when the workload is very high – one staff member had her work emails diverted to her home and read emails in her own time (F04S). The impact of heavy workloads upon the ability to attend support activities was linked by one respondent to retention:

… not many of the nurses have like proper lunch breaks or toilet breaks and that, I don’t think is satisfactory... Now I understand the pressure of nursing and the workload and the need to recruit more nurses, but you’re going to lose nurses if you don’t support them … (I27S:285-288)
The clinical workload also was exacerbated by the demands of administrative side of clinicians’ roles (I21S).

Effective communication between managers and staff is, as noted in the literature review, a key process in the successful implementation of organisational change (Ader et al., 2001). In undertaking to create a supportive working environment for staff and volunteers, the case study site’s management demonstrated an inconsistent quality of communication.

5.3.4 Implementation of creating supportive environments for consumers

Like the previous subunit of analysis, the case study site’s implementation of health promoting palliative care included numerous initiatives towards the integration of creating supportive environments for consumers. Conceptual congruence again was a fundamental feature of palliative care and support of consumers was seen to be the primary intention of both mainstream and health promoting palliative care. In this first level analysis, three themes emerged and are discussed below.

5.3.4.1 Holistic support of consumers is fundamental to palliative care

In a further reiteration of the emerging theme of conceptual congruence, the provision of holistic support was viewed as a fundamental intention of palliative care. For community based palliative care service providers like the hospice, that support was mostly provided in the home environment of the service recipient or their carer. In this study, consideration of the impact of creating supportive environments for consumers was primarily concerned with consumers’ perceptions of how the organisation enhanced their sense of being supported in
their dying experience through the provision of its services. Importantly, however, where the integration of health promoting palliative care is being studied, this consideration is not limited to an assessment of the reductionist set of medico-nursing interventions criticised by Kellehear (1999a) or the ‘symptomatology’ feared by Kearney (1992).

Indeed, the holism espoused by the palliative care profession is held to account in health promoting palliative care with its emphasis upon redressing the balance towards the psychological, social and spiritual aspects of human experiences of dying; in Kellehear’s (1999b) words, “the practice of health promoting palliative care is a practice that embraces all\(^1\) the concerns together, in concert” (p.23). One staff member of the hospice captured this imperative succinctly in saying:

\[
\text{I notice we’re talking about people's pain and often the time when all the things that should be working aren't working and the pain control, that there's some underlying psychological emotional issue that's being dealt with and right through to when, if the person is open and able and willing to explore those, that …can…yield amazing kind of outcomes. (I21S:130-135)}
\]

The relevance of a holistic approach to the provision of support in the palliative care setting is candidly illustrated in these multilayered descriptions of the consumers who were interviewed for this study:

- A woman who was her husband’s carer; their 20 year old son’s girlfriend initiated their separation upon his father’s terminal diagnosis, saying “…it’s getting too boring now” (I05C:357). This young man would not speak to

\(^1\) Researcher's emphasis
anyone about his struggles and was hostile towards any support resembling counselling, including that offered by the hospice (I05C).

- A man who was his wife’s carer. They lived with his 89 year old, frail mother and their eleven year old grandson who had a learning disorder. Their son (the boy’s father), who had the same learning disorder, was divorced; their married daughter had a two year old child and needed occasional child care support from her parents (I12C).

- A man who was the long-term carer of his chronically ill wife, who was now terminally ill. They lived less than one kilometre from a hospital that they could not access due to the temporary closure of its Accident and Emergency Department (I24C).

- A male patient whose sole family member was his wife. They had lived overseas most of their married life and now found themselves without a support network, despite their substantial material wealth (I25P).

- A woman who was the carer of her male partner. She had had a son who died in tragic circumstances a decade earlier, when she had accessed the hospice for bereavement support. Her daughter was undergoing treatment for breast cancer whilst living in an unstable, same-sex partnership in which she was the mother of two children. The woman’s surviving son had just undergone a marital separation and was negotiating custodial arrangements of his three year old daughter with his estranged wife (I31C).

When interviewed, these complicated family configurations and complex dynamics were identified by these consumers as directly relevant to their
experiences of consuming the supportive and palliative care services of the hospice. This is explored in detail below.

In this study, particular consideration is given to the impact of health promoting palliative care in creating supportive environments for those family members who have taken on the role of caregivers. The role of informal caregiver is reported as undervalued and marginalised in Australia, with outcomes upon their health and wellbeing linked to the quality of support services (Palliative Care Australia, 2004a). Their concerns, as Kellehear (1999a, 1999b) has suggested, are typically holistic, rather than solely symptomatic or biomedical in nature. Clearly, these factors directly impact upon the provision of palliative care services that respond appropriately to these specific concerns.

5.3.4.2 Provision of formalised support
An examination of the sort of formalised support given by the case study site to its consumers shows a range of clinical and psychosocial strategies – health status monitoring, troubleshooting unstable symptoms, hygiene and personal care, education and information, liaison with other members of the health care profession and government departments, respite care, volunteers and spiritual support.2 This corroborates the consumer needs identified in a number of studies (Bradburn & Maher, 2005; Jarrett et al., 1999; Steinhauser et al., 2003), where information sharing and assistance with meeting physical, psychological, social and spiritual needs were highly regarded. Importantly, in consideration of a health promoting approach to palliative care, these studies also demonstrated that consumers of palliative care services sought empowerment, advocacy, choice, and

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2 Multiple data sources: (I05C; I12C; I18C; I24C; I25P; I31C)
continuity of care. In this study, for all but one of these respondents (I12C), the on-call service was a significant element of the support provided by the hospice, leading to a perception of responsiveness and availability and the organisation was identified as making dying at home possible (F02V; I12C; I31C).

As described in Chapter 4, the hospice’s range of supportive programs were mentioned either specifically or obliquely by consumer interviewees or their usage described by staff, volunteers and key informants. Many families receive volunteer support (I26K) or the psychosocial support programs such as counselling, CHERISH, and spiritual care. The effectiveness of, and satisfaction with these programs has been formally sought episodically throughout the hospice’s history (I22K). It is evident in its quality improvement processes in the handling of grievances from consumers (DP14; DP31) and their undertaking of the “death audit” (F05:135) as a post-mortem review of the patients’ care given by the hospice to them and their families and carers.

Moreover, the provision of information, as a discrete program, was another form of formalised support. The call centre was seen as an element of creating supportive environments for consumers; notably, the ‘consumers’ of the call centre included members of the general public, patients, their carers and family members, and health care professionals (DP48; I09K; I31S).

5.3.4.3 Provision of wide-ranging support

Whether the case study site’s palliative care service was sufficient to create and provide a supportive environment for its consumers was addressed through a self-administered carer questionnaire and interviews with consumers,

3 Multiple data sources (I05C, I12C, I21K, I22K)
staff and volunteers. The instrument is described in Chapter 3 and represents the supplementary data source in the QUAL+quant equation. It provided information about five areas of support and the extent to which the organisation offered that form of support and is attached as Appendix 11. These five areas were:

- emotional/informational support
- tangible support
- affectionate support
- positive social interaction
- additional item (described below)

The level of satisfaction experienced by caregivers of the care provided by the hospice was also sought. The overall response rate is reported in Chapter 3.

In the area of emotional/informational support, respondents reported moderate to high levels of support in the eight items (\( \bar{x} \) range = 3.75-4.42),\(^4\) with more than 90% identifying the hospice as the source of this support to some extent or greater (\( \bar{x} = 3.78 \), sd = .95), including one quarter for whom the hospice was the sole source of emotional/informational support (see Table 5.1).

<table>
<thead>
<tr>
<th>TABLE 5.1: EMOTIONAL/INFORMATIONAL SUPPORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what extent does [the hospice] offer emotional/informational support to carers?</td>
</tr>
<tr>
<td>-------------------------------------------</td>
</tr>
<tr>
<td>Valid</td>
</tr>
<tr>
<td>a little</td>
</tr>
<tr>
<td>to some extent</td>
</tr>
<tr>
<td>greatly</td>
</tr>
<tr>
<td>totally</td>
</tr>
<tr>
<td>Total</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

\(^4\) Utilising a five point Likert scale with 1 = ‘not at all’ to 5 = ‘totally’ – see Chapter 3.
In the area of tangible support, respondents reported moderate levels of support in the four items (\(\bar{x}\) range = 3.48-3.61). However, the proportion of respondents who identified the hospice as the source of this support to some extent or greater was smaller at 86% (Table 5.2).

**TABLE 5.2: TANGIBLE SUPPORT?**

<table>
<thead>
<tr>
<th>To what extent does [the hospice] offer tangible support to carers?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>3</td>
<td>12.5</td>
<td>13.6</td>
</tr>
<tr>
<td>to some extent</td>
<td>9</td>
<td>37.5</td>
<td>40.9</td>
</tr>
<tr>
<td>greatly</td>
<td>6</td>
<td>25.0</td>
<td>27.3</td>
</tr>
<tr>
<td>totally</td>
<td>4</td>
<td>16.7</td>
<td>18.2</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>91.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

In the area of affectionate support, respondents reported moderate levels of support in the three items (\(\bar{x}\) range = 3.50-3.87). The proportion of respondents who identified the hospice as the source of this support to some extent or greater was again smaller at 77% (Table 5.3). This issue was raised in some phone queries to the researcher from respondents who were anxious to clarify that whilst they were comfortable with the nature of physical contact with the staff, a professional propriety was always evident. Interestingly, none of these callers consented to follow-up, in-depth interviews, and none of those other respondents who were interviewed raised this as a concern.
**In the area of offering positive social interactions, it is worth noting that**
the items referred to recreational and relaxation activities, not the nature of the professional communication demonstrated by hospice staff. Respondents again reported moderate levels of support in the three items (\( \bar{x} \) range = 3.00-3.13) with just over half of respondents identifying the hospice as the source of this support to some extent or greater (Table 5.4).

**TABLE 5.3: AFFECTIONATE SUPPORT**

<table>
<thead>
<tr>
<th>To what extent does [the hospice] offer affectionate support to carers?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid not at all</td>
<td>5</td>
<td>20.8</td>
<td>22.7</td>
</tr>
<tr>
<td>a little</td>
<td>3</td>
<td>12.5</td>
<td>13.6</td>
</tr>
<tr>
<td>to some extent</td>
<td>7</td>
<td>29.2</td>
<td>31.8</td>
</tr>
<tr>
<td>greatly</td>
<td>2</td>
<td>8.3</td>
<td>9.1</td>
</tr>
<tr>
<td>totally</td>
<td>5</td>
<td>20.8</td>
<td>22.7</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>91.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

**TABLE 5.4: POSITIVE SOCIAL INTERACTION**

<table>
<thead>
<tr>
<th>To what extent does [the hospice] offer positive social interaction to carers?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid not at all</td>
<td>11</td>
<td>45.8</td>
<td>47.8</td>
</tr>
<tr>
<td>a little</td>
<td>1</td>
<td>4.2</td>
<td>4.3</td>
</tr>
<tr>
<td>to some extent</td>
<td>6</td>
<td>25.0</td>
<td>26.1</td>
</tr>
<tr>
<td>greatly</td>
<td>4</td>
<td>16.7</td>
<td>17.4</td>
</tr>
<tr>
<td>totally</td>
<td>1</td>
<td>4.2</td>
<td>4.3</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>95.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>4.2</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

The final area of the first half of the questionnaire contained a single item relating to the extent to which the respondent can identify ‘someone to do things with to get [their] mind off things’. With a \( \bar{x} = 3.00 \), more than half the
respondents reported this support some or most of the time. The hospice was the source of this support for less than half (44%) (Table 5.5).

**Table 5.5: Someone to do things with**

<table>
<thead>
<tr>
<th>To what extent does [the hospice] offer someone to do things with to help carers get their minds off things?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid</td>
<td>not at all</td>
<td>13</td>
<td>54.2</td>
</tr>
<tr>
<td></td>
<td>a little</td>
<td>2</td>
<td>8.3</td>
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<tr>
<td></td>
<td>to some extent</td>
<td>3</td>
<td>12.5</td>
</tr>
<tr>
<td></td>
<td>greatly</td>
<td>3</td>
<td>12.5</td>
</tr>
<tr>
<td></td>
<td>totally</td>
<td>2</td>
<td>8.3</td>
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<tr>
<td>Total</td>
<td>23</td>
<td>95.8</td>
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</tr>
<tr>
<td>Missing</td>
<td></td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>24</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The second half of the questionnaire sought satisfaction scores from carers regarding specific clinical activities of the hospice in the provision of supportive services. Respondents reported\(^5\) moderate to high levels of satisfaction (\( \bar{x} \) range = 1.38-2.63) with the highest mean scores reported for satisfaction with the availability of hospice staff (\( \bar{x} = 1.38, sd = .92 \)), the answers provided from hospice health professionals (\( \bar{x} = 1.52, sd = .95 \)), the coordination of care by the hospice (\( \bar{x} = 1.58, sd = .97 \)) and the information given by hospice staff about pain management (\( \bar{x} = 1.59, sd = .96 \)). Lower mean scores (still in the range of ‘satisfied’ or ‘uncertain’) were reported for specific services such as medical support (\( \bar{x} =2.63, sd = 1.03 \)), clinical tests (\( \bar{x} = 2.22, sd = .88 \)) and the provision of family conferences (\( \bar{x} = 2.19, sd = 1.03 \)). Follow up interview data verified that some respondents had not accessed these particular services and had scored ‘undecided/uncertain’ as a result, with these items also scoring the greatest

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\(^5\) Utilising a five point Likert scale with 1 = ‘very satisfied’ to 5 = ‘very dissatisfied’ – see Chapter 3.
number of missing data. Detailed frequency data are provided in the frequency tables in Appendix 17.

It is important to note that “satisfaction does not necessarily ensure quality” (Monroe & Oliviere, 2003, p.101) and that any consideration of strategies to create supportive environments for consumers of palliative care should include, but not be limited to, the measurement of satisfaction. For example, in their study of people living with terminal cancer, Carter, MacLeod, Brander and McPherson (2004) identified the priorities of consumers of palliative care services. The continuing transition from wellness to living with a terminal illness was a pervasive concept for these consumers. The measurement of service quality had limited application for these consumers, insofar as it represented only a small proportion of their lived experience of approaching death. Indeed, in promoting individualised care for palliative care patients, PCA (2005c) conceded that “simple measures of effectiveness or quality will not capture [the] requirement for individualisation.”6 The provision of wide-ranging support requires multifaceted measurement of quality. What specific factors enable the integration of supportive environments for consumers and which present barriers?

5.3.5 Enablers of creating supportive environments for consumers

By and large at the moment, sitting here talking to you, I couldn’t live any better than what I do. (I25P:157-158)

This quote from an interviewed patient captures what many palliative care services would consider the best possible outcome of their support – that consumers perceive they are living with optimal quality of life within the

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6 No page numbers in original document.
constraints of their circumstances. Respondents reported a number of enabling factors to this, described below.

5.3.5.1 **Philosophy and values**

According to a number of respondents, a key enabler of the case study site’s achievement of this outcome for consumers is its view of “death, illness and loss [as] a natural and inevitable part of life’s journey” (DW01:1) and its willingness to discuss death in an open, yet sensitive way (I08K; I10K; F02V). This clearly captures the profession’s assertion of death being a normal part of life (Palliative Care Australia, 2004c) and the concern of health promoting palliative care to address death-denial in society (Kellehear, 1999b). For many respondents, the spiritual philosophy underpinning the hospice’s work, described above in Section 4.2.3 *Philosophy* influenced the implementation of this health promotion component. This has been captured eloquently by this respondent:

> [In] Buddhism, you cannot escape the discussion of and…the need to consider the concept of death because it’s intrinsic to Buddhist philosophy. It’s what karma revolves around, surrounds the whole concept of the meaning of life. Why are we here? And one cannot escape the discussion of and understanding of death. (I08K:141-144)

In the context of the broader health care system, the case study site’s willingness to discuss the deterioration and eventual death of a patient even when other professionals would not formed part of this openness; in the words of one carer:

> …I know [the hospice] is the only one that has ever said, “Well, yes, until he dies.” 7 (I18C: 420-421)

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7 Consumer’s emphasis; during interview, these words were emphasised by the consumer using hand gestures.
It was acknowledged that sensitivity was required in this action as individual patients and their carers may have differing degrees of readiness for open discussions of dying. Having patients and their families and carers more at ease with the existential issues around dying and death was viewed as a source of empowerment for them, requiring their gradual introduction into their role as participants in decisions making and care (I07S). This was particularly noted by the carer quoted above (I18C) who felt readied for her husband’s deterioration by the sensitive input of the registered nurse.

5.3.5.2 **Responsive and flexible staff**

Responsiveness and flexibility were two key attributes of the clinical personnel identified as enablers of support by both consumers and staff and is a desirable characteristic in an organisation that changes continuously (Kaluzny & Hernandez, 1988). The organisation’s small size was viewed as an important structural enabler in achieving this:

> Fortunately, I think that at [the hospice] we’re a small team and we’re able to ensure that we have nurses that really keep the client as the focus of care. And they’re quite sensitive to the emotional and spiritual issues that may be going on for a person… (I10K:58-61)

Carers and patients felt supported by the thorough assessment of their needs undertaken by the registered nurses (I25P; I31C) and expressed confidence in being able to ask anything for support (I05C; I12C). Nurses in particular were noted for their assistance with problem solving and troubleshooting (I05C) – this advocacy represents a core characteristic of health promotion (World Health Organization, 1986). It is also a recognised core value of palliative care (Palliative Care Australia, 2005a; Taylor, Glass, McFarlane, & Stirling, 2001) and
is closely aligned with the principles of the therapeutic relationship (Canning et al., 2005). One staff member, who was an original member of staff when the case study site first opened, observed a vast improvement in the empowerment of patients, families and carers over the ensuing decade and a half; she gave a poignant example where the hospice’s nurses and other staff and volunteers would have previously stayed all night with a dying patient, whereas now:

Well, we’ll have a family...which has a mum and three teenage girls. Well, the nurse spent about two to three hours yesterday and the need was huge of educating one of the girls, given a roster with friends and giving them ideas. We sometimes have occasions like that, but now the empowerment of the client is huge and this is [the hospice]...to me, has proved they’ve done that in a huge way. (I07S:179-183)

A carer reiterated the empowering nature of this rostering strategy when she expressed her doubt about her ability to do what was required for her husband; the hospice’s nurses constructed a roster and responded to any of her questions in the process (I05C).

5.3.5.3 Emphasis upon providing psychological and social support

The provision of psychological and social support has been identified as a core concern in health promoting palliative care (Kellehear, 1999b; Rao et al., 2005; Rao et al., 2002) and at the case study site, the spiritual support program was the source of great comfort for patients and carers:

...so far they’ve given us everything that we need, and they’ve been very, very good and they organised for a nun to come and see us... She came here to see her and she was fabulous, she talked to [patient] for two hours. She [patient] was good after she left. (I24C:95-98)
Notably, respondents were easily able to identify that whilst the hospice was itself a Buddhist organisation, the nuns who visited them in this capacity were respectful of other spiritual frameworks and religious practices (I12C; I24C; I30C). Similarly, the CHERISH program and counsellors were enablers of supportive environments through the provision of psychological, emotional, spiritual and social needs (I21S). To achieve this, counsellors also acknowledged the need to be responsive and flexible to the kind of highly individualised contexts they are faced with in working with the hospice’s clients (I21S), such as those noted above, and the highly personalised responses they require. Some concerns have been raised about the ‘niceness’ of palliative care workers, including those at the hospice:

Now, [hospice staff are] very nice and everything like that, but, you know, I’d say gee, too nice. (I12C:33)

In reference to this comment, one counsellor indicated that it was very important not to assume that conflict and confrontation had no place in providing effective psychosocial support and that, indeed, the role of the counsellor was to give permission to clients for the honest expression of feelings, even when they may be viewed as ‘not nice’ or negative (I21S).

5.3.5.4  Provision of quality resource information

In keeping with the moderate to high levels of satisfaction of carers with information provided by the case study site discussed above, written resources were also viewed as important enablers of providing support. In particular, the booklet *Caring at home with [hospice name]: a guide for carers* (DP48), was routinely given to carers. The goal of this resource was to provide information that upskilled and empowered family members and as such possessed some of the
qualities of health promotion in both its content and intent. However there was no
evidence that these health promoting strategies were specifically evaluated. More
generally, each recipient of the booklet received a Client Satisfaction Survey
(DP23) six weeks after patient admission to the home hospice program where an
opportunity to comment on its usefulness was provided. This feedback
mechanism confirmed the view of carers who identified it as very helpful (I05C).

This characteristic is by no means unique to health promoting palliative
care, but nevertheless was identified as a key enabler of creating supportive
environments for consumers. The presence of such overlap between conventional
and health promoting palliative care is discussed further in the following chapter.

5.3.6 Barriers to creating supportive environments for consumers

Despite high levels of satisfaction with the hospice’s provision of care and
tremendous community good will towards the organisation, three barriers to the
creation of supportive environments for consumers were identified.

5.3.6.1 Low public awareness of the hospice

This quote from a carer captures a simple yet significant barrier to the case
study site’s creation of supportive environments for consumers of palliative care –
all but one of the consumer participants\(^8\) in this study had never heard of the
organisation prior to becoming a patient or carer:

RESPONDENT: Well, I didn't know anything about
[hospice].

INTERVIEWER: You’d never heard of them?

RESPONDENT: Never heard of them, no. (I18C: 21-24)

\(^8\) Multiple sources of data: (I05C; I12C; I18C; I24C; I25P).
The exception was the carer (I31C) who had accessed the CHERISH bereavement support program a decade earlier following the tragic death of her son (noted above). Whilst there was no evidence that this impacted upon the quality of supportive care provided once the patient was admitted, it presented a barrier to timely and appropriate access, a concern raised by D’Onofrio and Ryndes (2002). Where public awareness of a specific service is low, it follows that consumer demand for that service is correspondingly limited. Although the hospice accepts self-referral by palliative care clients, the control of access rests, for the most part, with referring agencies that have dual roles as informers and referrers. The case study site’s dependence upon such agencies is a feature of this process barrier and illustrated a need for them to monitor referral processes.

This lack of community familiarity with palliative care organisations like the case study site represents a key challenge for the integration of health promoting palliative care and crosses components of health promotion. Whilst understood here in reference to creating supportive environments, it links closely to the key action area of strengthening community action. Strategies to raise the profile of the hospice specifically (and palliative care generally) are significant steps in promoting the health of the community in relation to issues of death and dying; limited awareness of the service may indicate limited accurate information about the subject, which in turn impacts upon both community resilience and consumer expectations of support. In turn, this may have a negative impact upon the levels of consumer empowerment.
5.3.6.2  **HPPC activities: extra work or core business?**

Proponents of health promoting palliative care and a public health approach to end of life care have argued that palliative care inherently contains public health elements (Byock, 2001; Faulkner, 1993; Kellehear, 1999b; Rao et al., 2005; Rao et al., 2002). Whilst palliative care organisations may need to add some activities in order to embrace this core business, a substantial proportion of existing palliative care is congruent with the health promoting approach (hence the conceptual congruence evident in this study). The *reorientation* of services becomes the goal of transition, rather than simply adding more work. This is discussed in greater detail in *Section 5.6 Reorienting Health Services*. Nevertheless, a conceptual barrier to the integration of creating supportive environments for consumers of the hospice’s services was the perception that patients and their families and carers might receive lower levels of support in an organisation that is allocating resources to non-clinical services as part of integrating health promoting palliative care (I22K).

The question of core business was considered by many participants of this study, particularly in the focus groups. In clarifying this question, respondents broadly viewed the non-clinical activities of the hospice, such as their death education program, as equally a part of core business as the provision of home-based palliative care (F04S; F05). One focus group participant put it this way:
Then we are fighting cultural perceptions as well because we are a culture which doesn’t want to talk about death and dying as a general rule…Our core business is that. [hospice name]’s shift into that [death education program] stuff and making people's lives better - it is a program of community education, covering a lot of different things, getting people ready for death. It is the background to it. We are teaching them to live. (F04S:281-285)

In this way, the non-clinical activity was seen to impact upon the receptivity of future clients of the case study site in the provision of support.

These perceptions of clinical and non-clinical activities respectively representing conventional and health promoting approaches to palliative care is an important consideration in the question of core business. Proponents of health promoting palliative care have been explicit in articulating that the model does not represent an ‘optional extra’ to conventional palliative care services (Kellehear, 1999a, 1999b, 2005; Kellehear et al., 2003). Many respondents in this study demonstrated a limited understanding of the scope of health promoting palliative care in how the whole organisation approaches the provision of both clinical and non-clinical services. In this way, a health promoting organisation is able to build its “critical mass” (Whitelaw et al., 2006, p.139) of personnel skilled and knowledgeable in health promotion principles and practice.

5.3.6.3 Outcome measurement
Outcome measurement has been widely identified as a problematic concept in palliative care (Eagar et al., 2004; Hughes et al., 2003; Kellehear et al., 2003; Palliative Care Australia, 2005c; Richardson, 2002; Robbins, 1998; Tierney et al., 1994; Wilkinson et al., 1993) and is underdeveloped in health promoting palliative care. Current developments in outcome measurement for palliative care...
services in Australia have provided substantial steps towards comprehensive
evaluation of service provision. Examination of these developments demonstrate
a capacity to evaluate health promoting activities such as evaluating levels of
support, raising community awareness and building community capacity (Eagar et
al., 2004). Notwithstanding this progress, it was evident for a number of
respondents in this study that they questioned the optimal way to determine
whether supportive environments had been created through the programs of the
hospice service. With reference to earlier concerns about ‘niceness’ in palliative
care, and considering the low levels of familiarity amongst consumers of the
hospice prior to the patients’ admissions, one staff member queried whether
clients, in their vulnerability and ignorance, were able to provide a genuine
assessment of the quality of care they receive:

    We go into homes and…everyone says you’re wonderful, but
that is not enough. As I keep saying, our clients are
vulnerable and who have they got to compare us with
something like that?” (I07S:69-71)

For one staff member objective measurement was conceptually incompatible with
the humanistic nature of palliative care:

    And, for me, I see that [objective measurement] as one of the
bigger threats… to this kind of work because…in a really
deep basic way, it's humanistic. It's humanistic work with
people and that is…traditionally really hard to quantify and
usually a lot of our advocates and people who will give
testimonial and valuable experience can't because they're put
under. And so because it's sort of, in a sense, deeply human
work, if it's tried to be captured and quantified and accounted
for in an inhuman way, it can really just dry up…(I21S:341-
351)
For this respondent, the requirement to provide quantifiable outcomes of psychosocial interventions was seen as a barrier to creating supportive environments for consumers. Yet a tension existed between these concerns for retaining the humanistic nature of palliative care with the obligation to provide measurable outcomes to funding bodies (I21S). Moreover, a key informant, with extensive experience as a bereavement counsellor, struggled with these competing and seemingly incongruent elements:

…as someone who has seen the results of a lot of bereavement care, I know some of the things that are presented, but how you measure that, I don't know. I don't know how you capture that. And just in saying that, I'm just aware of how much other unmet bereavement need is out there in the community and, you know, how many people would come off antidepressants if they actually got some good emotional support? So, yeah, some of them are hard to capture… (I22K:141-146)

At the case study site, the debate around outcome measurement was being addressed as it made the transition towards a health promoting palliative care approach. Consideration was being given in this debate to optimal outcome measurement strategies utilising multiple evaluation methods (I17K), such as in the framework suggested by Eagar, Cranny and Fildes (2004). In it the authors provide items for assessment, tiered into impacts on and outcomes for consumers, providers and the care delivery systems. This framework provides for some consideration of the impact of palliative care provision upon communities, and was utilised in the development of a population approach to the organisation’s strategic development (DP43). This approach to evaluation of palliative care
services may have application to social models of end of life care, such as health promoting palliative care, and is addressed later in this dissertation.

5.4 **Strengthening Community Action**

The third key action area in the *Ottawa Charter* is that of *strengthening community action*. In health promotion practice, this has referred to communities becoming empowered to be self-determining through a number of strategies including community development (Wass, 2000). In this study, it relates to the nature of the engagement of the hospice with the wider community, beyond the recipients of palliative care services, to promote community action towards improved support of people at the end of life. This goal is strongly linked to the participatory nature of health promotion and acknowledges the “social character of health and illness” (Kellehear, 1999b, p.12). Whilst strongly evident in the earlier decades of the modern hospice movement, these are attributes that have been eclipsed as palliative care services have become mainstreamed (Clark & Seymour, 1999; Hart et al., 1998). An attempt to reconsider the nature of the relationship between service providers and the communities from which consumers are drawn is a key endeavour of health promoting palliative care.

5.4.1 **Implementation of strengthening community action**

The implementation of this component of health promotion by the case study site predates the organisation’s interest in the health promoting palliative care approach. This first level analysis identified two emergent themes.
5.4.1.1 Death belongs to the community

The wider community needs to be doing something so that…dying doesn’t belong to a hospice service…it belongs to the community. (I29K:8-10)

In this study, there is substantial evidence that this component of health promotion has long been prioritised both organisationally and individually by respondents. One interviewee, who was one of the three remaining original staff members, recalled how even at its inception, the hospice was thinking about its influence upon community attitudes to death and dying:

Even back in 1992 when we started, probably the original way that we started affecting community attitudes was by - one of the first things that we did was to train a group of volunteers from the community and I think as soon as you start…bringing people from the general community into the organisation and particularly into people's homes, then you start affecting how they see death and dying and then it has a ripple effect because their families are people they connect with. (I22K:51-56)

Consequently, when the leadership of the hospice began to speak of a strategic shift towards the integration of health promoting palliative care in the two years or so preceding this study, the notion of strengthening community action was not a foreign one to its personnel. Given its conceptual congruence, there was little resistance to the notion that, as a health promoting palliative care organisation, the organisation might seek to empower community members to develop resilient communities with an enduring ability to confront issues of death and dying (Kellehear, 1999b). Indeed, most participants of one focus group for staff referred to the organisation’s role in normalising death and dying (F01S). The hospice’s role in achieving this goal through community engagement was also evident in the
organisational documentation, where the conceptual link between healthiness and dying was made:

[The hospice]’s vision is the creation of a healthy community attitude in relation to death and dying. We aim to help people do something as ordinary as dying, extraordinarily well. We believe that this service is best provided in a health and supportive community where death, dying and bereavement can be openly discussed and accepted. (DW04)

5.4.1.2 The community is death-denying

Kellehear (1999b) questioned the assumption of death-denial in society, suggesting instead that people are not mindful\(^9\) of issues of death and dying unless they are directly involved in them, which is different to being resistant to contemplating the presence of death as a part of life. Nevertheless, he goes on to say that “…the absence of thinking about death and dying on the part of most people does itself mean that people are usually poorly prepared for death and dying…” (Kellehear, 1999b, p.44). This apparent lack of preparedness was understood and named by many respondents in this study as death-denial, although death denial is itself a disputed term.

Ironically, most service recipients of the hospice service were perceived by staff to be representative of an enduring fear of death and dying still present in the wider community, despite the hospice’s long term efforts to counter such fears. Respondents reported interactions with the wider community that illustrated death-denial. There was, it was perceived, a general lack of awareness of the nature of palliative care work, demonstrated in an anecdote from a staff member who was recruited to address a community group, who then resisted any discussion of death

\(^9\) Researcher’s emphasis
and dying, rather keeping things practical and pragmatic (F01S). In another instance, one key informant was confronted with a blunt question about the value of palliative care in this way:

I was on the radio a while back and someone said, ‘We’ve always died, why do we need you?’ I said, ‘Very good question! A lot of people die in pain – emotional, physical or spiritual. Do you want that to happen to you?’ (I02K:417-419)

However, death denial is not simply a matter of limited awareness or conversational reticence, and as an organisation, the hospice acknowledged an underlying, widespread fear of death that underpins resistance to awareness-raising strategies (DW03; DW04). One participant in a focus group for volunteers indicated a wish for a more proactive approach to community engagement by the hospice to address this fear as well as raise awareness:

I suppose I would like to see [the hospice] become very proactive in educating the community and I suppose assisting the community in alleviating some of the fear that is surrounding death and dying. (F02V:406-408)

Although the goals of the organisation were applauded by one key informant, they were also concerned that the scope of its efforts was limited to service recipients and their networks, and that the wider community was yet to demonstrate the impact of such endeavours:

I think [the hospice]’s mission is to give that care and education to build a sustainable community is the overarching health promoting palliative care thing…building a sustainable community is the overall mission…at the moment we’re building a sustainable palliative community, but it’s not gone into the wider [community]… (I20K:222-226)
Again, the question of the hospice’s core business is raised here.

These approaches are integral to health promoting palliative care, representing the systemic need to reorient health services to the “idea of death and dying” (Kellehear, 1999b, p.44). Its inclusion in the hospice’s organisational goals is an important strategy towards addressing death denial and demonstrates the interrelationship between the health promotion components of strengthening community action and reorienting health services.

5.4.2 Enablers of strengthening community action

These factors in the implementation of the case study site’s integration of strengthening community action provide a context for the views of respondents who identified a number of enabling factors in the structures, processes and outcomes of the organisation.

5.4.2.1 The hospice’s Buddhist foundations promote HPPC uptake

Health promoting palliative care was viewed by one interviewee – who was an original member of the hospice staff – as an appropriate vehicle to achieve the goal of alleviating fear of death and dying (I07S). This provided a strong link between the Buddhist philosophy of the case study site and the goals of health promoting palliative care. The potential outcome of this was speculated upon by a key informant who anticipated the words of an empowered community in demanding health promoting palliative care services:

The community needs to be more involved in saying, you know, ‘Yes, we want palliative care, we want to die at home, we want to be active people until we die, we want to be making a contribution to the community until we die, my family needs to get back into the community after I’ve died.’

(I14K:210-213)
In their consideration of the practical ways in which the hospice might be able to effect a strengthening of community action, respondents saw a strong connection between the Buddhist foundations of the hospice and a sense of action-in-the-world. The socially-embedded nature of Buddhist practice was understood by one key informant as a “living example of compassion in action” (I08K:9). For example, the role of the bookstore in providing information for coping strategies for living and dying was viewed “as an extension of that compassion, it is this activity that strengthens community action towards acts of compassion to the dying” (I08K:9). This link between the hospice’s Buddhist philosophy and its practice of palliative care is a well developed feature of its integration of health promoting palliative care within the organisation. Whether this congruence is reflected in the wider community was difficult to determine. Whilst surveyed levels of client satisfaction were high (DP23), this was amongst the actual consumers of the hospice’s services, and whether its Buddhist foundations represented a barrier to access for some could not be established.

5.4.2.2 Existing involvement in strengthening community action

A key structural enabler lay in the presence of established organisational mission and goals that explicitly and publicly described the case study site’s commitment to achieving healthy outcomes for the wider community (DW01; DW04). The verification workshop group endorsed the necessity of this structural element as a key starting point in the integration of health promoting palliative care (F05).

The inclusion of a consumer representative at the governance level of the case study site was foreshadowed as structural enabler for the integration of
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strengthening community action (see Table 3.4). This was seen as a significant shift towards the hospice’s status as a health promoting palliative care organisation:

We have to involve consumers in planning and evaluating our services…what does the community out there, the wider community, think of this? (I14K:21;27-28)

Interestingly, the recruited representative was a former member of staff (and a key informant in this study) whose role in the organisation was now seen by the Board of Directors to encapsulate consumer representation, rather than the responsibilities of the former position held (I14K). As this took place in the final months of the data collection period of this study, the impact of this change was not immediately apparent.

Some outcomes were anticipated rather than actually measured. One key informant believed that the integration of this health promotion element would be evident once the hospice was viewed by the wider community as a leader in issues of death, dying, grief and loss, and undertake particular activities:

…what we're all becoming much more aware of now is there are so many more possibilities of what we can do and…with the [death education] Program and [the book store] and the use of the community wing…some of the things that I would like…to see are things like free public talks on things like grief and loss, preparing for a funeral, emotional resilience, bereavement support groups. You know, things that are much more publicly available.

(I22K:57-63)

Strategies to market these programs as “whole of life education” (DP50:¶2) were being devised to circumvent death denying attitudes amongst potential clients of
the program. Whether these are successful in achieving this will be measured in the pre/post evaluations structured into the programs.

5.4.2.3 **Death education programs**

The presence of such death education programs was another structural enabler identified in Table 3.4. Their presence in the organisation, even when funding is not available from government sources, demonstrated a high level, practical commitment to this feature of health promoting palliative care. Death education, it is worth recalling, is not simply the provision of information to the public by palliative care organisations of the services available (Kellehear et al., 2003), but aims to “encourage people to learn what they need to know about death and dying” (Kellehear, 1999b, p.79). During the data collection period of this study, the hospice conceived, developed and implemented death education program, with its rationale being:

> Individuals and communities are ill equipped to face issues related to death and dying. This is exacerbated by a western medical and societal model which sees death as a failure. Research has shown that attempts to address this situation via targeted education programs have not been successful. The wider community does not access them because of the pervasive, death denying mindset. (DP50:1)

It was perceived by the organisation’s leadership that clinical palliative care services, including the home hospice service, did not have the capacity to address these issues within current structural and funding frameworks (I33K). Instead, using a “whole-of-life” education approach (DP50:1), and with acknowledgement of its Buddhist underpinnings, the death education program targeted community and corporate clients with the aim of educating participants about life skills as a
preparation for death, apropos of the view stated above regarding the link between Buddhist philosophies of living and dying. Put simply by one key informant, the program had the function of “...normalising the fact that death is a part of the life cycle” (I22K:194; also I32K). To do this, its content included consideration of strategies for workplace wellbeing, meditation practices, harmony in relationships, self-help and healthy living and dying (DP50). Evaluation of the program’s impact was integrated into its structure and will be reported upon following a trial period that will take place after the data collection period for this study. Specifically, the establishment of the death education program was seen to be a key outcome in the case study site’s move towards integrating health promotion (F04S). In this sense, the death education programs were seen by informants as a socially valuable activity, and one which they appropriately could undertake to provide. There was a greater sense that these health promoting activities were a key component of the hospice’s core business.

5.4.2.4 Programs strengthening community capacity

Other programs at the case study site were also considered structural elements that enable the strengthening of community action around issues of death and dying. The purpose of the call centre was to “improve quality of life for people who have a terminal illness and provide links to carer support” (DW35:1) through the provision of a central reference point for information about palliative care for health care professionals and members of the general public, including those with life-limiting illnesses, their families, and those who care for them. The call centre was perceived by one key informant to empower the community through the provision of information (I22K) and reported positive feedback to its
booklet *Caring at Home with [hospice name]* (DP49). However, it could be argued that given its limited usage by callers other than potential service recipients and health care professionals, the extent of its enabling in this sense is minimal. Indeed, it may in fact play a more significant role in the creation of supportive environments than in strengthening communities. The difficulty in making this judgement lies in the complexity inherent in measuring the outcomes of health promoting palliative care.

When asked to consider the outcomes that evidence the extent of the organisation’s role in strengthening community action, respondents were quick to point to the recruitment of volunteers; a substantial proportion of the hospice’s volunteer corps were made up of former carers, assisting as office or family support volunteers (F01S). The volunteering program has been discussed in detail above, however it was regarded by some respondents as playing an essential part in strengthening communities, as volunteers were viewed as community members, rather than staff (I22K). The view was taken that participation in volunteering was evidence of stronger, more resilient community members with regard to issues of death and dying. Further, the hospice was considered to be flexible in finding a place for them in their palliative care work (F01S; F02V; F03V).

### 5.4.2.5 Raising the hospice’s profile

A foreshadowed process enabler noted in Table 3.4 that the hospice demonstrated clearly was their participation in community activities that showcase their organisation. Each year, they hold two major community events that serve the multiple functions of:
- raising awareness of the hospice and its activities.
- raising funds.
- raising awareness of issues of death and dying.

These were viewed by respondents as integral strategies for strengthening community action as part of their integration of health promoting palliative care. These events are the Art Market and the Christmas Market.

The annual Art Market is held in the third quarter of every year and presented a wide range of donated secondhand art and handmade craft items for sale to the general public (DW16). It had been recently rebadged and relocated to the grounds of the newly-occupied premises and was more explicitly connected to the work of the hospice. It has required considerable negotiation with neighbours, Queensland Health and the local city council, as it had in the past necessitated street closure and provision for extra street parking. The researcher attended this event twice during the data collection period and observed settings of concerted activity by staff and volunteers of the hospice in engaging with the large crowds that attended. This setting has been well captured in the documentation of the organisation, in a visual data source that informed the path of inquiry in this study. Shown in Figure 5.1, the image was originally an oil painting by a former caregiver – now volunteer – of the hospice, and depicts the Art Market. The painting has been reproduced as a postcard which is designed to meet dual purposes as a fundraiser and lifting the profile of the hospice in the local community in an aesthetic and accessible way.
The second major community event in the case study site’s calendar was the annual Christmas Market (advertisement shown as Appendix 16). Like the Art Market, it is an event that is designed to raise funds and awareness, and is well-attended by the general public. The extent to which it achieves the goal of strengthening community action is again difficult to measure, although both these events have elicited questions from strangers about the work of the hospice (I20K). The presence of these structural and process elements within the organisation is viewed as demonstrating outcomes consistent with the integration of strengthening community action. However, significant barriers to its full integration were also identified in the data.
5.4.3 Barriers to strengthening community action

The engagement of the hospice with the community, beyond its consumers, was a well integrated component of health promotion, however, respondents identified three barriers to strengthening community action.

5.4.3.1 Resources for non-clinical activities

This analysis has already identified two key – and related – structural barriers to strengthening community action for the case study site that lay in the issue of funding and limited resources to tackle non-clinical issues (I23S; I20K). Indeed, one staff member considered it “the biggest test for [hospice name]…” in implementing health promoting palliative care (I23S:88). Only partial funding for some of the hospice’s clinical program was provided by Queensland Health, primarily focussed on illness management. The organisation’s response to this barrier was to create programs, such as the death education program, that had potential to develop into an income-generating arm, although that itself presented risks to its success:

…like any business…if it needs to support itself then you’ve got to work out a way to do that, but not take itself away from the initial need that it’s trying to meet. (I33K:216-218)

It was feared that raised community awareness could create unrealistic expectations of the hospice and an over demand for its services (I22K), yet this view was not endorsed by the verification group. Instead, they argued that as demand increases, so too would the organisation’s capacity to obtain the necessary funds to respond:

We feel, as the demand goes up, the potential for raising the funding to match that demand will go up. (F05:200-201)
This concern was ameliorated somewhat by work by peak bodies in palliative care in Australia noted earlier, which promoted a systematic framework for a population-based approach to planning palliative care services (Palliative Care Australia, 2005b). The hospice’s capacity to respond to the demands that may result from raised community awareness would be addressed within this broader context.

5.4.3.2 Are non-clinical activities core business?

Interestingly, one key informant stated that the case study site’s small size and limited resources to address activities viewed as non-core business were further impeded by a perception of these activities as “airy-fairy” (I20K:142). Yet when this view was presented to the verification workshop, participants expressed strong disagreement with this assertion. Indeed, the consensus was that these activities were commendable priorities for the organisation and were being broadly embraced by the wider community as substantial matters of concern (F05). Whilst the size of the organisation was seen as inherently limiting to the organisation’s capacity to address these unfunded endeavours (I20K), it was also seen as an enabler insofar as it was perceived to allow organisational flexibility in the rapid adaptation to change (F05). A key strategy identified to address this barrier was for the hospice to self fund a dedicated role to address this element in the day to day running of services (120K). Importantly, establishing this role does not abrogate the responsibility in others within the organisation to take a health promoting approach to their roles, but rather to provide leadership and program oversight.
One key informant was concerned about the organisation’s strategic thinking around prioritising strengthening community action, expressing concern whether it could, despite its explicit written commitment, demonstrate processes indicative of health promoting palliative care as an organisational priority:

I think organisations like [hospice name] need to balance out between what they can’t see and what they can see…if they want long term sustainability, if they want to be leaders here, they need to think bigger and more visionary. The only tension there is to commit them to it, but if you can’t think bigger than this you won’t be able to find the funding for it…if it’s important enough, you will find it. (I20K:160-161; 163-164; 167-168)

5.4.3.3 Humanistic outcome measurement

Outcome measurement in the strengthening of communities was considered a substantial barrier to its integration, as seen elsewhere in the components of health promotion (I20K). This is illustrated in an interview with a respondent about outcome measurement in the book store, where the commercial benefits are easily calculated, yet the humanistic benefit cannot be measured, although the subject matter of titles purchased may give some indication of the level of interest in issues of death and dying (I08K). Further, despite being a foreshadowed process element (see Table 3.4) no community assessment had been undertaken by the case study site and consequently, there was no attempt to develop indicators of strengthened communities (I20K). Verification workshop participants who addressed this health promotion component linked the need for community assessment to the hospice’s progress in integrating health promoting palliative care:
We feel it is a demand-led service and that there is gradual growth because we have to control ourselves. We have limited resources. We can only progress if we spend of a lot of time doing comprehensive community assessments. We can't take action.

(F05:193-196)

Community assessment is an established component of health promotion practice (Talbot & Verrinder, 2005) and is readily transferable to health promoting palliative care. Its absence in Kellehear’s (1999a; 1999b) earlier work and the organisation’s apparent reluctance to conduct community assessments represents a significant barrier to the integration of health promotion components.

5.5 Developing Personal Skills

The fourth component of health promotion described by the Ottawa Charter to be considered is that of developing personal skills. In health promotion practice, this has addressed issues of empowerment “…so that [people] have the skills necessary to make healthy choices” (Wass, 2000, p.18). The role of the interpersonal and therapeutic relationship between provider and recipient in facilitating this process has been studied (Canning et al., 2005; Richardson, 2002), however a health promoting palliative care service should, Kellehear (1999b) asserts, provide both this individualised approach and address the personal skills development in the wider population. For example, death education programs have been suggested as a key strategy for a health promoting palliative care organisation to undertake. In this study, the case study site’s participation in the development of personal skills to assist individuals to deal with issues around death and dying includes both consumers and health care professionals.
5.5.1 Implementation of developing personal skills

The provision of supportive and palliative care services by health care professionals requires a broad range of clinical and interpersonal skills. The holistic nature of palliative care clinical work requires a breadth of skills which may be called upon at any time (Canning et al., 2005; Palliative Care Australia, 2005a). Those who seek work in palliative care were seen to require personal development strategies within the context of professional development activities (I07S; I15S; I17K). For some, this was sought outside of the hospice and the support it offers its staff and volunteers, whilst for others, this proximity did not present any impediment to personal growth (F03V). The need to ensure strategies for personal development and self-care are in place is highlighted by PCA in Standards for Providing Quality Palliative Care for all Australians (Palliative Care Australia, 2005a). Further, the capacity to work flexibly with the wide-ranging needs of clients and their families is a personal skill identified in the Competency Standards for Specialist Palliative Care Nursing Practice, which state in Competency Standard 5 that the specialist palliative care nurse:

Demonstrates advanced palliative care knowledge and skills in meeting the multiple, complex care needs of individuals with life-limiting illnesses, their caregivers and family, across the continuum of care including bereavement, and in the context of an interdisciplinary approach to care.

(Canning et al., 2005, p.111)

This mixture of clinical skills and knowledge with a range of personal attributes is a characteristic of competence in nursing practice that is recognised elsewhere
(Watkins, 2000) and forms an important part of identifying the need for the development of personal skills.

### 5.5.1.1 Linking palliative care to personal skills development

The inclusion of this component of health promotion as part of the health promoting palliative care agenda is, like that of creating supportive environments, a familiar one within palliative care organisations. Consequently, in this study, a number of structural, process and outcome elements within the organisation were foreshadowed (see Table 3.4) as features of the development of personal skills. These include the presence of professional development for staff and volunteers, performance appraisal processes that target personal skills, and the provision of death education programs and caregiver education resources. Further, it was anticipated that the measurement of improved outcomes relating to the integration of higher level personal skills would be evident.

### 5.5.1.2 Existing involvement in developing personal skills

As identified in Chapter 4, a range of strategies promoting the development of personal skills were evident at the hospice upon commencement of the data collection period for this study. Some, such as the volunteer training course, were discrete programs; in organisational policy and procedure for Training and Development (DP01; DP16), individualised training and development needs were identified as the basis for an annual skills audit, which in turn shaped the strategies for further training. Performance appraisal processes were clearly spelled out (DP05; DP19) and evidence of their implementation was obtained (I19K).
Volunteers identified a number of attributes that the palliative care volunteer needs to possess for palliative care work, such as a sense of altruism and compassion, openness to differences in how individuals face death, a high level of communication skills, flexibility and a willingness to let go of the feeling of needing to ‘fix it’.\(^{10}\) Focus group participants described a necessary calm detachment that enabled them to accept the mortal nature of the human condition and enabled them to feel comfortable with talking about death (F02V; F03V). These skills were obtained firstly from personal experiences of caring for a dying relative or friend, but also from individuals’ working backgrounds (I04V; I06V).

The personal skills required to work as a nurse or counsellor in the palliative care setting were strongly aligned to those mentioned above by volunteers (F01S; F04S). In particular, the ability to set boundaries around personal and professional lives was viewed as an essential personal skill in palliative care work (I07S; I15S), as described in the *Competency Standards for Specialist Palliative Care Nursing Practice* (Canning et al., 2005) noted above. This staff member spoke to this need for balancing the professional and personal aspects of her life in this way:

> Yeah, this is huge. [hospice name] is a very busy place. It’s always having activities and if a person wanted to, they could…spend a lot of time here. I think it’s a matter of finding your boundaries, time management and doing it and making sure you have another life because, let’s face it, with this place, in the big picture, it’s a job isn’t it? It’s just a job. Whatever happens, in the big picture, one day I’ll leave [hospice name] and what will I have? (I07S:148-155)

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\(^{10}\) Multiple sources of data: (F02V; F03V; I01V; I04V; I06V; I29V)
Nurse respondents in this study considered the attainment of personal—and other—skills as a lifelong process; even those with substantial working histories in palliative care saw the need to continue learning in order to be responsive to the holistic needs of their clients. This highly experienced palliative care nurse stated:

...after 15 years in palliative care...it’s great to go to education where it makes you stop and think, you know, what other things you might need to address in situations.

(I15S:28-29)

Other strategies were less tangible, such as the support provided by clinicians that upskilled carers, illustrated in this quote from the wife of a client:

I think I'm learning new skills because I'm getting that support. Okay, when [patient name] comes home this time, they're going to have to teach me a whole heap of new stuff like bed-bath, and you name it. There's stuff I don't even know and I will be competent at that, but I've never had that sort of background and up until now, I never really wanted to. [laughs] (I05C:87-90)

The education of carers in caregiving skills was viewed as an integral part of the work of the hospice’s specialist palliative care nurses and was viewed as an evolving strategy that had improved markedly over the organisation’s history (I07S).

### 5.5.2 Enablers of developing personal skills

The case study site’s integration of this health promotion component illustrates that development of personal skills is a conceptually congruent one when considered at the interpersonal level. A number of enabling factors for this
component were identified in the structures, processes and outcomes of the case study site.

5.5.2.1 **Concrete strategies targeting skill development**

Several programs were designed specifically with the explicit goal of developing the personal skills of participants in addressing issues regarding death and dying, grief and loss. Firstly, the volunteer training program was widely held as a key strategy in upskilling its participants as they prepared for voluntary work with the hospice.\(^{11}\) For almost all volunteer respondents, a personal experience of caregiving, particularly involving the palliative care of a family member, was the primary motivating factor in the decision to volunteer with the hospice.\(^{12}\) For many volunteers, there was a significant spiritual meaning attached to their volunteering:

> I do it to make meaning of my life experience and I guess that’s why I chose [hospice name] to do voluntary work with, because it honours what I learned from [caring for my deceased family member] and in terms of my spiritual beliefs…it is making sense of my life experience. (F02V:68-70)

Personal development opportunities for volunteers were seen to be an important strategy to clarify the personal and professional boundaries within volunteering. The opportunity to work in a specifically Buddhist environment where their personal values were congruent with organisational values provided a further motivation for some volunteers, including non-Buddhists (F02V; F03V; I29V). As for many of the paid staff, the volunteers identified a link between the

\(^{11}\) Multiple sources of data: (F02V; F03V; I01V; I04V; I06V; I29V)

\(^{12}\) Multiple sources of data: (F02V; F03V; I01V; I04V; I06V)
Buddhist philosophy underpinning the hospice’s work and its transition to a health promoting palliative care model.

Given these foundations, it is perhaps no surprise that many of the volunteers were able to so easily identify the personal skills they required for volunteering, having themselves been recipients of these skills in the past. Importantly, however, is the role played by the organisation as a training body of volunteers as an enabler of the development of personal skills necessary in the provision of palliative care. Respondents strongly endorsed the suitability of the volunteer training program at the case study site in assisting participants to obtain or further develop their personal skills, with the program of monthly support meetings viewed as a key enabler in skills development (F02V; F03V; I23S), and thus of the hospice’s integration of health promoting palliative care. The verification group described the volunteer training program as “second to none” (F05:88).

Secondly, the case study site’s professional development programs for staff attached similar weight to the development of personal skills. In addition to the orientation program (DP04), staff members were provided with an ongoing schedule of educational activities, including clinical supervision (I15S) which this respondent found a valuable mechanism for reflective practice:

We had one on dealing with difficult people yesterday, as part of our clinical supervision and that was excellent because it just makes you think more about what else you can do in that situation apart from just listening and while that probably defuses, from my experience, probably 90% of the situation, just listening to them and asking people what they want, there are certainly a certain percentage that … there's more to do ...

(I15S:31-35)
The hospice also enabled the development of personal skills necessary for the provision of palliative care through its participation in two specific training programs. The Program of Experience in the Palliative Approach [PEPA] is a national program of clinical placements of generalist health care professionals in specialist palliative care settings in order to upskill them in the palliative approach to care (Centre for Palliative Care Research and Education, 2006). The case study site was one of approximately twelve host sites in its state and hosted both general medical practitioners and registered nurses who identified specific learning needs in palliative care, often including personal skills development such as interpersonal communication.

The second program the case study site participated in was a joint training program between themselves, a major tertiary hospital and the Centre for Palliative Care Research and Education [CPCRE]. This program was designed to train registered nurses with the skills required as specialist palliative care nurses and included a period of clinical placement. These skills – ranging from clinical to psychosocial to interpersonal – were observed by this participant of the training program when she accompanied one of the hospice’s specialist palliative care nurses into clients’ homes:

… [to] see the demands made of the nurses in the space of one hour, to move from medication regimes to basic hygiene, to being able to talk to a family about what to do with a dead body, in the space of an hour! Now in other areas of nursing you might have…longer time to talk about clinical stuff… but in palliative care you do it on the spot. You have to be able to extend yourself in whatever direction’s needed. (I27S:80-84;87-88)
Chapter 5: Findings – Impact, Enablers and Barriers

This modelling of specialist practice, in which both clinical expertise and personal skills were demonstrated by an experienced registered nurse, showed a positive outcome in the process of attainment of personal skills (I27S).

5.5.2.2 Personal development

Individual attributes, beyond the provision of training programs, were viewed as important enablers for the development of personal skills. For example, the ability to maintain a balance between personal and professional lives was viewed as an essential personal skill in palliative care work (I07S; I15S).

This staff member spoke to this need for balance in this way:

I think that [striking a balance between personal and professional] is something that is constantly there and certainly...I am in positions where you have to develop a lot of things for the organisation, that is a balance with how much of that intrudes into your own time, and I have always been someone that really enjoyed doing those things, developing things, but it’s just, you know, the constant having to look and see that that’s not taking over your life. (I15S:58-62)

Moreover, the need to have confronted one’s own mortality in order to work fruitfully in palliative care was seen as another essential skill (I04V; F01S; I31S):

INTERVIEWER: So what are some of those skills you’ve drawn from your extensive background in working in oncology palliative care that you feel help you to do your job...?

RESPONDENT: First and foremost, not being afraid of death. A lot of people are very frightened by it, by death and people dying, and my way of dealing with that has been to put myself in the patient’s position. (I31S:41-46)
Interestingly, this ability was identified by respondents from differing disciplines – nursing and other clinical staff, family support volunteers, and call centre workers.

5.5.2.3 Consumers’ preparedness

The skilfulness of consumers of palliative care and the wider community in dealing with issues of death and dying is an element of health promoting palliative care that has been foreshadowed elsewhere (Kellehear, 1999b) and subsequently noted in this study (see Table 3.4). These skills amongst carers of the hospice’s clients were hugely varied, with some carers indicating little experience in caregiving (I05C) to those who had been supporting chronically ill family members for years (I12C) or were even retired health care professionals (I24C). Regardless of their backgrounds, all carers were given the Caring at Home with [hospice name] booklet (DP49) or a booklet prepared by the call centre entitled Palliative Care at Home [reference deleted for deidentification]. The support provided by the hospice was regarded by carers as enabling them to feel more capable of providing care at home and is strongly linked to the health promotion key action area of creating supportive environments. In particular, the provision of information, clinical advice and practical demonstration of skills were viewed as key enablers in achieving home care (I05C; I12C; I30C) and mechanisms were in place for consumers to provided feedback to the organisation about the services they received (DP23). Rather than encouraging dependency upon service providers, this support was linked to increased independence and positive client outcomes; during interview with one carer, the possibility of dependence was raised:
**INTERVIEWER:** Sometimes carers like yourself can feel that they are more helpless and more dependent upon the support of a group like [hospice name], but other people it's really a matter of doing what has to be done in the most efficient way possible, so the person who’s the patient can have what they need.

**RESPONDENT:** Mmm. That's how I feel. So I don't feel inadequate or anything. I'm feeling that I'm learning new stuff and as time goes by, if he comes out of hospital this time, we'll probably end up having [hospice name] out more than once a day and so if I can do other stuff, it enhances his feelings of being less dependent. (I05C:98-105)

Another carer believed that, at 59 years of age, her life experience, combined with the acquisition of caregiving skills, enabled her to look after herself in the process of providing care for her dying partner (I31C).

This raises the question of how members of the general public might obtain personal skills for dealing with issues of death and dying, prior to learning them – often reluctantly – as a consequence of becoming consumers of palliative care services, as this quote from a carer shows:

Oh, I'm strong, yeah. Yes, I am, but I am not wanting to be. (I05C:200-201)

As the profile of consumer participants in this study shows, personal preparedness for caregiving in the home setting with palliative care support was highly individualised, with some consumer respondents indicating that whilst some of the personal skills they require were pre-existing, others were lacking. In this sense, the need for flexible and responsive staff was emphasised and linked to strategies to promote the empowerment of consumers.
5.5.2.4  **Death education programs**

Education forms a central strategy in health promotion. Strategies to educate the wider communities about issues of death and dying have been proposed (Maslen, 1998; Scott, 1992). As a service provider attempting to integrate a health promoting palliative care approach, the hospice identified death education as a significant enabler of this process of skill attainment for members of the general community. During the period of data collection for this study, the case study site developed and trialled a program entitled *Open Heart, Peaceful Mind* as part of the death education program (I32K). The goals of this program were to provide a six week experiential learning process promoting self-awareness and wellbeing, enabling better stress management, teaching meditation techniques and enlarging the participants’ personal capacity for compassion (DP52). Given the philosophical link between Buddhism and acceptance of mortality, this program included consideration of issues around death and dying, and was viewed as a means of equipping its participants to more skilfully address these matters when they inevitably arise (I32K).

Notably, whilst *Open Heart, Peaceful Mind* was understood to be strongly based upon Buddhist principles, it was not explicitly for Buddhists or even those interested in learning more about Buddhist teachings; indeed, a separate program entitled *Introduction to Buddhism* was planned for as another death education program to address that demand (I22K). This was viewed as addressing the needs of the wider community because of Buddhism’s central concern with death as a normal part of living.
5.5.3 Barriers to developing personal skills

Despite the substantial number of organisational elements enabling the development of personal skills, a number of barriers were identified within the organisation by interviewees and participants in focus groups.

5.5.3.1 Death denial

The notion of death-denial was again evident in the thinking of respondents in this study. The inherently confronting nature of palliative care work was acknowledged (I28S) and thought by respondents to reflect a more widespread, death-denying societal attitude. Respondents linked it to the need for addressing the mortal human state, as described above (I17K).

5.5.3.2 Paradigmatic constraints

This need for personal skills in palliative care work was understood not simply as ticking off a checklist of psychosocial abilities. Rather, it was conceptualised by this staff member as a process of personal growth:

It’s not about, not just about learning techniques and skills. It’s about growing as a person because that’s who you are in a counselling relationship. That’s the main tool you have is yourself and that relationship with the client, so I’m finding, I struggle anyway with this concept for me between nursing as a clinical role and how nursing traditionally and health, has been steeped in medical model and now it is this evidence based bullshit. Now I don’t like it…I would prefer to, I suppose for me, that counselling, personal growth stuff sits a whole lot better. (I27S:204-210)

As this quote illustrates, this respondent felt constrained by the influence of the medical paradigm and the demands of evidence-based practice and was attempting to reconcile what was seen as two opposite viewpoints in the
scientific and humanistic imperatives. Indeed, this tension lies at the very heart of health promoting palliative care (Kellehear, 2005b; Rao et al., 2005) and the attempts of organisations like the hospice to reconcile them in their models of care.

### 5.5.3.3 Ongoing support of staff/volunteers

Beyond these philosophical concerns, a number of structural barriers were identified within the case study site’s programs – whilst the volunteer training program was previously noted to be of a high standard, the uptake of graduates from the program was low, although the reasons for this were not clear (F03V; I03V). This was perceived to increase the risk of burnout amongst volunteers when their numbers were lessened and the expected contribution was high (I06V). One volunteer believed that an annual refresher program was warranted and that its absence presented a barrier to the development of their personal skills in palliative care (I01V). Volunteers also expressed a poor sense of place prior to the move into the restored premises – their prior accommodation in buildings in poor states of repair had a negative impact on their sense of belonging and morale (I06V). Significantly, most volunteers interviewed for this study reported reacting negatively to instability in the volunteer coordinator’s role; during the data collection period the role was occupied by a number of different people, including a time where family support volunteers and administrative volunteers each had their own coordinator. This led to unstable processes between the coordinators and volunteers which left the volunteers feeling directionless, with a
great deal of uncertainty about their skills development when there were so many
incumbents in short spaces of time.\textsuperscript{13}

Indeed, beyond the volunteer coordinator’s role, the rapid turnover of staff
in key roles, and the reconfiguration of roles and responsibilities, not only
detracted from the creation of supportive environments (I13K), but presented key
barriers to the continuous development of personal skills amongst other staff
because of unstable leadership (I14K).

Absent from the personal skills development programs at the time of data
collection for this study were strategies that explicitly prepared health care
professionals for the promotion of consumer skills. Whilst the role of the
palliative care nurse in particular in educating clients and carers in practical and
life skills was identified (I07S; I15S; I28S), this was not formalised in any of the
skills development programs. The use of a community development approach to
training in adult learning principles may be have had application here, given its
prominence as a practice within health promotion (Talbot & Verrinder, 2005).
Adding this to existing professional development programs and incorporating
feedback from consumers through satisfaction surveys are strategies that had not
been considered despite the ease with which they could be introduced within
existing organisational structures and processes.

\textbf{5.6 Reorienting Health Services}

The \textit{Ottawa Charter} states its fifth key action area as \textit{reorienting health
services}. In health promotion practice, this has addressed systemic issues, such as
the global education of health care professionals (Wass, 2000). Although this

\textsuperscript{13} Multiple sources of data: (F02V; F03V; I01V; I04V).
component of health promotion is placed last in order in the *Ottawa Charter*, it can be seen as fundamental to the integration of the other key areas of health promotion; whilst the other areas pinpoint *what* activities of health promotion require consideration, the *reorientation of health services* focuses upon *how* organisations might strategise to integrate health promoting principles and practices. In this study, it relates to the activities of the hospice in reorienting its members to a health promoting approach, and has a particular focus on the holistic needs of its client population, and changes in organisational attitudes.

### 5.6.1 Implementation of reorienting health services

Whilst this fifth component of health promotion has systemic elements, respondents in this study were more focused upon the transition being undertaken within the organisation. A number of issues were relevant to this implementation.

#### 5.6.1.1 Conceptual congruence

Many of the elements of health promoting palliative care were reported to be familiar to respondents, their implementation philosophically straightforward, and their integration underway to some extent, as this focus group member stated:

> I think they are all elements that are integrated into palliative care and [hospice name], but others not so much. Developing personal skills – we all have to do that, otherwise we wouldn’t be working in an environment like this. (F04S:220-223)

This quote illustrates the notion that health promoting palliative care does not represent the cessation of conventional service provision, but a reorientation in approach to the provision of those services and the introduction of potentially
neglected areas. However, it represents a view not shared by all staff, as others felt that the integration of health promoting palliative care was far from complete:

There are things that every…in every one of those five areas [of health promotion] there’s lots of work that needs to happen…I don’t know…great concept though! [laughs]
(I23S:253-257)

5.6.1.2  Linking organisational vision to strategic goals

At a strategic level, the goal was set for the case study site to become a Level 1 specialist service (Palliative Care Australia, 2005b) and partially incorporating the health promoting palliative care agenda (I16K). Whilst PCA’s description is conceptually congruent with the health promoting palliative care approach, it does not fully capture the elements of a social model of palliative care (I17K). Nevertheless, a vision to achieve the optimal outcomes of health promoting palliative care was articulated by this key informant:

[hospice name] wants to grow, palliative care has got to promote that vision, we’ve got to put strategies in place and when…the vision is the right vision, and in palliative care their vision is to build caring, sustainable communities that only need specialist care to come in and make these people grow. That’s all. That’s it. That’s the message…For me, that is health promotion, what my definition of health promoting palliative care is.
(I17K:304-308;311)

To achieve this, the leadership team was charged with the responsibility of implementing the change to a health promoting palliative care approach using a quality framework that must underpin any organisational configuration (I16K). Interestingly, one key informant who was an original staff member of the hospice pointed out that the core values of the organisation had not changed in 15 years,
although how they are expressed and how services are provided had changed a great deal (I22K).

5.6.1.3 **Organisational stability**

The pragmatic issues of implementation were more problematic. For example, it took time to finalise the structural configuration of the organisation (see Figure 4.4 and Appendix 14) in order to most effectively implement quality improvement strategies that integrated this change (I19K). Once this structure was finalised, strategies for its implementation were devised; leaders of a palliative care service such as the case study site were seen as having primary responsibility in reorienting their members to a health promoting approach (I02K). Early education of staff and volunteers to the principles of health promoting palliative care was one practical strategy utilised to implement the reorientation of the hospice, although this was no longer being scheduled during the data collection period of this study (I02K).

5.6.1.4 **Consumer engagement**

The hospice’s role in educating the consumers of palliative care services was seen as integral to its reorientation to health promoting palliative care, through its contribution to normalising issues of death and dying (F01S). Health education was seen as the primary means to achieve this, but again was seen as a pre-existing activity of the hospice and its staff:

> The re-orienting health services as part of the health promotion, I think this health education project is a part of that process. It's like everything. You have to find the niche to get in to start the changes and it's taken - we have been working on doing this for three years. Because [hospice name]'s director started wandering around a couple of years
ago, talking about health promoting palliative care, when the book came out it became our bandwagon two and a half, three years back now, which is why the shift into community education, community input and community contact - and for the clinical team, this has been our first opportunity to get that shift into health care. That is my perception. We have always done education. It has been on specific things.

(F04S:294-302)

Primarily consumer engagement was implemented through the public education activities of the death education program (I10K). The possibilities for other public education strategies were identified, including the application of early intervention approaches, such as talking to school children about issues of death and dying (I11K). One volunteer saw the value of the organisation’s shift to health promoting palliative care lying in its positioning to respond to an anticipated change in social expectations of palliative care services:

With all the baby boomers coming into old age and sickness…and death and all that and it’s a big cultural shift from that generation and the hippies of the sixties for instance, that are getting cancer and stuff now and needing palliative care. Their values are so different now and there is such a business opportunity let alone social needs for the caring, palliative care that I’ve tried…there’s such an opening for and a need for palliative care and nursing that aren’t these typical government…[but the] social sort of profile that we’ve had.

(I29V:423-427; 433-434)

Another enabler of the reorientation was the enormous goodwill of the wider community, from which a robust volunteer corps was drawn and who, with other staff, were willing to undertake meaningful work (I29V). This was seen to provide
a receptive audience for the elements of health promotion that relate to public education and the potential for greater community engagement

5.6.2 Enablers of reorientating health services

5.6.2.1 Conceptual congruence

Influencing public policy and strengthening community action were viewed as core business for the hospice (F04S). Yet this tension between an articulated and strategic shift towards health promoting palliative care versus the integration of health promotion’s principles and practice without naming them as such is an important finding in this study and is considered further in Chapter 6.

Fundamentally, the perceived conceptual congruence of palliative care and health promotion translated into a willingness to embrace the change because it was consistent with the personal and professional values of so many affected personnel (I16K). This synergy between the elements of health promotion and the practice of palliative care was clearly reflected in this comment by a focus group participant, who stated:

I think they [elements of health promotion] all link in together because to be able to work in palliative care you have got to have the skills. (F04V:226-227)

As noted above, there was some debate amongst respondents during the data collection period whether it was even necessary to use the language of health promoting palliative care or simply underpin the usual activities of the organisation with its concepts. In response to this question, one focus group participant saw some advantage to explicitly articulating a health promoting palliative care approach:
Putting a health promoting label on it [palliative care] can help decision making...if that framework [HPPC] is used for decision making, that could make for the person having optimum health, whether they are going to die or whatever. (F01S:420-423)

5.6.2.2 Existing strategies for reorienting health services

As with any organisational change, the inclusion of health promoting palliative care in the mission, values, objectives, and policies and procedures reflect a strategic orientation towards implementing this organisational change (I16K). Its small size was understood to enable such change to be easily undertaken, although elsewhere the change process is reported to be problematic (I17K) and this is discussed further below. Similarly, organisational flexibility was seen as an essential means by which the hospice implements a reorientation to health promoting palliative care in response to an ever changing external environment; indeed, this capacity was viewed as necessary to the organisation’s survival (I22K). In the context of integrating a health promoting palliative care approach, this translated into the adjustment of the organisational structure to accommodate the inclusion of the call centre and the death education program (see Figure 4.4). This restructuring was also viewed as a highly positive direction for the hospice to take in terms of raising the profile of its Buddhist philosophy (I29V). Again, however, this flexibility was not entirely advantageous and this is discussed further below.

In governance, an enabler of the case study site’s reorientation to a health promoting palliative care approach was a foreshadowed issue noted in Table 3.4, that of the appointment of a consumer representative to the Board of Directors. This was viewed favourably:
The evidence is saying that if the community or the consumer is involved in their care, you’ve got better outcomes. (I14K:9-10)

This occurred late in the data collection period and the position was filled by a former member of staff. Whilst this was seen as an appropriate choice for the role by the incumbent (I14K), its validity as an authentic representation of consumers’ perspectives is open to question (Broughton, 2003).

Prior to the data collection period, and at the beginning of the case study site’s move towards a health promoting palliative care approach, staff and volunteers were given education and information about the new approach and the methods planned to implement the change. These sessions, however, did not continue and with a relatively high turnover of staff, the familiarity of personnel lessened with time (F05). The question of whether new strategies were required emerged in discussion with the key informant responsible for its integration (I02K) and was unresolved at the conclusion of the data collection period. Suggestions were made by other respondents of its inclusion in orientation (F04S) and in web-based resource information (I29V).

The participation of the organisation in research projects with a public health perspective was foreshadowed and noted in Table 3.4. One focus group participant reflected upon their involvement in this study in this way:

…a PhD thesis like this is - as we all know, it is putting evidence out there that this is a valuable thing to do. We have to hit them with evidence and evidence and evidence. You are becoming part of our evidence that this is a valuable thing - not to us. We are the converted. It's hitting that policy maker. (F04S:328-331)
The hospice had participated in a number of other research projects, although these were to some extent focused upon clinical issues. This participation was viewed as a means to effect change towards evidence-based practice in palliative care and reorienting palliative care services to a health promoting approach.

### 5.6.2.3 Death education programs

With the evolution of the implementation of health promoting palliative care, a number of programs have emerged that demonstrate its integration into the organisation’s organisational structures and processes. Perhaps most notable was the introduction of the death education program as part of a public education series to address the needs of the wider community for life and death education, which included *Open Heart, Peaceful Mind* with workplace wellness, and an *Introduction to Buddhism* course which had altruistic – rather than proselytising – goals, as discussed previously (I14K) and illustrated in this quote:

> From a Buddhist perspective death is part of life and the purpose of life is basically preparing for death and the next life, it’s one journey, sort of thing. So without getting into the Buddhist philosophical content, actually taking some of those principles and making that part of that [death education program].

(I10K:145-148)

There is a vision for such ‘essential education’ courses to include a residential retreat format to educate and support people in key life events, including death (I32K). Again, the influence of Buddhist philosophy upon the case study site’s implementation of health promoting palliative care is noted.

Interestingly, the death education program and the other programs have been designed to create an income-generating activity to support the home care
service. This has raised some questions about whether there is a tension between running a business and providing a high quality, health care service (I14K), although this interviewee responded to this suggestion with equanimity:

I don’t think a philosophical point of view is going to be less if you run it in a business like way. (I29V:490)

Indeed, as noted previously, the original core values of the hospice had remained unchanged in its 15 year history, although the ways they have been expressed and the hospice has provided a service have changed a great deal in this time:

How I feel that we have been changing and are changing is that we're now looking to benefit people in a much broader spectrum of the community. So now it's much more - so while our core business remains home-based palliative care and education and support for families, it's also looking at affecting community attitudes to life and living, death and dying, funerals, the whole topic of death and preparing for death. (I22K:31-35)

For this key informant, the health promoting palliative care agenda represented an evolutionary step in the organisation’s history, rather than a threat to its future. Nevertheless, the reorientation activities have unsettled many personnel and at the conclusion of data collection for this study, these concerns remained current.

5.6.2.4 Is HPPC core business?

Indeed, the issue of enabling the transition to health promoting palliative care through business practices was another key enabler for discussion. A key informant believed that each organisation contemplating a reorientation to a health promoting palliative care approach needed to assess whether such a change was congruent with, or constituted a move away from, their core business (I02K). This question was debated amongst respondents of this study throughout the data
collection period. Whilst health promoting palliative care was officially recognised as core business, the ramifications of its integration upon elements of conventional palliative care services, such as clinical care, were questioned (I22K) and are discussed further below. Nevertheless, utilising a quality improvement framework, the organisation’s goals for health promoting palliative care were identified, and strategies devised (I14K). Their implementation, of course, constitutes the phenomenon of interest for this study. The leadership of the organisation was seeking alternative sources of income so that health promoting activities could be implemented without negatively impacting upon the resourcing of clinical services such as nursing, counselling and spiritual care. This relieved some of the pressure previously felt by clinicians to participate in non-clinical activities and allowed for dedicated positions to pursue the health promotion agenda. Notably, however, this allocation of responsibility for health promoting programs to individual roles within the organisation came with the risk of creating the perception that health promoting palliative care activities are largely non-clinical in nature. In this study, this perception appears to have contributed in some way to participants’ concerns about the core business of the hospice.

Some discussion was evident of whether, within the context of providing an overall strategic plan, it was more appropriate to implement the changes simultaneously or incrementally:

I think…we need a whole plan under the five strategies rather than doing one thing at a time. If you’re changing public policy, you should be able to build sustainable communities at the same time…you have to create awareness, so people are aware what palliative care is…to effect public policy change, you have to get the voters to change public policy, so
creating awareness is part of building sustainable communities. (I20K:198-200; 202-204)

A key argument in favour of this approach was put forward – in order to reorientate the organisation, it was necessary to restructure it; implementation therefore, must initially be an organisation-wide act, which can then be followed by an incremental process (I16K). This example demonstrates a whole-of-organisation approach but was not an understanding of health promoting palliative care widely evidenced amongst respondents.

5.6.2.5 Benefits beyond the organisation

The reorientation of the case study site to a health promoting palliative care service was seen not just to benefit the organisation and its clients, but potentially to impact upon other services to the benefit of consumers and the wider health care system:

Well you know I really believe that the act of dying is something that people don’t want to talk about…and I think that people need to talk about it. You know we’ve got like everybody keeps telling us, an ageing community and so I think the more people know about [hospice name] then maybe other organisations might model themselves on [hospice name] or, we might have more support out there for the community and take the pressure off hospitals and people can die in an environment that… is known to them. (I26K:417-418; 420-424)

This perspective was supported by another focus group participant, who saw important ramifications for the hospice in adopting a taxonomy that governments would listen to:
By having the language [of health promotion] we can talk upwards to the bean counters and the politicians, maybe we will get a better acceptance. They may not understand what we do. If we start to talk in their language, we will have a better acceptance of what we do. (F01S:442-444)

Finally, this key informant succinctly summarised the potential impact of a reorientation to health promoting palliative care upon all key stakeholders:

What I would like to see out of this reorientation is what does [hospice name] do? What are its processes? What are its structures? In the palliative arena you would be able to then copy that across, so it’s all about being…marketing and getting the processes right, so that they’ll all want to change. Best practice organisations have…very simple processes so that you’d have places that you would have, that the clients would feel they are getting what they asked for, the staff would feel valuable in their contribution, use plans to get where you’re going, use an evidence base, continue to strive for best practice…and never lose best practice, as the goal posts always change. (I17K:192-200)

5.6.3 Barriers to reorientating health services

As is the case with the enablers of this key action area of health promotion, a number of philosophical and conceptual barriers have been identified, along with issues relating to palliative care as a whole rather than solely the case study site as a palliative care provider.

5.6.3.1 Focus upon illness, not wellness

Firstly, a conceptual barrier suggested by a key informant (I02K) is that palliative care, as a profession, is mostly illness-focussed, rather than wellness-focussed, a view shared by Kellehear (1999a, 1999b, 2005) and others, including this respondent:
The psychosocial stuff is where I think a lot of the palliative care people should be putting the effort into. I don’t believe that 80% of people don’t need a lot of emotional and spiritual support. I believe, again by observation of life experiences, that people need more psychosocial and emotional support, spiritual support than they do hands-on. And that’s where I think the gap is with palliative specialists. It’s been hijacked by a medical model, rather than a community or other sort of model. (I20K:360-365)

Consequently, it could be argued, a paradigm shift from health care paternalism to health promotion must underpin any reorientation of palliative care services. This shift would require, at the very least, the kind of educational interventions in the workplace described above. However, the palliative care profession is not a homogenous group and, as illustrated in the Literature Review, services differ in the extent to which they demonstrate a health promoting approach. The self-assessment auditing tool proposed by Salau (2006) provides one mechanism that organisations attempting to integrate a health promoting palliative care model might utilise to identify existing components of health promotion and priorities for service development.

5.6.3.2 Systemic barriers amongst palliative care profession

Moreover, one key informant identified a systemic barrier to the integration of health promoting palliative care in the “silo mentality” (I02K:460) of palliative care service providers, whose focus is upon competing with each other for the funding dollar, rather than upon a collective response to community need; this mentality, this key informant argued, prevents the shared benefits of a health promoting palliative care model being imagined, let alone achieved. Further to this attitude towards other palliative care services, one key informant
was concerned that an élitism still existed in the thinking of many palliative care specialist practitioners towards non-specialist palliative care:

My observation...is that they’re very incestuous, that they’re very narrow, they only go to same conferences, they don’t go out to other conferences – they might go out to oncology, but they don’t go to leadership or they don’t go to motor neuron conferences...you know, they don’t spread their wings a little bit higher. They think that if they’re not the top professionals, that the other RNs that are doing it don’t know what they’re doing...I find that appalling in a profession that...caring for the dying is just not the duty or prerogative of palliative care specialists. Yes I do believe we need palliative care specialists, we want it to be a profession so that expertise, evidence-based stuff happens so that we are intervening correctly, the best way to relieve pain, the best way to do that...but I see the specialist as being the educator of the rest of the community out there, so that they can do it. Too many people die for one or two people to do all the care.

(I20K:346-357)

This illustrates that, perhaps, an influential barrier to the health promoting palliative care approach lies in the attitudes of the palliative care profession towards itself and others. This issue is discussed more fully in Chapter 6.

5.6.3.3 Nomenclature of palliative care

This systemic issue is exacerbated somewhat by the taxonomy of palliative care. A number of respondents were ambivalent about the evolution of language in the care of people at the end of life – there was a strong preference for explicit use of the words ‘death’ and ‘dying’ amongst staff (F04S), reflective of the hospice’s use of these terms in their official documentation (DW02) and, as previously noted, a key strategy in countering a death denying society (I10K). The
link between language and funding was seen as particularly problematic; Kellehear’s (1999b) concern that ‘palliative care’ actually means ‘terminal care’, rather than a descriptor of a social and holistic approach to issues of death and dying, was seen as a significant limitation to the funding of services and the measurement of the outcomes of palliative care interventions (I02K). Further, confusing or unclear language could create poor recognition by funders, referrers, and potential consumers; this key informant summarised the gravity of this difficulty thus:

So somehow, language is important and it’s not just a matter of us using different language, it’s a matter of us…the struggle for us is expressing what we do in a way that still fits but that isn’t limited to what palliative care has been known as.

(I10K:200-203)

Not surprisingly, this issue was unresolved at the conclusion of the data collection period of this study.

5.6.3.4 **Is HPPC just the latest trend?**

Conversely, the conceptual congruence between palliative care and health promotion noted by many respondents was that health promoting palliative care was viewed as an unnecessary reconceptualisation of the existing work of palliative care services. There was a sense that health promoting palliative care was simply another name for that which the organisation already did and that the current organisational emphasis upon reorientating to a health promoting palliative care approach would have little bearing upon the work of the hospice:
Chapter 5: Findings – Impact, Enablers and Barriers

I think that all we are doing is putting a name to what we have been doing for a long time. I don’t think we will be doing anything different to what we are doing now.

(F01S:393-394)

Such a viewpoint may logically lead to reluctance by some staff and volunteers to consider the health promoting palliative care activities undertaken by the hospice that are beyond participants’ understanding of what this entails. As noted above, this is a key issue in this study and is discussed at length in the following chapter.

5.6.3.5 Is HPPC core business?

Adding to this reluctance was the concern expressed by some that health promoting palliative care activities, despite its perceived conceptual congruence, represented a shift away from the core business of the organisation. This illustrates a major theme of this study and presented a challenge to the case study site to reorientate its own personnel to the principles of health promoting palliative care in order to facilitate the clarification of this tension. To some extent this concern of participants was specifically related to the workload of these clinicians in such a small organisation (I23S) who were asked to undertake health promoting activities, such as public education (I16K; I23S; I31S). Clinicians expressed concern that a serious consequence of this was that they were usually absent from strategic planning activities despite being key players in the perceived core business of the organisation and often first to feel the impact of a smaller, busier organisation (F04S).

However, a broader debate was underway within the hospice’s staff and volunteers about what activities actually constituted the organisation’s core business:
I think that the other thing that [hospice name] has to think about as an organisation is just how much it wants to be a public advocacy [sic] for the voice [of patients] and how much it wants to concentrate on its core business of looking after people at home because it does take time and energy to be out there in the public. So I think that's something that we're still grappling with.

(I22K:146-150)

Others stated that clinical care and non-clinical activities were equally core business concerns of the case study site and that the impact of the “usual suspects of resources, time, money, people, skill” (I22K:94-95) were barriers to thinking about palliative care more broadly. Indeed, whilst the limitations of current models of palliative care funding were seen to be a barrier to health promoting palliative care activities, it was also seen to offer an opportunity to seek alternative funding sources and shape these activities without imposed parameters of government funders (I23S).

The question of the nature of core business was associated with respondents’ views of the perceived corporatisation of the organisation. The provision of clinical services was strongly linked to the exercise of compassion, reflecting both a core value of palliative care (Palliative Care Australia, 2004b) and a central tenet of Buddhism (DW04), whilst the integration of health promoting palliative care activities such as public education and participation in the development of public policy were tied to an emphasis upon the business, corporate elements of the organisation (120K). A view strongly held amongst the volunteers was that this corporatisation represented a threat to the hospice’s history as a compassionate, humanistic response to suffering (F02V; I01V; I04V).
These were not viewed, however, as mutually exclusive by this key informant, who responded emphatically:

   It’s nothing personal, it’s business. It’s business. It’s healthcare and yes, there’s the compassionate thing in it, but it’s a business. Yes, you have to look at it with compassion, but it’s a process. Whether you’re making the public aware or wiping bottoms, it’s a process. And we need to take the personality out of it.
   (I14K:157-160)

This view was shared by the then manager of the bookstore who saw the bookstore as both a business and an act of compassion (I08K).

5.6.3.6 Management of organisational change

Beyond these foundational issues there were barriers identified in the manner of how this reorientation was implemented. It was the source of some confusion amongst staff and volunteers that the organisation’s structural configuration was constantly changing and evolving as the leadership team considered how health promoting palliative care elements might be structurally integrated into the organisation.14 This concern was commented on by a key informant who noted that as the goalposts were constantly changing, the hospice’s potential outcomes required constant reassessment (I14K). Nevertheless, as noted previously, a member of the leadership team conceded that the manner in which these changes have been communicated has been unsettling for staff and volunteers when changes are communicated before they are “bedded down” (I19K:127).

14 Multiple sources of data: (F01S; F02V; F03V; F04S)
5.7 Chapter Summary

This chapter has utilised the five key components of health promotion described in the *Ottawa Charter for Health Promotion* (World Health Organization, 1986) to provide analysis of the data collected from documentation review, in-depth interviews, focus groups, and carer questionnaires. The data demonstrate the organisation’s endeavours to integrate the change to a health promoting palliative care approach have had varied impact upon its structures, processes and outcomes, and upon its personnel. Some of the components of health promotion were familiar to respondents; the implementation was considered philosophically straightforward although resource intensive and the integration of health promotion principles and practices considered well underway. The data demonstrate that these components have differing degrees of uptake within the organisation, subject to (a) their perceived conceptual congruence with existing palliative care principles and practice, (b) the apparent limited understanding of many personnel of health promotion, and (c) the resources available to implement them. Multiple factors that advance or impede this integration have been identified and discussed. These findings are discussed further in the following chapter where key themes have been identified and examined for their implications for the case study site and the wider implementation of health promotion principles and practices in palliative care organisations.
CHAPTER 6: EXAMINATION OF KEY THEMES /
DISCUSSION

6.1 Introduction

This chapter examines the key themes that emerged from second level analysis of the data reported in Chapters 4 and 5. In utilising the interpretive matrix, this analysis has identified four key themes which are, in turn, examined in light of the aims of this study and the issues identified in the Literature Review.

6.2 Development and Examination of Key Themes

The findings reported in Chapters 4 and 5 underwent second level thematic analysis utilising the interpretive matrix to further reduce and analyse the data to develop the key themes of this study. This thematic analysis was highly focused upon obtaining completeness in describing, interpreting and understanding the complexity of the phenomena of interest. The patterns evidenced in the first level analysis which enabled their allocation into four key themes are illustrated in the interpretive matrix (see Appendix 18). The four key themes are:

- Establishing conceptual congruence
- Determining core business
- Managing organisational change
- Anticipating outcomes of health promoting palliative care.
Each theme is examined with reference to its data-driven elements derived from
the case study and the discourse in the literature about the integration of health
promotion into end of life care.

### 6.2.1 Theme 1: Establishing Conceptual Congruence

The perception of the conceptual congruence of the components of health
promotion with the established philosophy, values and practices of palliative care
influenced the impact of implementing health promotion principles and practices
in the case study organisation. Fundamental to the integration of health
promotion with palliative care was the acceptability of the key concepts to the
stakeholders in its implementation. In undertaking an organisational transition
such as this, the ability of stakeholders to perceive the ‘fit’ between these two
fields was a foundational issue. This phenomenon is characteristically identified
in the literature regarding organisational change – with a sense of the ‘fit’ of the
change, participants are more likely to support it (Begun et al., 2003).

Staff, employees and volunteers at the case study site were able to grasp
the conceptual congruence asserted in the literature. This is well articulated in
this quotation from an interview with another key informant:

> It’s going to be taken up more readily and incorporated more
> readily because there’s an alignment there…it’s not out of place
> with what is already in the philosophical thinking or with the work
> practice… (I16K:214-217)

Respondents expressed awareness of many elements of the history of the modern
hospice movement and, in particular, saw synergy between early attempts to
promote personalised, contextual care of dying people and the case study site’s
embracing of health promoting palliative care. This awareness of both historical
and contemporary social perceptions of death and dying reflected an engagement by some respondents in debate about developing models of palliative care that are highly congruent with longstanding philosophical positions and established practices with palliative care. For example, whilst founded upon Buddhist principles, the philosophical position of the case study site was viewed as congruent with the contemporary secular values of end of life care discussed in the Literature Review in Section 2.2.1.3 From the religious to the secular. Given the distinction Buddhism places upon itself as a belief system rather than a theistic religion per se (Sherwood, 2003), its accord with secular humanistic values increasingly evident within the palliative care field presented no barrier for the case study site to the goals of social models of end of life care. In this sense, it is reasonable to envisage that these secular values could also find congruence within the Christian palliative care organisations that comprise so much of the history of palliative care. The values underpinning the provision of services by the case study site were consistent with Buddhist teachings around death and dying, and are shared with Christian and secular palliative care organisations. Whilst it seems likely that these differing philosophical foundations would present no impediment to the conceptual congruence of health promotion with palliative care, it is an issue worthy of further consideration in future research.

The case study organisation itself was driven by a concern for the return of death and dying to community ownership, moving beyond models of care dominated by biomedical approaches (Clark & Seymour, 1999). Social models such as health promoting palliative care were seen to be congruent with these
organisational goals and health promotion was widely regarded by respondents as a fitting approach to the provision of palliative care.

6.2.1.1 The intersection between public health and end of life care

It is worth reiterating that the premise of conceptual congruence is implicit in the Ottawa Charter for Health Promotion (World Health Organization, 1986) in asserting the promotion of health and wellbeing of all of life’s stages.1 Whilst this has not always been evident in the practice of public health and health promotion (Stjernsward, 2007), this congruence has been made explicit in the proposals of Kellehear (1999b, 2005) and the commentaries of Rao et al., (2002) and many others (Buckley, 2002; Byock, 2001; Byock et al., 2001; Richardson, 2002; Rosenberg, 1992; Russell & Sander, 1998a, 1998b). In the Charter for the Normalisation of Death, Dying and Bereavement (International Work Group on Death, Dying and Bereavement, 2005) introduced in Section 2.3.3 Health promotion at the end of life, an argument for the congruence of these fields is made. The authors of this charter implied that when this conceptual congruence is embraced, the transition of dying people from active into palliative care can take place in a less disruptive and potentially traumatic way because of its highly contextualised nature. This is identified elsewhere, with the preservation of social networks (including family) being seen as a priority for recipients of palliative care services and a validation of the desirability of social models of care that facilitate this (D’Onofrio & Ryndes, 2003). Critics of conventional models of palliative care have argued that current approaches to service provision lack this perspective which highlights the need for the integration of health promoting

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1 Researcher’s emphasis
Chapter 6: Examination of Key Themes / Discussion

principles and practice into palliative care organisations (Kellehear, 1999a, 1999b; Rao et al., 2002).

In proposing health promoting palliative care as an approach to the provision of end of life care, Kellehear’s (1999b) utilisation of the Ottawa Charter both advanced and impeded its integration in the case study site. Following their initial exposure to the model during Kellehear’s lecture tours, as noted in Chapter 4, the case study site’s leadership team approached the organisation’s transition through the framework offered in Health Promoting Palliative Care (Kellehear, 1999b). Core concepts of health promotion, such as enabling, advocacy and mediacy (Russell & Sander, 1998a), were instantly recognisable to case study respondents as core concerns for palliative care. However, the individual components of the Ottawa Charter were subject to further consideration by study participants before their congruence was judged. The basis for the foundation of health promotion described by Bunton and Macdonald (2002) – that the biomedical model failed to account for the contextual, real-world experiences of the recipients of care – was reflected in participants’ discussions about health promoting palliative care.

Notably, as the case study site’s implementation was ongoing and incremental rather than time-limited and organisation-wide, perceptions of health promoting palliative care were largely shaped by respondents’ conceptualisation of the model’s discrete components, rather than as a whole. This is evidenced in the elements of this theme discussed below and impacted upon the implementation of health promotion principles and practices in the case study site. This appeared to lead to some uncertainty amongst respondents regarding health
promoting palliative care being anything more than new descriptions for conventional methods of delivering end of life care, and points to the need for professional development strategies advancing health promoting palliative care as a whole-of-organisation model.

6.2.1.2 Understanding HPPC as a whole-of-organisation model

In generic health promotion programs, the goals and outcomes of the project itself, rather than its broader impact upon health and wellbeing, has largely been the focus of evaluation. Therefore, Dooris’ (2006) concern regarding the small scope of health promotion program evaluation was verified in the case study site. In this study, the only respondents who demonstrated an understanding of the model as a whole were (a) the senior staff member charged with responsibility for the implementation of health promotion principles and practice at the hospice, and (b) a general staff member who had undertaken post-graduate studies in health promoting palliative care. That is to say, while other respondents commented on specific components of health promotion, these two respondents articulated a view of the concept of a health promoting palliative care model as comprising a number of interrelated elements and a concern for the whole organisation. This is a key concern for the reorientation of the case study site as a health service. The promotion by Whitelaw et al., (2006) of a critical mass of organisational personnel skilled and knowledgeable in health promotion noted previously appears underemphasised at the case study site, requiring strategies to reintroduce health promoting palliative care perspectives to a greater number of staff and volunteers. With an organisation-wide perspective evident in the organisational documents, and expressed through community development
programs such as the death education program, examples of these strategies can be readily identified in the organisation’s educational processes.

A view of organisations as organic, rather than mechanistic, aptly reflected the nature of the hospice as an organisation (Begun et al., 2003; Morgan, 1998). With this paradigm, however, came the appearance of unpredictability in the operationalisation of the model’s integration. Moreover, evidence of the systematic facilitation of organisational change through, for example, the application of quality improvement strategies was scant. Further, the *Practice Guidelines for Health Promoting Palliative Care* provided by Kellehear, Bateman & Rumbold (2003) were not in use, an oversight that may have enabled the case study site to more systematically implement the transition. Whilst the senior staff member noted above was documenting plans that adapted a quality improvement framework to facilitate this organisational transition, the uptake of these plans as a whole by the leadership group was less apparent and may represent an impediment to the transition. This *ad hoc* approach was verified by staff and volunteers who expressed concern about an apparent lack of planning in change management. Further development of tools for organisational change to a health promoting palliative care approach have been more recently attempted (Salau, 2006). Future evaluation of the frameworks offered by Eagar, Cranny and Fildes (2004), Byock et al. (2001), Kellehear, Bateman and Rumbold (2003) and Salau (2006) and consideration of their suitability for consolidation may provide a comprehensive and systematic approach to the integration of health promotion principles and practice in palliative care organisations.
6.2.1.3 **Familiar components of health promotion**

Many respondents were more familiar with particular components of the *Ottawa Charter* than others. In particular, the two components that were most readily viewed as conceptually congruent were (a) *creating supportive environments* for consumers and for staff/volunteers, and (b) *developing personal skills*.

Professional strategies that allow patients, their families and caregivers to feel supported by palliative care service providers are central to end of life care (Palliative Care Australia, 2005a) and are evident in the history and values of contemporary palliative care explored in the literature review. For example, Buckley’s (2002) linking of holism and health promoting palliative care was validated in this study by respondents who understood the creation of supportive environments within an holistic framework. The findings of this study were consistent with these core concerns of supporting the physical, psychological, social and spiritual ramifications of life-limiting illness. They presented no barrier to the implementation of related health promotion principles and practices.

Similarly, the notion of palliative care practitioners equipping patients, their families and caregivers with the personal skills necessary to undertake the various challenges of dying is congruent with the values and practice of both palliative care (Doyle & Jeffrey, 2000) and health promotion (Kellehear, 1999b; Rao et al., 2005; Russell & Sander, 1998a; Weaver, 2004).

In the same way, self care by health care professionals and organisational support of staff and volunteers have long been features of palliative care practice and are evident in contemporary documentation (Canning et al., 2005; Palliative Care Australia, 2005a). The presence of high level personal skills in the
workplace was a familiar notion to palliative care workers and volunteers in this study and evidence to some degree of the conceptual congruence necessary for the implementation of health promotion principles and practice. This was linked by respondents to personal development, not just skills attainment; congruence of personal values with organisational philosophy was also seen as a key strategy in creating a supportive working environment.

This premise is embedded in the philosophical foundations of health promotion (McMurray, 2003; Wass, 2000) and evident in discussions of end of life care (Twohig & Byock, 2004). Whilst at the case study site it was especially true for Buddhist practitioners working or volunteering there, opportunities for personal development were widely reported by respondents as an important element in their sense of working in a supportive environment. In light of the Judeo-Christian origins of the modern hospice movement, it is interesting to note that conceptual congruence extends to the Buddhist values illustrated in the case description and the humanistic nature of the core values of palliative care, shown in Table 2.1. This lends support to the notion that as a Buddhist organisation, the case study site was not unique in the way in which its philosophical foundations were congruent with the core values of palliative care found in Christian and secular organisations alike. This congruence was clearly illustrated by a focus group participant who remarked that embracing and developing the personal skills required for palliative care support brought benefits to the volunteers themselves:
One thing you gain from this [volunteering] is that it keeps your feet on the ground, keeps your life in perspective, the things that are important in your life. I think that is something we gain from doing this sort of work particularly. I find that about a lot of the small stuff that you used to fret about. That is not important. You value what is important in life. (F02V:145-148)

This volunteer connected her volunteering work with the spiritual meaning she ascribed to it. The meaning making and conceptual congruence described by this volunteer was strongly evident amongst other staff, who reported that the opportunity for personal development was also a motivating factor in seeking employment at the hospice. It was seen as an important characteristic of a supportive working environment:

I got sick of the distance in my life with what I was studying, what I was passionate about while I was working, and hence the move here is definitely, there’s no split there any more.

(I26K:365-367)

These views were strongly endorsed by the verification group who reiterated the grounded perspective and clearer personal priorities expressed above that palliative care work can bring about (F05). Where conceptual congruence is strongly recognised, therefore, it can be seen as having a multilayered impact upon the implementation of health promoting palliative care, influencing both the personal experience and organisational practice.

6.2.1.4 Other components of health promotion

Whilst other components of health promotion were less familiar to some respondents, they were, for the most part, viewed at the case study site as appropriate inclusions in the work of palliative care. For example, strategies for
strengthening community action were seen as a fitting set of activities but resource intensive. Respondents’ concerns about affordability and prioritising underpin the discussion of the next theme regarding the identification of core business in health promoting palliative care organisations and link to the notion of health promotion being a whole-of-organisation approach.

Similarly, with the health promotion component building public policy, there were some concerns expressed about the capacity of small, under funded palliative care organisations like the case study site to participate, notwithstanding the relevance of this component. However, a greater impediment to the implementation this component of health promotion was an apparent lack of understanding of the scope of public policy itself. Whilst the few examples of participation in committees responsible in some part for policy development that impacts upon the provision of palliative care, an understanding of the scope of public policy was not strongly evident. This includes the notion of advocacy by palliative care service providers to governments for consumers’ needs as an organisational responsibility rather than simply a characteristic of individual practitioners, although this was not strongly embraced by respondents. As a key action area in the Ottawa Charter, the role of health promoting organisations – palliative care or otherwise – in the development and/or uptake of public policy was more recently the focus of attention in the Bangkok Charter for Health Promotion in a Globalized World (World Health Organization, 2006). This latter document expresses the view that “policies and partnerships to empower communities, and to improve health and health equality, should be at the centre of global and national development” (¶2). In translating this view into organisational
terms, active participation in policy development and advocacy are essential activities in a health promoting organisation.

As explored in the literature review, Kellehear and colleagues (1999a, 2003, 2005), Rao and colleagues (2002, 2005) and others have conceptually linked palliative care to public policy, arguing that death and dying are concerns for whole communities and society, and is consequently a concern of governments in their policy-making role. In turn, therefore, organisations that utilise a social model of health, such as that presented in health promoting palliative care, are validly able to include the development of public policy within their remit. This lends some support to Rao et al.’s (2002) view that the end of life is indeed a public health concern, given the “universal incidence” (p.215) of death. In *Compassionate Cities* Kellehear (2005) proposed a comprehensive policy framework for public health approaches to the end of life, including but not restricted to health promoting palliative care (see Appendix 19). For example, Kellehear suggests the expression of compassion around issues of end of life translates into local health policies that recognise compassion as an ethical imperative, demonstrated in community education strategies including public forums, discussion groups, and crisis intervention. The responsibility of developing, implementing and evaluating these activities rests in partnerships between communities and organisations concerned with end of life issues. Notably, whilst this includes palliative care services, these public health strategies could be provided by grief and bereavement support services, aged care facilities, funeral directors, and other organisations concerned with end of life issues.
Clearly, a failure to do this presents a risk to palliative care organisations in the integration of health promotion, insofar as an incomplete understanding of the scope of developing public policy could result in untenable demands upon workload. Careful planning, including a realistic appraisal of the possible implications of the transition in question, might adequately manage this risk (Donabedian, 2003). Again, the need for systematic approaches to implementing organisational change, such as quality improvement or project management frameworks, is established.

6.2.1.5 The nomenclature of HPPC

In the analysis of the key theme of conceptual congruence, the question of the nomenclature of health promoting palliative care arose. Amongst some of the respondents, there was a sense that the hospice already demonstrated the components of health promotion in its practice. As noted, this led to the question of whether health promoting palliative care was just the latest jargon used to describe established and familiar elements of palliative care practice, particularly the components of *creating supportive environments* and *developing personal skills*. As it was perceived as a new way of describing much of what was already done, the integration of health promotion principles and practice was viewed by some as already underway at the case study site. The main barrier to implementing a new model inherent in this view is that health promoting palliative care can be viewed as an unnecessary renaming of existing activities. This exceeds Kellehear’s (1999b) fear that health promoting palliative care might be viewed as simply “an additional thing to do” (p.23).
However, despite this question about trends, the respondents who made this criticism conceded that health promoting palliative care offered a more structured and measurable approach to providing palliative care than conventional services. This view demonstrates a lack of insight into the differences between conventional and health promoting approaches to palliative care. The need for a strategic approach to reorienting health services by palliative care organisations like the case study site in order to reorient both within and without the organisation is again made clear. Following the principles of health promotion, this reorientation would utilise a broad range of organisational educational, professional and personal development strategies to equip and empower its personnel and external stakeholders to broaden their understanding of the model. Moreover, this reorientation would include raising understanding of the socio-political contexts in which the case study site operates, including its relationships with peak bodies and governments and the organisation’s role in advocating for a health promoting approach to end of life policy development. In this sense, the organisation could play a leadership role in promoting health systems reform towards a social model of palliative care.

A second issue in considering the nomenclature of health promoting palliative care is that the case study site had chosen to retain the term ‘hospice’ in its organisational title. This is uncommon at a time when many organisations in Australia have abandoned it in favour of other terms such as ‘palliative care service’. This semantic discrepancy reflects a conceptual distinction the hospice’s leadership was anxious to make without compromising the health promoting palliative care approach. Its use of ‘hospice’ symbolised its philosophical
alignment with the original intent of the modern hospice movement. This is captured by Howarth’s (2007) description of hospice philosophy as holistic, interdisciplinary, non-hierarchical, not rule bound, vocational and committed to research and education. Whilst elements of this description are found in some conventional services, the case study site’s intention was to utilise a nomenclature that reflected the social nature of death and dying.

When questioned about the language of health promoting palliative care, this key informant viewed ‘hospice’ and ‘health promoting palliative care’ as much the same thing – closer to both the origins of the modern hospice movement and the social model represented in health promoting palliative care:

_FACILITATOR:_ To what extent do you think we’re really talking about the same thing when we’re talking about health promoting palliative care, or hospice, or even palliative care outside of those medico-nursing assumptions?

_RESPONDENT:_ … I think from the definitions I’ve read of health promoting palliative care, and the principles of it, and then hospice, they seem to fit together very closely, and I suppose I very consciously use words like “hospice” because I feel quite strongly about “palliative care” and the way it’s used and understood by people…known as being a smaller component. So what palliative care is supposed to mean maybe is the same, just what’s it’s become to be understood as, but if it continues in that direction then we do need to make a decision, are we…do we promote ourselves as “palliative care”? Is that what we’re promoting that we’re doing? And I don’t think it is.

(I10K:165-176)

The description here of palliative care as a ‘smaller component’ of hospice reflects the key informant’s view of the work of the hospice to be a social – rather
than solely clinical – endeavour. This supports the premise of this thesis noted in the introductory chapter that the end of life cannot be considered solely as the concern of health care services, but as a societal issue with individual, personal, interpersonal and social domains, and impacting upon whole communities (Kellehear, 2005). The key informant saw its use of language as confronting professional and community assumptions about what conventional palliative care comprises.

6.2.1.6 Summary of Theme 1

Conceptual congruence was facilitated by a sense of a set of values and practices held in common. The familiarity of these shared factors added to the collective sense that health promoting palliative care was congruent with the philosophy and practice of palliative care generally and the organisation’s Buddhist-based, hospice position specifically.

Barriers to conceptual congruence were evident where respondents perceived that some components of the Ottawa Charter were able to be omitted from a health promoting palliative care approach. These perceptions appeared to be underpinned by limited understanding of the full scope of health promotion and the implications of its integration into palliative care organisations such as the case study site.

6.2.2 Theme 2: Determining Core Business

The question of core business relates very closely to the issue of conceptual congruence. Determining whether health promoting activities represented the core business of palliative care organisations had a direct impact upon the case study organisation. Study participants gave consideration to the
case study site’s existing programs and practices to ascertain whether health promoting activities – in light of their conceptual congruence – should be viewed as essential concerns or ‘optional extras’ in its work. It should be noted again that the entertainment of this latter option by case study participants was divergent from views of health promotion as whole-of-organisation model noted in the literature review and elsewhere in this dissertation.

In this study, the key theme of determining core business concerns emerged from the study participants’ reflections upon the proposed and actual changes being made by the hospice to reorient it to a health promoting palliative care model. As noted, participants indicated the concept of health promoting palliative care was not illogical or counterintuitive but was indeed largely viewed as conceptually congruent. Rather, questions were raised whether the hospice possessed the capacity to undertake these activities given the resources required to provide and administer their core clinical services. This apparent ambivalence about elements of a health promoting palliative care model is worth considering in light of Kellehear’s assertion noted previously that:

*Supplying health education or social support does not make a palliative care service health promoting any more than the provision of pain relief and a chaplain constitutes a conventional palliative care service. The practice of health promoting palliative care is a practice that embraces all the concerns together, in concert.* (Kellehear, 1999b, p.23)

Despite this definitional clarity and the established conceptual congruence, health promoting activities were considered by some study participants to lie outside of
the organisation’s core business and therefore a lesser priority than established, and more conventional, clinical services.

The official documentation of the case study organisation demonstrated an embracing of the health promoting palliative care approach as a whole. For example, the organisational documentation mentions “…the creation of healthy community attitudes in relation to death and dying” (DW04:1) as a clear strategy in the integration of a key health promoting principle into organisational goals. Moreover, evidence of all five components of health promotion was located elsewhere in the documentation, as noted in Chapters 4 and 5, although this was highly varied between components. This key informant, who held a senior position in the case study site, was able to reconcile the shifting priorities in becoming a health promoting palliative care organisation:

How I feel that we have been changing and are changing is that we're now looking to benefit people in a much broader spectrum of the community. So now it's much more - so while our core business remains home-based palliative care and education and support for families, it's also looking at affecting community attitudes to life and living, death and dying, funerals, the whole topic of death and preparing for death. (I22K:31-35)

Yet the views of most participants in this study were focused on single components rather than health promotion as a whole model. As with the first theme of conceptual congruence, this theme was also conceptualised within the individual components of the Ottawa Charter.

An inconsistency within the case study site’s implementation of a health promoting palliative care model was identified in its view of undertaking a community assessment. Despite being viewed as an essential strategy within
health promotion practice, particularly where a community development focus is in place (Talbot & Verrinder, 2005), the key informant from the case study site with responsibility for the decision to utilise this strategy clearly asserted that it would not be of value in this instance (I32K). As noted in Section 5.4.3.3 Humanistic outcome measurement, community assessment was viewed as desirable but dispensable in an under resourced organisation and outside of the organisation’s core business.

These issues add weight to the earlier discussion in the first theme of the limited understanding of the whole health promotion agenda demonstrated by many individual study participants.

6.2.2.1 Components in place
The components of creating supportive environments and developing personal skills were not questioned as core business in palliative care by study participants and were viewed as already being done to varying levels. Importantly, however, health promoting palliative care aims to redress the imbalance between the physical and psychosocial/spiritual elements in the human experience of illness (Kellehear, 1999b). The mere presence of a clinical service that creates supportive environments for patients and carers, and develops the personal skills of consumers and providers alike, does not possess a sufficiently distinct character that would enable a palliative care organisation to call itself ‘health promoting’. Indeed, it could be argued that these attributes are essential in any conventional palliative care service; moreover, they are apparent in Australian national standards for palliative care service provision (Palliative Care Australia, 2005a).
Echoing the earlier concerns with the nomenclature raised by some respondents, this familiarity of elements of core business perhaps led to the perception that health promoting palliative care is a new term for established practices. This focus group participant asserted that “…health promoting is what we do. Someone has now come up and given it a name. I think all we can keep doing is keep on at it” (F01S:417-418). Whilst this claim showed conceptual congruence is strong, it overlooks consideration of other elements of health promoting palliative care as equally important in end of life care.

In this instance, the nature and comprehensiveness of the health promoting clinical palliative care service become important. A concern of health promoting palliative care is to ensure that clinical services do not simply offer a “medico-nursing set of services [that] place[s] the emphasis on physical care…” (Kellehear, 1999a, p.76) but embrace an holistic perspective in its practice. The intensely interpersonal nature of palliative care does not automatically constitute the provision of psychological, social and spiritual facets of support. Indeed, Kellehear (1999b) gives this bleak criticism of palliative care organisations’ attempts to provide psychosocial care:

…so many ‘psychosocial’ programs or models in palliative care seem to have no underlying philosophy or theory. Who can blame students of palliative care who might mistakenly believe that these kinds of interventions or approaches are so arbitrary that anyone can simply invent them? It is crucial to know that the social care of others can be systematic and therefore thorough in it attention and concerns. (p.xiv)
The implementation of a social model of health by a palliative care organisation, such as the case study site, requires the clear identification of core business. Palliative care services that undertake to embrace health promoting approaches in order to offer a broad and theoretically sound scope of service must include an assessment of their existing health promoting nature, such as that suggested by Salau (2006).

Frameworks to facilitate such an evaluation have been proposed and may offer useful techniques for determining core business. For example, the health promoting palliative care practice guidelines developed by Kellehear and colleagues (2003; see Table 2.3) provides a framework to guide palliative care organisations to undertake concrete health promoting activities such as support groups, death education and policy development at governmental levels. One criterion of this framework is comprised of elements of a discrete community development program. As previously mentioned, Salau (2006) proposed her “Big 7 Checklist” based on the work of Kellehear and his colleagues, which enables palliative care organisations to assess the alignment of end of life programs with public health and health promoting criteria. This checklist goes beyond the Ottawa Charter components to include prevention of social difficulties around death and loss through early intervention, participation of community members, the sustainability of programs, and evaluation of their outcomes. Salau’s framework was unable to be utilised in this study as it was developed subsequent to the data collection period. Nevertheless, consolidation and testing of these two frameworks may provide a useful tool for organisational self-assessment and
contribute to organisational planning for a transition to health promoting palliative care.

There was evidence that the remaining components of health promotion were partially in place at the hospice. The nascent death education program to strengthen community action was underway, with community-focussed activities such as the art market significant informal events in exposing the wider community to the hospice as an organisation and its goals for a healthier view of death. Some limited participation in building public policy was similarly present, although limited in scope and underdeveloped. As noted above, Kellehear’s (2005) Compassionate Cities is a more recent framework that again may assist organisations like the case study site to address this deficit in their integration of health promotion principles and practices. Further, the reorientation of health services was a noted goal of the hospice’s organisational change, although the strategies to achieve this appeared unsystematic. For the most part, these activities not as directly related to day to day clinical interactions as others represented in the health promoting palliative care model were of concern to study participants given the financial and human resources required for their implementation.

6.2.2.2 Resourcing

The basis of the argument for bypassing components of health promoting palliative care when it is clear that implementation of the whole model is considered necessary lies in the matter of resourcing. When a palliative care organisation like the case study site embraces the precepts of health promoting palliative care but does not possess the financial or human resource capacity to
implement the whole model, clinical services were viewed as having a greater claim on these resources. This created a dichotomy in the views of some that clinical services represented conventional approaches to palliative care whilst non-clinical services were largely part of the organisation’s health promotion programs. The non-clinical activities may be viewed as desirable, and indeed even as ‘core business’, but of a lesser priority. This key informant was able to explain this distinction when questioned in interview:

INTERVIEWER: Another issue that has come up is the question of [hospice name]’s core business. Is it firstly providing that in-home face to face service in all of its different disciplines and levels or is it… this other component of developing a stronger, healthier community around issues around death, dying grief and loss? Or are those two components equal in the core business stakes?”

RESPONDENT: I think for me, the core business is home based palliative care, but the larger agenda is creating healthy communities with people with more realistic attitudes towards death and dying… So in one way, I'm kind of thinking…they are equally important, but it's almost like…the vision is the creation of the healthy communities and the way we work towards that - or one of the ways we work towards that is by the provision of care and involving people from the community as volunteers…So it's hard to say that one's more important than the other, but for me, one is a vision and the other one is the way to move towards it and it's one of the ways. (I22K:151-158; 161-168)

The interrelationship between clinical and non-clinical components of palliative care is an important consideration in the health promoting palliative care model. As noted in the previous chapter, a social model for the end of life incorporates an approach to palliative care that is present in both these groups of activities. The
task of balancing stakeholders’ understanding of, and resources for, clinical and non-clinical activities clearly requires formalised, strategic planning in any organisation (Mickan & Boyce, 2002). In the case study site, there were inconsistencies in strategic planning, implementation and adherence to stated goals and strategies. This barrier to the implementation of health promotion principles and practice impacted upon two key stakeholder groups in the transition, staff and volunteers.

However, the absence of government funding necessitated the paced resourcing of new programs and activities, hence the incremental and continuous integration of health promoting palliative care elements at the case study site. Where this resourcing was made available through independent funding sources, as it was for the death education program, its implementation was straightforward. This reiterates the imperative for highly managed organisational change (Moullin, 2002) but also has implications for the government regulation of palliative care services. The development of health promoting public policy demands “political will and, in particular, a commitment to equity and ensuring that all members of society receive the health benefits of social changes” (Talbot & Verrinder, 2005, p.79). To become the beneficiaries of changes to public policy that support a health promoting palliative care approach to the end of life, it appears palliative care organisations such as the case study site must embrace their role as participants in this process of policy change.

6.2.2.3 Summary of Theme 2

The determining of organisational core business was a necessary process of clarification for the case study site in its implementation of health promotion
principles and practice. This process was largely driven by concerns about conceptual congruence described in the previous section of this chapter. Whilst the components of health promoting palliative care were seen as conceptually congruent, some were also perceived as somewhat optional when the organisational capacity and resources to implement them were limited. This understanding is not entirely consistent with the need for a systematic, whole-of-organisation approach to the integration of health promotion that is espoused by writers such as Kellehear, and may represent a challenge to the effective implementation of this organisational change.

6.2.3 Theme 3: Managing Organisational Change

The management of organisational change has had a substantial impact upon the case study site’s implementation of health promoting principles and practice. Indeed, for many of those affected by the organisation’s reorientation to a health promoting palliative care model, the strategies used to effect the transition had a direct impact on their day to day work. This feature of the case study site is consistent with “…the constant challenge of change” (Mickan & Boyce, 2002, p.49) explored in the Literature Review. One key informant stated this characteristic of the hospice very clearly: “I certainly…have experienced more change here than I have in other organisations and sometimes that can be disconcerting and sometimes it’s okay” (I32K:267-268). The challenge for the case study site lay in incrementally implementing a change to their organisational model where some components were perceived to be in place already and others were viewed as suspiciously resource-intensive.
This dynamic context is illustrated in Figure 6.1. The central circle represents the goal of achieving a health promoting palliative care model, with the larger circle illustrating an overarching process of reorientation. As this figure shows, two components of health promotion – creating supportive environments and developing personal skills – are well-embedded already, whilst two others – strengthening community action and building public policy – have only limited integration. The reorientation of the health service requires organisational strategies that address the structures, processes and outcomes of the organisation.

Despite the unique features of the case study site, the implementation of health promotion principles and practice within a palliative care organisation such as the hospice can be systematically planned, as paradigmatic change would be for any other organisation. The utilisation of quality improvement systems was identified as one approach to the implementation of a transition such as this.

6.2.3.1 Quality improvement strategies

The utilisation of established quality improvement frameworks is an option not necessarily embraced by palliative care organisations in the earlier decades of the modern hospice movement. As noted previously, Howarth (2007) described the hospice model of care as holding as one of its basic tenets being “not rule-bound” (p.140). With its rebellious sense of exemption from the regulations of mainstream health care, it is perhaps not surprising that palliative care does not demonstrate a track record for the widespread use of quality improvement strategies. However, despite these early intentions, hospice and palliative care organisations have increasingly assimilated mainstream strategies
for quality improvement, such as the *EQuIP Standards* (Australian Council on Healthcare Standards, 2002, 2006).

The development of systematic evaluation frameworks specifically for palliative care services have been introduced, refined and sanctioned by Australian governments (Eagar et al., 2004). Moreover, from 1 July 2007, the *EQuIP Standards* will include a new assessment criterion looking at decision making at the end of life (Australian Council on Healthcare Standards, 2006). It
includes guidelines for decision making, acknowledgement of cultural and religious issues, conflict resolution, care provision and risk management. Notably, whilst a health promotion approach is not explicit, its outcome measurement items include organisational and public policy, staff education, provision of support, ongoing service reorientation and leadership in end of life care. When these are considered in light of the current imperative in Australian palliative care to consider the public health agenda at the end of life, it becomes clear that the systematic approach, such as that offered by quality improvement frameworks, can support the integration of contextualised, social models of care.

Once the priorities for change have been established by an organisation, such as those illustrated in Figure 6.1, the application of TQM as discussed in the literature review to plan strategies, monitor their integration and evaluate their effectiveness, can be undertaken. This quality improvement process applies equally to the clinical and non-clinical activities of any health promoting palliative care organisation. For example, the use of quality improvement in preparing palliative care organisations for participation in research activities has been successfully trialled in a palliative care program in Canada and considerable detail about organisational structures and processes was provided in its reporting (Stajduhar, Bidgood, Norgrove, Allan, & Waskiewich, 2006). Within the organisation in question, systems to collect and analyse data to inform clinical practice and organisational development were implemented. Outside of the organisation, representatives joined a quality improvement collaborative that linked managers, multidisciplinary clinicians, researchers and academics. These activities facilitated the identification of gaps in service provision, such as “the
complex psychosocial and emotional issues that are often associated with the
dying process” (p.26). The authors of this Canadian project reported an increased
understanding of roles and expertise, better-informed decision-making, and the
establishment of a culture of quality improvement in the organisation.
Importantly, they also report challenges with limited staffing and other resources,
and – in a fashion reminiscent of Kellehear’s concern about health promoting
palliative care being seen as an optional extra – a perception that quality
improvement represented “an add-on to an already busy workload” (Stajduhar et
al., 2006, p.27). Byock et al. (2001) had similarly highlighted the need for
strengthening the evidence base in palliative care and linked research and quality
improvement in their operational model, illustrated previously in Figure 2.2.

6.2.3.2 Single or incremental implementation?

There was some debate amongst respondents of this study as to whether a
paradigmatic shift of this scale should – or even could – be implemented
incrementally or in a single, organisation-wide adjustment. In the case study site,
implementation of health promotion principles and practice was apparently
piecemeal and, apart from a single planning document, seemed to lack a
systematic, planned and organisation-wide perspective. This perhaps reflects
limited understanding of the whole-of-organisation approach and the broader
health promotion agenda. Nevertheless, the author of this planning document
held a view that spoke to the interrelated nature of the components of health
promotion:
…we need a whole plan under the five strategies rather than doing one thing at a time. If you’re changing public policy, you should be able to build sustainable communities at the same time…you have to create awareness, so people are aware what palliative care is…to effect public policy change, you have to get the voters to change public policy, so creating awareness is part of building sustainable communities.

(I20K: 198-200; 202-204)

Despite this view, the case study site struggled to formulate such a plan during the data collection period. This outcome is itself indicative of the complex nature of the task and the multifaceted response it requires for success.

Support for an incremental approach is found in the Canadian project described in the previous subsection wherein Stajduhar et al. (2006) chose an incremental approach, in order to limit the risk of staff becoming overwhelmed by paradigmatic change of this magnitude. Further, in exploring methods by which substantial organisational change can be made, others describe a lengthy, cyclical and complex process (Elwyn & Rhydderch, 2002). These characteristics are evident in the operational model for community based quality improvement in palliative care proposed by Byock et al. (2001) mentioned above and shown in Figure 2.2, which demonstrated a method by which an organisation can establish the basis for its planned change, target priorities, develop and apply interventions and evaluate their effectiveness. It utilised Donabedian’s (2003) SPO framework and the quality improvement cycle. With organisation-wide goals, it accommodates incremental implementation of strategies on an ongoing basis. In its emphasis upon a community approach to end of life care, it offers one approach to implementing health promoting palliative care. In future, where such
Chapter 6: Examination of Key Themes / Discussion

A framework is utilised in palliative care organisations like the case study site, an opportunity exists to evaluate its effectiveness in facilitating this change.

An essential element of effective management of organisational change is the communication of the goals, strategies and potential outcomes of the change (Shortell & Kaluzny, 1997). Where this was achieved in the case study site, respondents described much greater ease with the change. The converse was, of course, also true – where changes were not well communicated, staff and volunteers reported their disquiet. This related to the apparent non-adherence of leadership personnel to stated operational goals. With an appropriate level of consultation, the communication of planned changes made in timely fashion, and adherence to the strategic direction, palliative care organisations like the hospice have an opportunity to limit instability and increase the success of implementation (Moullin, 2002). The effective management of organisational change towards a social model of care may well benefit from operational models that systematically and incrementally facilitate the transition. In this case study, this systematic approach appears to be a greater need than the timing of the implementation of elements of the organisational change.

6.2.3.3 Consumer involvement

A defining feature of both palliative care and health promotion is that of their participatory nature and this represents a significant area of conceptual overlap between the two fields. In managing paradigmatic change in organisations, therefore, the imperative to develop services that promote health built upon the input of the potential consumers of those services is reflected in the historical origins of the modern hospice movement (Field & James, 1993) and
health promotion (Bunton & Macdonald, 2002). Whilst its prominence in palliative care services has diminished with their mainstreaming, consumer feedback is again being viewed as essential to informing the nature of end of life support required and implementing possible subsequent changes to practice (Monroe & Oliviere, 2003). However, participation in the health promotion tradition is not limited to simply providing feedback on service provision, although this is clearly an important consideration. Health promotion advocates the participation of the community (including actual and potential consumers) “…in all stages of planning, implementing and evaluating policies and services that impact on health” (Wass, 2000, p.60).

To meet this goal, strategies to measure consumer satisfaction with the case study site’s services were in place and consumer participants in this study were mostly complimentary of the support they received and satisfied with the services provided. As noted previously, this is not a surprising outcome from the measurement of consumer satisfaction and represents a limitation of this method of evaluation. Attempts to include a consumer representative at the level of organisational governance were under way in the case study site, but flawed in the appointment of a former member of staff to the role. It has been proposed that effective consumer participation in a health promoting palliative care organisation should stand up to scrutiny against the key criteria in the health promotion field, as well as in the ways proposed for health promoting palliative care (Kellehear, 1999b; Rao et al., 2005). These criteria include:
Clear and formalised organisational commitment to community participation

Organisational structures and processes that promote ongoing involvement of consumers

Acknowledgement of potentially divergent agendas of community and organisation

Commitment of resources to support participation

Use of accessible, everyday language that includes non-health professionals

Training for staff, management and community members in values-clarification and development of shared goals

Appropriate evaluation of the effectiveness of community participation.

(Adapted from Wass, 2000, p.66)

Implementing a health promoting palliative care model in an organisation clearly requires strategies for the involvement of community members beyond conventional palliative care practices such as volunteering and fundraising. A social model of health care requires an organisation to embrace the contribution of community members in all aspects of their strategic activity.

6.2.3.4 Summary of Theme 3

The management of change in palliative care organisations from a conventional to health promoting approach is a process requiring detailed planning, systematic implementation, skilled communication and consumer participation. Whether an incremental or time-limited approach is taken, the evidence in this study supports a systematic approach with clear goals and transparent processes as optimal to produce the anticipated benefits of such a transition. Whilst quality improvement frameworks have been proposed as
appropriate for this type of organisational change, their specific application to health promoting palliative care requires further consideration.

6.2.4 Theme 4: Anticipating Outcomes of HPPC

The fourth and final key theme of this second level analysis was concerned with the anticipation of outcomes of implementing health promotion principles and practice by the case study site. As the hospice had not undertaken an organisation-wide and time-limited implementation process, data informing this key theme were not indicative of a measure of outcomes per se. Rather, in this study, the data provide insights into the views of study participants of the likely outcomes should the organisation’s transition to a health promoting palliative care model succeed.

Much has been anticipated by proponents of health promoting palliative care about its impact, with Kellehear (1999b), Rao et al., (2002) and Scott (1992) all viewing it in this tiered way. Indeed, Scott’s (1992) hopes were high in envisioning a ‘revolutionary’ impact from the implementation of a public health approach to palliative care, specifically in the relief of suffering at the end of life. A more sober assessment of its impact was offered by Buckley (2002) who, building upon the conceptual congruence inherent in notions of holism in both paradigms, suggested that the reorientation of palliative care services’ attitudes through education and some relatively straightforward adjustments to organisational configuration could enable the transition. In a major policy document, the government in the Australian State of Victoria (Laverick, 2004) detailed the expected outcomes of a framework of guiding principles for strengthening palliative care. Others have focused specifically upon the impact of
health promoting palliative care at an individual level. For example, Richardson’s (2002) study examined the nature of the change to the therapeutic relationship between patient and nurse.

The qualitative impact of this paradigm shift upon the case study site was generally positive amongst study participants. It is not surprising that they also viewed with optimism the potential it had to benefit at individual, organisational and community/societal levels. Notwithstanding the scepticism reported above that health promoting palliative care was a new term for old ways, it was widely viewed as enhancing, rather than threatening, outcomes of the palliative care provided. In this study, the evidence suggests that there was substantial comprehension amongst staff and volunteers of the broader social benefits of health promoting palliative care. Moreover, the organisational documentation demonstrated its social goals, as reported previously. Elsewhere, others (Byock, 2003; Byock et al., 2001; Kellehear, 2005) have emphasised its potential contribution to building social capital and give their attention to its impact upon communities, governments and health care systems. Notably, whilst the Charter for the Normalisation of Death, Dying and Bereavement (International Work Group on Death Dying and Bereavement, 2005) provided strategies that imply the social benefits of a public health approach to end of life care, it does not offer explicit descriptions of the kinds of outcomes it anticipates from this approach.

The basis for consideration of outcomes in generic health promotion has been primarily focused upon its impact upon individuals, groups (for example, families, groups of demographically similar individuals, ethnically distinct groups, and workplaces), organisations, and whole communities (McMurray,
2003; Wass, 2000). Whilst other approaches have focused upon program evaluation (Hawe et al., 1990; Dooris, 2006), outcome measurement in health promotion is widely understood from this triple-layered hierarchy. Notably, Eagar et al.’s (2004) framework is constructed upon this hierarchy and is indicative of the early integration of public health approaches to program evaluation. The framework is sufficiently adaptable to evaluate the outcomes of a health promoting palliative care model. Its triple-tiered structure addresses the impact upon and outcomes for individuals (including their families and carers), organisations (including governmental health care and social support systems), and society. This hierarchy is utilised here to provide the framework for examining this final key theme.

6.2.4.1 Individual benefits

The promotion of a social model of health does not relinquish the substantial gains made in individual interventions, such as pain and symptom control, that promote physical comfort (Rumbold, 2004). The difference between health promoting palliative care and conventional palliative care services at the individual level lies in the response to whole person in their personal, interpersonal and social contexts. In addition to its emphasis upon the redressing the balance in favour of the social and other components of end of life care, health promoting palliative care upholds the contextual elements of care that Kellehear (1999a, 1999b) has claimed are commonly neglected in conventional palliative care services. As mentioned previously, he believes that in the process of palliative care services becoming more mainstreamed and medicalised, the social needs of people at the end of life were increasingly overlooked at the expense of
psychological, social and spiritual care. Whilst hospice and palliative care services of earlier decades largely claimed these attributes of holistic care, critics like Kellehear have questioned how validly contemporary, mainstreamed palliative services can claim to have an holistic approach when these attributes are not evident. Highly reminiscent of the descriptions of the emergence of health promotion (Bunton & Macdonald, 2002), Buckley’s (2002) emphasis upon holism in health promoting palliative care put forward the view of end of life illnesses as having impacts upon the whole person within their social context. A strong link between holism and the countering of death denial in individuals was made, and verified in this study, where the hospice’s holistic philosophy and organisational values (especially those based in Buddhist thinking about death) were understood by study participants to directly challenge death denial at the individual level. This key informant – a nurse – spoke to this goal of countering death denial amongst patients:

…because I think at the heart of most palliative care nurses practice… is this whole thing that we would just dearly like better resolution, in the sense of dealing with death and dying, isn't something to run way from and hide from and that dealing with death and dying is, you know - get with it, basically. This is the 21st century. What do you think happens to your parents and grandparents and whatever?

(I16K:265-273)

The key to a ‘good death’ was, in the view of most respondents at the case study site, the acceptance of the inevitability of one’s own dying. This was seen as ‘healthy’ by a number of respondents in this study and the concept of a ‘healthy death’ presented no difficulty for the respondents as elsewhere (Pegg & Tan, 2002). At an organisational level, healthy dying was a familiar notion and
illustrated in case study site’s documents, as noted. When viewed collectively, this assertion has an impact at a community level, which is discussed in the next subsection.

Secondly, the potential benefits of a health promoting palliative care approach have an impact upon individual staff and volunteers. In Buckley’s (2002) discussion paper, she asserts the health promoting palliative care nurse is not only empowered by the approach, but has an opportunity to be “self-aware, self valuing and to practice self-care” (p.505). Others assert the role of the nurse in the therapeutic relationship (Canning et al., 2005; Richardson, 2002) and as a change agent and care provider (Russell & Sander, 1998a) is enhanced through a health promoting palliative care model. Occupational therapists practicing in palliative care and using a health promoting approach have a valuable opportunity to enhance quality of life of patients (vanderPloeg, 2001). In this study, nurses, other staff and volunteers widely reported enhanced roles and increased satisfaction, although for a number of respondents the corresponding workload presented impediments to these outcomes. Closely linking to notions of conceptual congruence, these outcomes were viewed to some degree to be present in their existing work but their potential augmented by a health promoting approach.

6.2.4.2 Organisational benefits

A number of substantive organisational evaluations are evident in the history of the development of diverse palliative care services, and have been described in the literature review. The anticipated benefits of implementing a health promoting model for palliative care organisations have been discussed in
the case study site in two ways. Firstly, there are altruistic benefits that are seen as being inherently valuable, such as that demonstrated in the case study site in its Buddhist perspectives of human impermanence and the exercise of compassion. This alignment of values with practice has been described as a sign of organisational and individual integrity (Twohig & Byock, 2004). However, this is not simply left as an element of organisations that has no impact elsewhere. In other areas of human service provision, this altruistic intent and integrity is viewed as fundamental to the provision of quality services that actually meet the expressed needs of consumers of those services (Kendrick, 2006).

Secondly, therefore, a further organisational benefit of implementing a social model may also include focused purpose and improved efficiency, a responsive and flexible service, role clarity, and increased satisfaction amongst staff (Buckley, 2002; Richardson, 2002; Stajduhar et al., 2006). This is not to suggest that the complexity of providing palliative care is lessened by a shift from conventional to health promoting approaches, or even that these attributes are more evident in the latter than the former. Rather, it suggests a relationship between the conceptual congruence, as many have reported in this study, with an approach to the provision of end of life care that embraces the fundamental palliative care notions of holism, socially contextualised care, and consumer empowerment and autonomy. These are organisational, as much as individual, outcomes, given the strongly values-driven origins of palliative care. This key informant in this study made reference to the challenge of marketing the health promoting palliative care approach as retaining the provision of ‘conventional’ palliative care interventions whilst offering something more:
As discussed in the literature review, the refinement of health promoting palliative care as a ‘model’ of care may present an opportunity to clarify its nature. Utilising the three points made in Section 2.4.1.2 Health promoting palliative care as ‘model’ of care, the case study site can be seen firstly to have clearly articulated its mission and values. Secondly, its implementing of these missions and values through the application of strategic planning and organisational goals and objectives is less clear; again, the potential benefit of implementing a systematic and rigorous quality improvement framework is reiterated. Thirdly, clarity in the identification and application of organisational structures and processes might logically follow from employing the first two points. With broad strategies noted above for both internal and external stakeholders, a more widely informed focus upon the effective implementation of health promoting palliative care might result.

Eagar et al’s (2004) Evaluation Level 2 allows for the identification of organisational goals as “evaluation focus areas” (p.7). Whilst in its current form it does not explicitly address health promotion elements, it could be applied to health promoting palliative care organisations like the hospice with modification. It application to outcome evaluation could potentially assist palliative care organisations in their reconfiguration of organisational structures, processes and outcome measurement that comes with a transition to the health promoting palliative care model. In this lengthy but poignant quotation from an interviewee in this study, the potential benefits for the hospice were described:
What I would like to see out of this reorientation is what does [hospice name] do? What are its processes? What are its structures? In the palliative arena you would be able to then copy that across, so it’s all about being…marketing and getting the processes right, so that they’ll all want to change. Best practice organisations have…very simple processes so that you’d have places that you would have, that the clients would feel they are getting what they asked for, the staff would feel valuable in their contribution, use plans to get where you’re going, use an evidence base, continue to strive for best practice…and never lose best practice, as the goal posts always change. But that’s a best practice organisation, and they use information to make their decisions from.

Whether utilising Eagar’s framework, the EQuIP4 Standards, or any of the other quality improvement processes described in this dissertation, the benefits of implementing a health promoting palliative care model are likely to be optimised through a systematic approach that addresses the core concerns of health promotion, palliative care and contextual influences found in health systems.

Reiterating the description of complex adaptive systems given in the literature review (Begun et al., 2003), there was evidence that the case study site demonstrated a multifaceted structure with the capacity to self-modify. It took an holistic and interconnected approach to its components (Sauerborn, Nitayarumphong, & Gerhardus, 1999) and was highly contextualised in its social and systemic contexts. The case study site was in a constant state of change, according to constantly changing priorities (Kaluzny & Hernandez, 1988). The use of systematic frameworks such as quality improvement does not appear to represent a threat to the organic, changing characteristic of palliative care organisations like the case study site insofar as they offer sufficient flexibility to
allow for such variations between organisations (Begun et al., 2003; Morgan, 1998).

### 6.2.4.3 Societal benefits

It is worth recalling Kellehear’s (1999b) claim that social models of care such as health promoting palliative care are mutually beneficial to both public health and services providing end of life care. This is reiterated by representatives of WHO (Stjernsward, 2007) and supported by the findings of this study. The intersection between the two fields – illustrated in Figure 2.1 – is not unidirectional. Kellehear has highlighted that social science and public health perspectives are palpably absent in the provision of palliative care services, and that end of life issues are underdeveloped in social science and public health. Social care, early stage care, active treatment and life-threatening illness are all elements of end of life care neglected by conventional palliative care services that can be enhanced by a health promoting approach (Kellehear, 1999b). These are evident in Salau’s (2006) framework. Conversely, public health could benefit from the inclusion of end of life issues to counter naïve interpersonal interventions, underdeveloped policy initiatives and non-inclusive participation (Kellehear, 1999b). Understandings of what it means to be healthy and well would be challenged by the presence of people at the end of life in the public health discourse. Beyond conceptual congruence lie opportunities for mutual improvement by the combining of the two fields.

Health promotion is theoretically and practically participatory and emphasises the social character of disease and illness, education, information provision and policy development; it is designed for the well and the ill, and is
responsibility of all, not just individuals (Kellehear, 1999b). Russell and Sander (1998a) saw the elements of advocacy, enabling and mediacy as core principles in health promotion that promote optimal health of patients, facilitate the centrality of the dying person and their family in decision making, and ensure that death takes place in the setting of choice for the individual. The benefits spill over into the optimal health and wellbeing of families as death approaches (Lloyd, 2000; Weaver, 2004) and following the death of the individual (Faulkner, 1993). The health promoting palliative care organisation is focused on being responsive and relevant to the needs of the population it serves, not only in terms of the palliative care service it provides but in its contribution to community attitudes towards, and skills in confronting, issues of death and dying (Scott, 1992). To put it bluntly, “dying people are not dead” (Kellehear, 1999b, p.18) and participation in guiding their own health care is not an unreasonable expectation to anticipate in implementing a health promoting approach.

A health promoting palliative care model provides impetus for increasing community resilience in issues at the end of life by confronting assumptions about wellbeing. In this study, respondents showed a grasp of the benefits of talking about health and wellbeing in the presence of life-threatening illness:

Changing the language around palliative care…we have to get it more acceptable. It’s a cultural barrier for us here in the Western world. If we use the right words then it’s okay to talk about a dying person being healthy. We are talking about increasing their health and well-being for where they are in their disease continuum. You’re talking about being healthy to people. They say, ‘But I’m dying’. They can still be healthy. (F01S:437-441)
Stronger, more participatory communities are better equipped to deal with the issues of death and dying they encounter amongst their members and collectively, whether gradual, premature or catastrophic in nature (Clark & Seymour, 1999). This is a need identified in this study and strongly put by this key informant, who was aghast at the death denial she encountered in her palliative care work despite the prevalence of death in daily life:

…but I just think it's almost cowardly, almost, on part of the society to not be prepared to face these issues and that - I see palliative care [has got] that approach to face these issues and that it's disturbing and saddening … I just don't think in the days that we face terrorism, we face, you know, such hideous things throughout the world, I think it's just totally naïve beyond belief almost for me that we hide behind this curtain that says ‘Don't talk about that. Don’t mention the words “dead body”’ or something as ghastly as that, and meanwhile we have got terrorists out in the street blowing up dozens of people on a night. (I16K: 275-279)

With a more highly developed sense that death belongs to community, more empowered, active communities are likely to respond differently to issues of death and dying wherever they are encountered, whether in workplaces, schools, communities or family homes. It can be speculated that a longer-term impact of implementing health promoting palliative care approaches would change the dynamics of service provision as community members become consumers of palliative care services and demonstrate a greater preparedness for either their dying or caregiving responsibilities. This was certainly reported amongst consumer participants of this study whose readiness for caregiving was increased by past exposure to palliative care situations.
It can also be anticipated that a transition to health promoting palliative care approach to end of life care can have an impact upon the governance of palliative care. As noted in the literature review, current legislative and policy frameworks in Queensland continue to originate from biomedical approaches to health care (Queensland Health, 2000). Yet there are sufficient alternatives immediately at hand which could facilitate the establishment of policies promoting social models of health care including end of life care. Building on the foundation provided by the *Ottawa Charter*, the *Bangkok Charter* (World Health Organization, 2006) provides strategies for addressing the global policy agenda for health; in light of the *Ottawa Charter*’s implicit inclusion of all stages of life, this agenda includes end of life issues. As public policy development is targeted in health promotion, it can be expected that subordinate organisations would have a policy framework from which to reassess their structures, processes and outcomes; the Victorian example described above provides a good example of this (Laverick, 2004). As noted, Kellehear’s (2005) *Compassionate Cities* has provided a substantial policy framework for the provision of end of life care. The impacts of revised public policy relating to issues of death and dying could be felt not simply in governments and the service organisations they oversee, but more broadly in society, amongst workplaces, schools, communities and family units. Moreover, a review of public policy around the funding of palliative care services would be required to have governmental funding bodies consider social models of health care where the promotion of wellness, rather than simply the provision of clinical responses to illness, is prioritised.
6.2.4.4 Summary of Theme 4

The anticipation of outcomes of the implementation of health promotion principles and practices was a key theme in the case study site. Organisational documentation, workplace attitudes and consumer views supported the expectation that a social model of palliative care was likely to bring about outcomes that were consistent with the core values of palliative care whilst embracing a health promoting approach. There was, however, a level of ambivalence about the feasibility of measuring such benefits in this setting, given the humanistic and highly contextual nature of end of life care.

6.3 Chapter Summary

This chapter has synthesised the issues and themes raised in the first and second levels of data analyses and the historical and contemporary issues located in the literature review. In examining the key themes of (a) establishing conceptual congruence, (b) determining core business, (c) managing organisational change and (d) anticipating outcomes of health promoting palliative care, this chapter has addressed the aim of this study to understand the impact of the implementation of health promotion principles and practice upon palliative care organisations.
CHAPTER 7:
CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

7.1 Conclusion

The aim of this study was to investigate the integration of health promotion principles and practice by an existing palliative care service by examining the impact of this change on the organisation. Specifically, it endeavoured to identify the factors that advanced or impeded this integration by examining how the structures and processes of, and outcomes for, the organisation reflected a health promoting approach. To accomplish these aims, this research study undertook an in-depth examination of the incremental implementation of a health promoting palliative care model by a selected community based palliative care organisation. A mixed-method [QUAL+quant], instrumental case study was utilised to obtain data from multiple sources.

The findings of this study indicate that the transition from a conventional model of palliative care service provision to a health promoting palliative care approach is one in which widespread organisational impacts are likely to be experienced. Health promoting palliative care is an approach to the provision of end of life care that is inherently deeply embedded in both the historical and current socio-political contexts of contemporary palliative care provision. The implementation of the health promoting palliative care approach is fundamentally concerned with both the internal structures, processes and outcomes of the
organisation and the issues of death and dying encountered within society. Such a paradigmatic transition is incomplete without comprehensive engagement of palliative care organisations with communities and those responsible for governance of end of life services. This study has identified issues relating to organisational reorientation that address issues of comprehensive organisational change. It has also noted that such a transition relates to the socio-political agenda of peak bodies and governments, and that advocacy for a supportive systemic policy framework is a key task for palliative care organisations seeking to integrate health promoting principles and practice.

The implementation of health promotion into conventional palliative care services represents a substantial paradigmatic shift, but one that embraced somewhat familiar elements in the case study site. The conceptual congruence between palliative care and health promotion, particularly in the areas of creating supportive environments and developing personal skills, was a key enabler of this transition. It allowed participants in the transition to identify recognisable elements of palliative care in the proposed destination of organisational change. That is to say, the transition involved the reconceptualisation of some features of conventional palliative care services in order for their continued inclusion in the provision of end of life care during the implementation of the health promoting palliative care model. For managers and governors of palliative care organisations, adequate resourcing that permits both the introduction of health promoting programs and continuation of these ‘conventional’ services allowed stakeholders to view the new programs as core concerns of the organisation. This represented another key enabler. The skilled and systematic management of the
transition also instilled confidence and promotes cooperation amongst staff and other stakeholders in participating in the organisational change.

Barriers to the implementation of health promoting palliative care into conventional palliative care services were also evident. Whilst most of the data in this study supported the conceptual congruence asserted by Kellehear (1999b), Rao et al., (2002) and others, with organisations there was a clear need for more ongoing comprehensive reorientation of staff and volunteers through the provision of a broad range of strategies to inform, educate, empower and reorient. This may well be facilitate by participation in Public Health and Health Promotion professional associations and the presence of public health practitioners or health promotion officers in palliative care organisations like the case study site. A further barrier was encountered in the resourcing of health promoting activities, and whilst education towards the approach could be provided as part of the existing professional development program, there was a persistent view that, when funding was so limited and workloads so high, clinical services held a higher priority. Not surprisingly, organisational change that was not carefully planned and managed presented substantial impediments to the implementation of the transition to health promoting palliative care.

Whilst public health approaches to end of life services palliative have achieved increased levels of influence within peak bodies for palliative care in Australia, their uptake at national and state governmental levels is less evident. Although financial support of health promoting palliative care programs has been forthcoming, the reorientation of government departments of health towards public health – including at the end of life – remains largely unattended. This
substantial barrier to the integration of health promotion principles and practice at
the organisational level presents the need for lobbying and other representation by
palliative care organisations for its consideration in health systems reform. In
light of this systemic limitation, the achievements of the case study site towards
implementing health promotion principles and practice are notable.

Generally speaking, health promoting palliative care was viewed as likely
to bring about significant benefit to individuals, palliative care organisations and
society more broadly. Kellehear (1999b) summarised these benefits, saying:

*It is true that health promoting palliative care is a style of palliative care
that returns our interest to the early period of dying. But it is much more
than this. It also focuses our attention on the worthy practice principles of
participation, support and consultation right up to the end of life…a health
promoting palliative care philosophy renews our practical commitment to
the social side of life. 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. (p.177)*

To achieve these goals, it is clear that a multifaceted, cyclical and systematic
approach to organisational change and advocacy for systemic policy revision are
essential. A quality improvement framework that builds upon the established core
concerns of both health promotion and palliative care may enable a focussed and
disciplined process of transition, limiting negative outcomes for staff, volunteers
and consumers whilst maintaining a sound financial base and the achievement of
identified goals. As noted, the need for proactive political activity by
organisational representatives in peak bodies in palliative care to promote a broad health promotion policy framework is apparent.

7.2 Limitations of the Study

7.2.1 Generalisability Issues

The case study site was a single community-based palliative care service located in the state of Queensland, Australia. Whilst its headquarters are based in a metropolitan location, its service catchment included regional centres and semi-rural communities, and as such contained sufficient demographic variation to be relevant to the context of palliative care in Australia.

However, it is acknowledged that in utilising case study design, this study was not intended to provide results that were generalisable to a population. It is not argued that this case study site was representative of all palliative care organisations, even like ones. Instead, this study aimed to facilitate the generalisation of theoretical propositions relating to the application of health promotion principles and practice in palliative care organisations. Whether health promoting palliative care is applicable to other conventional models of palliative care, such as consultative services within tertiary hospitals for example, was not determined. Rather, this study has sought to contribute to the discourse about social models of health such as health promoting palliative care as a nascent paradigm in the provision of end of life care. Further research into the breadth of application of health promoting palliative care is warranted.
7.2.2 Methodological Issues

As the process of implementation of health promotion principles and practice by the case study site was continuous and incremental rather than time-limited and organisation-wide, this study did not lend itself to quantification of impact through pre- and post-measurement. The identification of qualitative impact was selected as a more appropriate method in these circumstances. Further, after Morse and Chung (2003) it is acknowledged that the use of mixed method design such as that used in this study is the source of significant workload.

Limitations were inherent in the utilisation of a single data collector; similarly, the researcher has primarily undertaken data analysis singly. To address this limitation, data were collected from multiple sources – organisational documents, self-administered questionnaires, in-depth interviews and focus groups. The duration of the data collection period was constrained by both time and recruitment issues.

7.3 Recommendations

This research study contributes to the current discourse regarding social models of care in the provision of end of life care. In particular, it offers an analysis of the experience of a selected community based palliative care organisation in implementing a health promoting palliative care approach. This study offers recommendations both to the case study site and to other palliative care organisations considering a transition to a health promoting palliative care model, and serves as a forerunner to further research in the field.
7.3.1 Implications for the case study site

Firstly, to the case study site in particular, the following recommendations are offered as strategies to build the capacity of the hospice to successfully implement and maintain health promoting palliative care into its structures, processes and outcomes:

1. That an ongoing program of professional development and reorientation to health promotion be developed, implemented and evaluated in order to promote accurate knowledge of the health promoting palliative care model and its concrete impact upon the workplace.

2. That a systematic approach, such as one based upon a quality improvement framework, be applied to the implementation of further health promotion principles and practices, whether this process is undertaken incrementally or within a single period of transition. This would require development by a broad group of representatives from within and outside of the organisation and include consumer representation.

3. That this systemic approach includes a communication plan to promote the exchange of information between organisational leaders and stakeholders, including staff and volunteers, consumers and others. The circulation of the communication plan would promote transparency and also support adherence to the planned processes of the organisational change.

4. That a community assessment is undertaken as an integral element of its health promoting approach. Established frameworks are able to be found within existing health promotion literature and determining their suitability for
modification to end of life issues would be an appropriate step in planning the assessment.

5. That ongoing partnerships with public health and health promotion professional associations and peak bodies are established in order to increase the organisation’s understanding of health promotion and to raise the profile of end of life issues within the public health and health promotion fields.

6. That ongoing partnerships with academic institutions with an interest in public health and health promotion issues are established to facilitate the organisation’s participation in relevant research and scholarly work.

7. That ongoing partnerships with peak bodies in palliative care are maintained.

In combination with the partnerships noted in the previous two recommendations, the organisation would be well positioned to participate in advocating for the inclusion of public health and health promoting issues in public policy frameworks relating to the end of life.

8. That the organisation considers the appointment of a health promotion officer whose responsibilities would include implementing the above recommendations and systematically integrating their outcomes into the organisation.

7.3.2 Broader implications for palliative care

In contributing to the wider discourse on this subject, this study also offers these recommendations:

1. That the above recommendations may be considered for their specific relevance to palliative care organisations considering a transition to a health promoting palliative care model.
2. That the development of a systematic quality improvement framework specific to health promoting palliative care be undertaken, in order to explore further the implementation of health promotion principles and practices in palliative care organisations, providing a systematic and strategic approach to reorienting health services by palliative care organisations. This would be based upon consolidation of existing frameworks discussed in this dissertation.

3. That further research into the specific components of health promotion may elicit more detailed information about the enabling and impeding factors peculiar to each. Where appropriate, research methods that utilise intervention design with pre- and post-intervention assessment of impacts may be of benefit. This could be achieved through:

a) Development and implementation of specific health promoting palliative care programs that address issues of death and dying, such as death education and community development.

b) Collaboration with expert health promotion researchers in such studies may assist in integrating the public health and palliative care paradigms in the generation of further evidence.

c) Comprehensive engagement with communities by those responsible for governance and delivery of palliative care services to inform the development of health promoting palliative care.

d) Promotion of, and participation in, partnerships between palliative care service providers, health promotion providers, and peak bodies in both
fields to inform discourse on social models of end of life care and develop strategies for implementation.

4. That these recommended activities be utilised by palliative care and health promoting peak bodies for building evidence to lobby for systemic policy reform towards a public health approach to end of life care within governing bodies and those delivering services for the end of life.

7.3.3 Recommendations for further research

This research is the first detailed study of the implementation of health promoting palliative care and represents a potential forerunner to further research in field of health promoting palliative care. Whilst further research might take any number of forms, this study elicits a number of specific recommendations:

1. That the study of the integration of health promotion principles and practices be expanded to include examination of the congruence of health promoting palliative care in those palliative care services that have emerged from the Christian or secular (rather than Buddhist) tradition of service provision, in order to confirm whether the experience of the case study site was unique due to their Buddhist philosophy.

2. That further studies be conducted in a range of organisations with differing configurations, such as inpatient settings (including hospital based services and freestanding hospices) and in the residential aged care sector.

3. That the implementation and evaluation of the integration of health promoting palliative care at systemic levels of governmental jurisdictions be examined, including cost-benefit analyses and impact evaluation.
Whilst these broad topics could be addressed in future research, this study also recommends that smaller research studies into elements of health promoting palliative care could also be conducted in areas such as:

- Promoting the community’s capacity to address issues of death and dying.
- Examining consumer participation in palliative care.
- Evaluating nascent death education programs to refine the effectiveness of such programs.
- Evaluating educational strategies to reorient palliative care organisations to health promoting approaches.

Importantly, in recommending smaller studies focussed on particular elements of health promotion at the end of life, it must be remembered that such studies would take place in the broader context of research into health promoting palliative care.
### APPENDIXES

#### Appendix 1: Transcript Summary Form

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| Focus Group |
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| KEY HEALTH PROMOTION ELEMENTS IDENTIFIED: |
| Building public policy |
| Creating supportive environments |
| Strengthening community action |
| Developing personal skills |
| Resourcing health services |

**ISSUES:**

- personal experience of death equipped person for vol work
- philosophical/spiritual view from part of motivation to volunteer
- need to confirm own assumptions + values
- need to be adaptable, flexible, comfortable, co-operative
- need for annual refresher programs for vols

**ENABLERS:**

- Volunteer training = experiential; focus on relational issues
- Experience as volunteer = volunteer trainer
- Volunteer coordination processes when ramp up well

**BARRIERS:**

- Volunteer support = quality variable due to different incumbents
- Increasing focus on efficiency rather than quality
- Inflexibility of organisation’s response to difficult social situations
- Communication of new information needs to be “sharpened
- “patient-support” before family-support

**OTHER EMERGENT THEMES:**

- Boundaries = crossing from professional to personal

**ISSUES FOR FURTHER INVESTIGATION/ACTION:**

- Volunteer coordinator’s role
- Policies for vols re: no. of clients at once
Appendix 2: Correspondence re Ethics Clearance

Wendy Heffernan, 11:09 AM 4/08/2005, Re: Level 3 (Full) Ethical Clearance - 4138H

Dear John

I write further to the response received in relation to Level 3 (Full) ethical clearance provided for your project, “A study of the integration of health promotion principles and practice in palliative care organisations” (QUT Ref No 4138H).

On behalf of the Chair, University Human Research Ethics Committee (UHREC), I wish to advise that this response has addressed the additional information required by the Committee.

Consequently, you are authorised to immediately commence your project on this basis.

The decision is subject to ratification at the 20 September 2005 meeting of UHREC. I will only contact you again in relation to this matter if the Committee raises any additional questions or concerns in regard to the clearance.

The University requires its researchers to comply with:

- the University’s research ethics arrangements and the QUT Code of Conduct for Research;
- the standard conditions of ethical clearance;
- any additional conditions prescribed by the UHREC;
- any relevant State / Territory or Commonwealth legislation;
- the policies and guidelines issued by the NHMRC and AVCC (including the National Statement on Ethical Conduct in Research Involving Humans).

Please do not hesitate to contact me further if you have any queries regarding this matter.

Regards

Wendy

University Human Research Ethics Committee
Information in relation to ethical clearance
What is the duration of my ethical clearance?

The ethical clearance awarded to your project is valid for three years commencing from 26 July 2005. Recruitment, consent and data collection / experimentation cannot be conducted outside the duration of the ethical clearance for your project.

Please note that a progress report is required annually on 26 July or on completion of your project (whichever is earlier). You will be issued a reminder around the time this report is due. The progress report proforma can be located under Forms on the University Research Ethics webpage.

Extensions to the duration of your ethical clearance within the 3-5 year limit must be made in writing and will be considered by the Chair under executive powers. Extensions beyond 5 years must be sought under a renewal application.

Standard conditions of approval

The University’s standard conditions of approval require the research team to:

1. conduct the project in accordance with University policy, NHMRC / AVCC guidelines and regulations, and the provisions of any relevant State / Territory or Commonwealth regulations or legislation;

2. respond to the requests and instructions of the University Human Research Ethics Committee (UHREC);

3. advise the Research Ethics Officer immediately if any complaints are made, or expressions of concern are raised, in relation to the project;

4. suspend or modify the project if the risks to participants are found to be disproportionate to the benefits, and immediately advise the Research Ethics Officer of this action;

5. stop any involvement of any participant if continuation of the research may be harmful to that person, and immediately advise the Research Ethics Officer of this action;

6. advise the Research Ethics Officer of any unforeseen development or events that might affect the continued ethical acceptability of the project;

7. report on the progress of the approved project at least annually, or at intervals determined by the Committee;

8. (where the research is publicly or privately funded) publish the results of the project in such a way to permit scrutiny and contribute to public knowledge; and
9. ensure that the results of the research are made available to the participants.

Modifying your ethical clearance

The University has an expedited mechanism for the approval of minor modifications to an ethical clearance (this includes changes to the research team, subject pool, testing instruments, etc.). In practice this mechanism enables researchers to conduct a number of projects under the same ethical clearance.

Any proposed modification to the project or variation to the ethical clearance must be reported immediately to the Committee (via the Research Ethics Officer), and cannot be implemented until the Chief Investigator has been notified of the Committee's approval for the change / variation.

Requests for changes / variations should be made in writing to the Research Ethics Officer. Minor changes (changes to the subject pool, the use of an additional instrument, etc) will be assessed on a case by case basis and interim approval may be granted subject to ratification at the subsequent meeting of the Committee.

It generally takes 5 - 10 days to process and notify the Chief Investigator of the outcome of a request for a minor change / variation.

Major changes to your project must also be made in writing and will be considered by the UHREC. Depending upon the nature of your request, you may be asked to submit a new application form for your project.

Audits

All active ethical clearances are subject to random audit by the UHREC, which will include the review of the signed consent forms for participants, whether any modifications / variations to the project have been approved, and the data storage arrangements.

At 02:07 PM 2/08/2005, you wrote:

Hello Wendy, thanks for this notification and for speaking with me earlier today. In response to your feedback to my application:

- Protected data will be stored in two forms. Firstly, for the duration of the project, electronic data will be stored on the Al Drive of my PC in my QUT office (N531) which is password protected; back up files will be placed on a USB device which will be carried on my person and stored in a locked filing cabinet at my residence when not in use. Data in hard copy form will be stored in the locked filing cabinet in my QUT office. Secondly, upon completion of the project, all electronic data and files will be removed from the PC onto a storage device (CDs
or USB) and, with hard copy files, stored in QUT archives for five years, then destroyed.
• I attach a Carer Questionnaire with an amended cover sheet reiterating that participation is voluntary and also showing the minor amendments to the questionnaire items that we discussed – rather than each item asking the source of support, there are additional items dealing with sources of support separately.
• Please note that the full title of this project is “A study of the integration of health promotion principles and practice in palliative care organisations” (my emphasis – this word is missing from your message below).

I trust this meets the conditions you’ve set out.

Regards, John.

John P. Rosenberg
PhD Student
Queensland University of Technology
Phone: 07 3864 5953
Mobile: 0423 211 743
CRICOS No. 00213J

Wendy Heffernan | Research Ethics Officer
Office of Research | Queensland University of Technology | GPO Box 2434, Brisbane QLD 4001 |

phone: 07 3864 2340 | fax: 07 3864 1304 | email: w.heffernan@qut.edu.au | CRICOS No. 00213J

Printed for John P Rosenberg -jp.rosenberg@student.qut.edu.a...
Dear John,

Thank you for your email advising us in relation to ethical clearance for the project, QUT Ref No 3363H.

I have noted on the ethics database that this project has been SUPERSEDED by 4136H.

Information regarding the completion of this project will be provided to the University Human Research Ethics Committee at its 27 September 2005 meeting. I will only contact you again in relation to this matter if the Committee raises any additional questions or concerns in regard to this report.

Please do not hesitate to contact me if you have any further queries in relation to this matter.

Janette Lamb
Administrative Assistant | Research Ethics Support Officer
Office of Research | Level 5 | O Block Podium
Queensland University of Technology
GPO Box 2347 | BRISBANE | QLD | 4001

Phone: 07 3864 5125 | Fax: 07 3864 1504
Email: jlamb@qut.edu.au | CRICOS No 00003U

Printed for John P Rosenberg <jp.rosenberg@student.qut.edu.au>
Appendix 3: Case Study Site Correspondence

Identifying words and letterhead logos have been covered to preserve confidentiality.

To whom it may concern

RE: Letter of Support for John Rosenberg for his project “Development of a service improvement framework based on health promotion principles for community-based specialist Palliative care service” PhD Student (QUT 2004-2006)

[Redacted] is a not-for-profit public benevolent institution and registered charity. It is a member of the international Buddhist organization The Foundation for the Preservation of the Mahayana Tradition (FPMT). With a philosophy based on Buddhist principles of love and compassion, [Redacted] offers people with a terminal illness, and their loved ones, the highest quality of life.

[Redacted] was established twelve years ago in “alleviate the fear around death and dying”. Our aim is to improve the comfort and quality of life for dying people, their carers as well as many others who are affected by illness and death. [Redacted] offers its clients care “at home”. Interdisciplinary teams provide comprehensive care of the physical, emotional, social and spiritual needs of adults and children living with a life threatening illness, this includes early intervention as well as the palliative stage. [Redacted] nurses, counselors, spiritual care and family support volunteers offer coordinated and comprehensive support 24 hours a day (on call) free of charge. [Redacted] is accredited by the Australian Council on Healthcare Standards (ACHS)

[Redacted] Board, Management Team and Clinicians support Mr John Rosenberg’s application for the above project. We are delighted to participate in the pilot and will assist in any way to ensure a successful outcome.

On behalf of the Board and Management Team I am providing ethical clearance for the above project.

Yours Sincerely

[Redacted] Board Member and Director
14th June 2005

Queensland University of Technology

To whom it may concern

Further to my letter dated 5th January 2004, I wish to reiterate the support of the Board of Management of the proposed project and, in addition to our frequent liaison with [redacted] have had the opportunity of presenting an overview of this project to the Board of Directors. While the Board does not have a constituting Ethics Committee, I can confirm on its behalf that we will accept the ethical clearance granted by Queensland University of Technology’s University Human Research Ethics Committee for John’s study.

I am also able to confirm that [redacted] is able to offer the support of counsellors for any staff, volunteers, patients or carers in the unlikely event of distress arising in the course of John’s data collection.

We are delighted to participate in the study and will assist in any way to ensure a successful outcome.

Yours sincerely

[Redacted]

Board Member and Director
2 May 2007

Mr. John Rosenberg

Dear John

In relation to your request for clarification on retaining the organization’s identity or to de-identify the organization in your PhD study into health promoting palliative care, [redacted] asks that you de-identify the organization and replace [redacted] with “the case study site” in your dissertation.

We understand you need to use the word “hospice” in your case study but we request that you not use a pseudonym. We would also request to have removed any reference as to the location of the site.

We trust that with these changes your dissertation will not be compromised and wish you all the best with the finalization of the project and your future.

Kind regards.

Yours sincerely

[redacted]

Director
Appendix 4: Consent Package

Contains:
• Information Sheet – Carer Questionnaire
• Information Sheet and Consent Form – Patient / Carer Interview
• Information Sheet and Consent Form – Staff Volunteer Interviews and/or Focus Group

[Researcher’s note: formatting has been altered to enable ease of inclusion of documents in Appendices]
Information Sheet –
Carer Questionnaire
A study of the integration
of health promotion principles and practices
in palliative care organisations.

John Rosenberg RN
PhD Student, School of Nursing, Queensland University of Technology
Telephone: 07 3864 5953  Mobile: 0423 211 743
Email: jp.rosenberg@student.qut.edu.au

What is this study about?
Past research has shown that some approaches to providing palliative care may be more beneficial than others. This study is looking at how a health promoting approach to palliative care might change palliative care organisations to the benefit of those receiving their services.

Karuna Hospice Services is integrating a health promoting palliative care model. The purpose of this questionnaire is to examine the nature of the support given to you by Karuna.

Who is running the study?
I am – John Rosenberg. I’m a registered nurse with more than 15 years experience in community-based palliative care. As part of my PhD studies, I’m studying at Queensland University of Technology [QUT] under the supervision of Professor Patsy Yates. The Executive Director of Karuna Hospice Services, Ven. Yeshe Khadro, has granted written permission for this study to be conducted and the project has met the ethical requirements of QUT University Human Research Ethics Committee [UHREC].

What are you being asked to do?
I’m requesting your assistance in completing this brief questionnaire. It should take no more than about 15 minutes of your time to answer the questionnaire. The questionnaire will ask a series of questions about your experience of receiving support from Karuna.

You are also being asked to indicate at the end of the questionnaire whether you are willing to be contacted by me to participate in an interview. If you do, I’ll contact you very shortly afterwards and arrange to meet you. More information about the interview will be provided when I make contact.

Even if you choose not to be interviewed, you can complete the questionnaire and return it in the envelope provided.
Who will benefit from this study?
You might find it a helpful process to participate in this questionnaire, as it provides an opportunity to consider the sort of support you are receiving and the extent to which it meets your needs. It is expected that the results of the study will benefit future patients and carers of [insert name] and other organisations that provide palliative care by describing the pros and cons of health promoting palliative care.

Are there any risks to you or your family?
There is a low risk that you may find the questionnaire distressing. If this is the case, I encourage you to contact [insert contact information] and talk to their counselling staff.

Will your privacy be affected?
No. The names of individual persons are not required in any of the responses. Unless you choose to provide contact information for interview, I will never know your identity. [insert name] staff will not know if you agree to be interviewed by me unless you choose to tell them. All questionnaire responses will be treated confidentially.

Is your participation voluntary?
Yes, your participation in this project is entirely voluntary. If you do agree to participate, you can withdraw from participation at any time during the study without comment or penalty.

Your decision whether or not to complete and return this questionnaire will in no way impact upon the support you receive from [insert name].

If you want to know more, who do you contact?
If you need more information about the questionnaire or have specific questions about it, please do not hesitate to contact me at QUT on 3864 5953 or on mobile on 0423 211 743 or by email on jp.rosenberg@student.qut.edu.au.

What if you are concerned about this questionnaire?
Please contact the Research Ethics Officer on 3864 2340 or ethicscontact@qut.edu.au if you have any concerns or complaints about the ethical conduct of the project.

How do you give your consent?
The return of the completed questionnaire is accepted as an indication of your consent to participate in this questionnaire.

Thank you.

JOHN ROSENBERG
What is this study about?
Past research has shown that some approaches to providing palliative care may be more beneficial than others. This study is looking at how a health promoting approach to palliative care might change palliative care organisations to the benefit of those receiving their services.

Karuna Hospice Services is integrating a health promoting palliative care model. The purpose of this project is to examine the nature of the support given to you by Karuna Hospice Services. I’m interested in both the positive and negative aspects of your experience. I’m also interested in the personal skills you see yourself needing in your current circumstances.

Who is running the study?
I am – John Rosenberg. I’m a registered nurse with more than 15 years experience in community-based palliative care. As part of my PhD studies, I’m studying at Queensland University of Technology [QUT] under the supervision of Professor Patsy Yates. The Executive Director of Karuna Hospice Services, Ven. Yeshe Khadro, has granted written permission for this study to be conducted and the project has met the ethical requirements of QUT University Human Research Ethics Committee [UHREC].

What are you being asked to do?
I’m requesting your participation in an interview. It will take about 40-60 minutes to complete, and will take place in your home or in another location of your choosing. The interview will involve a private, face-to-face conversation between you and me regarding the nature of the support and care you receive from Karuna Hospice Services.

If you are a patient (rather than a carer) I’m asking your permission to view your Karuna patient file to help me understand the context of the care and support you receive.

Who will benefit from this study?
You might find it a helpful process to participate in this interview, as it provides an opportunity to identify the sort of support you are receiving and the extent to which it meets your needs. In the longer term, it is expected that the results of the study will benefit future patients and carers of Karuna Hospice Services and other organisations that provide palliative care by describing the pros and cons of health promoting palliative care.
Are there any risks to you or your family?
There is a low risk that you may find the questionnaire distressing. However, remember you are free to withdraw from the interview without penalty. If this distress persists, I encourage you to contact [Contact Information] and talk to their counselling staff.

Will your privacy be affected?
Whilst the staff of [Institution Name] are aware that this study involves interviews with some patients and carers, and are participating themselves in a number of ways, no-one at [Institution Name] will know of your agreement to be interviewed by me unless you choose to tell them.

Our discussion will be audiotaped, but no identifying information will be included when the interview is transcribed and the confidentiality of our discussion will remain intact. Information you provide may be used in a non-identifying way when the research report is written.

Any information from your patient file will not be used in any way that will identify you.

Is your participation voluntary?
Yes, your participation in this interview is entirely voluntary. If you do agree to participate, you can withdraw from participation at any time before or during the interview without comment or penalty.

Your decision whether or not to participate in this interview will in no way impact upon the support you receive from [Institution Name].

If you want to know more, who do you contact?
If you need more information about the study or have specific questions about it, please do not hesitate to contact me at QUT on 3864 5953 or on my mobile on 0423 211 743 or by email on jp.rosenberg@student.qut.edu.au.

What if you are concerned about this study?
Please contact the Research Ethics Officer on 3864 2340 or ethicscontact@qut.edu.au if you have any concerns or complaints about the ethical conduct of the project.

How do you give your consent?
If you are happy to participate in the interview, please read and sign the Consent Form attached.

Thank you for taking a moment to read this letter.

JOHN ROSENBERG
Consent Form for Patient / Carer Interview

A study of the integration of health promotion principles and practice in palliative care organisations.

John Rosenberg RN
PhD Student, School of Nursing, Queensland University of Technology
Telephone: 07 3864 5953 Mobile: 0423 211 743
Email: jp.rosenberg@student.qut.edu.au

Statement of consent

By signing below, you are indicating that you:

- have read and understood the information sheet about this project;
- have had any questions answered to your satisfaction;
- understand that if you have any additional questions you can contact the researcher;
- understand that you are free to withdraw at any time, without comment or penalty;
- understand that you can contact the researcher if you have any questions about the project, or the Research Ethics Officer on 07 3864 2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project;
- agree to participate in the interview;
- agree to allow the researcher noted above access to your [redacted] patient file.

Name

________________________________________

Signature

________________________________________

Date

______ / ______ / ______
Information Sheet – Staff / Volunteers

A study of the integration of health promotion principles and practice in palliative care organisations.

John Rosenberg RN
PhD Student, School of Nursing, Queensland University of Technology
Telephone: 07 3864 5953  Mobile: 0423 211 743
Email: jp.rosenberg@student.qut.edu.au

What is this study about?
The purpose of this project is to examine the elements of health promotion in a palliative care service such as Karuna Hospice Services. These elements are:
- Building public policies that support health
- Creating supportive environments
- Strengthening community action
- Developing personal skills
- Reorienting health services

For some of you, all these elements are important, whilst for others, only one or two are relevant to your work with Karuna and their clients.

Who is running the study?
I am – John Rosenberg. I’m a registered nurse with more than 15 years experience in community-based palliative care. As part of my PhD studies, I’m studying at Queensland University of Technology [QUT] under the supervision of Professor Patsy Yates. The Executive Director of Karuna Hospice Services, Ven. Yeshe Khadro, has granted written permission for this study to be conducted and the project has met the ethical requirements of QUT University Human Research Ethics Committee [UHREC].

What are you being asked to do?
- **Interview**
  I’m requesting your participation in an interview. It aims to explore in greater depth the health promotion issues relevant to your role at Karuna. The interview will take about 40-60 minutes to complete, and will take place in private. The interview will involve a face-to-face conversation between you and me which will be audiotaped.

- **Focus Group**
  I’m requesting your participation in a focus group. It aims to explore the ways in which you think health promotion elements might be integrated into palliative care, and in particular will look at the personal skills you believe you require for your work in palliative care and the nature of the organisation’s engagement with the wider community. The focus groups will comprise between 5–10 fellow staff members / volunteers from Karuna and will take place in the meeting spaces at a predetermined time during normal working hours. If you agree to participate, further information about the subject matter will be provided in writing beforehand.
Who will benefit from this study?
You might find it a helpful process to be involved in these activities – as it provides an opportunity to reflect on the nature of the support you provide the patients and carers of Karuna Hospice Services. It is expected that the results of the study will benefit future patients and carers of and other organisations that provide palliative care by describing the pros and cons of health promoting palliative care.

Are there any risks to you?
There is a low risk that you may find the questionnaire distressing. If at any time you find this to be the case, remember you are free to withdraw. If this distress persists, I encourage you to contact counselling staff.

Will your privacy be affected?
Whilst the management of are aware of that this study involves interviews with some staff and volunteers, and are participating themselves in a number of ways, no-one will know of your agreement to be interviewed by me unless you choose to tell them. Our discussion will be audiotaped, but no identifying information will be included when the interview is transcribed and the confidentiality of our discussion will remain intact. Information you provide may be used in a non-identifying way when the research report is written.

Clearly it is not possible to conceal the identity of focus group participants, however, the group will be made up of your peers in the workplace, so no members of the Board or senior management will be present. I am not seeking to access your personnel file.

Is your participation voluntary?
Yes, your participation in either or both of these activities is entirely voluntary. If you do agree to participate, you can withdraw from participation at any time before or during the activities without comment or penalty.

Your decision whether or not to participate in this interview and/or focus group will in no way impact upon your employment or voluntary work at.

If you want to know more, who do you contact?
If you need more information about the study or have specific questions about it, please do not hesitate to contact me at QUT on 3864 5953 or on my mobile on 0423 211 743 or by email on jp.rosenberg@student.qut.edu.au.

What if you are concerned about this questionnaire?
Please contact the Research Ethics Officer on 3864 2340 or ethicscontact@qut.edu.au if you have any concerns or complaints about the ethical conduct of the project.

How do you give your consent?
If you are happy to participate in the activity or activities marked above, please read and sign the Consent Form attached.

Thank you.

JOHN ROSENBERG
Consent Form – Staff / Volunteers for Interview and/or Focus Group
A study of the integration of health promotion principles and practices in palliative care organisations.

John Rosenberg RN
PhD Student, School of Nursing, Queensland University of Technology
Telephone: 07 3864 5953 Mobile: 0423 211 743
Email: jp.rosenberg@student.qut.edu.au

Statement of consent

By signing below, you are indicating that you:

◦ have read and understood the information sheet about this project;

◦ have had any questions answered to your satisfaction;

◦ understand that if you have any additional questions you can contact the researcher;

◦ understand that you are free to withdraw at any time, without comment or penalty;

◦ understand that you can contact the researcher if you have any questions about the project, or the Research Ethics Officer on 3864 2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project;

◦ agree to participate in:

☐ Interview
☐ Focus Group

Name ____________________________________________________________

Signature _________________________________________________________

Date ______/_____/______
Appendix 5: Public Information Sheet

Hello, my name is JOHN ROSENBERG.

You will be seeing me around [redacted] during much of 2005. Let me introduce myself and tell you why I'm here.

WHO AM I?
- I’m a registered nurse with almost 20 years experience. For most of that time, I’ve been a community palliative care nurse.
- Currently, I’m studying for a PhD at QUT. My research project is studying the impact of health promotion on palliative care organisations.

WHAT AM I DOING AT [redacted]?
- Over much of 2005, I’ll be undertaking fieldwork at [redacted] as part of my research.
- This fieldwork involves a number of activities:
  - Interviews with some staff, volunteers, members of the Board, and other stakeholders in [redacted]
  - Where appropriate, I’ll be interviewing some patients and carers too.
  - Focus groups with some staff.
  - Small scale questionnaires of some carers.
  - Review of organisational documentation.
- As an experienced palliative care nurse, I’m really aware of the need for sensitivity and care when conducting research with palliative care patients and their families. Any activities involving patients or their carers will have to meet strict ethical guidelines required by QUT and endorsed by the [redacted] Board.

WHAT WILL IT MEAN TO YOU?
- You may be invited to participate in a number of the fieldwork activities. This participation is entirely voluntary. YOU ARE NOT OBLIGED TO PARTICIPATE!

WHAT AM I NOT DOING AT [redacted]?
- My study is NOT an accreditation audit of the organisation, nor is it a review of positions, or performance appraisal.
- Any participation you have in my research study will have NO IMPACT whatsoever on your employment.

HOW CAN YOU FIND OUT MORE?
- Throughout the year, I will speak at meetings and distribute written information about any fieldwork activities where I seek your participation.
- If you have any questions at all about my research project, and especially if you are concerned about any aspect of the research, please talk to me! You can talk to me in person at [redacted], or you can call me on 0423 211 743, or email me on j.p.rosenberg@student.qut.edu.au.

If you would like to discuss any ethical issues about my study, I encourage you to contact Wendy Heffernan, QUT Ethics Officer, on 07 3864 2340 or email her on w.heffernan@qut.edu.au.
## Appendix 6: Document Log

**LEGEND:**
- **D** = document
- **P** = printed data (hardcopy/paper or electronically stored)
- **V** = visual data
- **W** = web-based data
- **01** = numerical order by subcategory
- **:1** = page (in text)

### Printed data

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<td>ID09: Family Support Volunteers Code of Conduct</td>
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Appendixes

DP32 ID405: Presentations by External Presenters at Karuna
DP33 ID406: Booking Procedure

DP34 Report Annual Report 2003-04
DP36 Report Strategic Plan Quarterly Report – July 2005
DP37 Schematic Company Structure 4 November 2005 version 1
DP38 Schematic Company Structure 4 November 2005 version 2
DP39 Schematic Company Structure 13 December 2005
DP40 Schematic Organisational Structure January 2006 version 2
DP41 Schematic Organisational Structure January 2006 version 3
DP42 Draft document Orientation to the Community Liaison Role
DP43 Draft document Population Approach for Karuna
DP44 Booklet Information Booklet
DP45 Brochure In commemoration of the consecration of the Stupa at Karuna House 17 June 2006
DP46 Brochure Generic information brochure version 1
DP47 Brochure Generic information brochure version 2
DP48 Brochure [call centre]
DP49 Book Caring at home with Karuna: a guide for carers
DP50 Draft document Business Plan [death education program]
DP51 Handout What is [death education program]? PowerPoint presentation handout
DP52 Draft flyer [death education program]
DP53 Draft flyer Open Heart, Peaceful Mind (Essential Education course)
DP54 Draft flyer Introduction to Buddhism (Essential Education course)
DP55 Newsletter News Autumn-Winter 2004
DP56 Newsletter News Spring-Summer 2004
DP57 Newsletter News 1st Issue 2005
DP58 Newsletter News 2nd Issue 2005
DP59 Newsletter News Autumn/Winter 2006
DP60 Letter Mid Year Appeal 2005
DP61 Letter Christmas Appeal 2005
DP62 Letter June Appeal 2006
DP63 Letter Letter to supporters January 2006
DP64 Flyer Art Market advertising
DP65 Flyer Fundraising event advertising – “Menopause the Musical”
DP66 Newsletter Team News 09/05
DP67 Newsletter Team News 02/06
DP68 Document Staff Satisfaction Survey Tool
DP69 Document Volunteer Satisfaction Survey Tool
DP70 Document Exit Interview Survey Tool
DP71 Report Staff & Volunteer Satisfaction Survey
DP72 Newspaper Sowing peace and goodwill Jackie Sinnerton,
### Visual data (dates on images)

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>DV01</td>
<td>Photo</td>
<td>Karuna House [premises] from NW aspect</td>
</tr>
<tr>
<td>DV02</td>
<td>Photo</td>
<td>Karuna House [premises] from NE aspect</td>
</tr>
<tr>
<td>DV03</td>
<td>Scan</td>
<td>The Chenrezig Buddha</td>
</tr>
<tr>
<td>DV04</td>
<td>Photo</td>
<td>The Stupa</td>
</tr>
<tr>
<td>DV05</td>
<td>Photo</td>
<td>Mandala Books [bookstore] with its former manager</td>
</tr>
<tr>
<td>DV06</td>
<td>Scan</td>
<td>Postcard of painting ‘Art Market’ by Katy Edwards</td>
</tr>
<tr>
<td>DV07</td>
<td>Scan</td>
<td>Drawings by volunteer</td>
</tr>
<tr>
<td>DV08</td>
<td>Scan</td>
<td>Christmas Market flyer</td>
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### Web-based data (as at 10 August 2005 unless otherwise stated)

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<tbody>
<tr>
<td>DW01</td>
<td>Hospice website</td>
<td>Welcome to (home page)</td>
</tr>
<tr>
<td>DW02</td>
<td>Hospice website</td>
<td>About Us</td>
</tr>
<tr>
<td>DW03</td>
<td>Hospice website</td>
<td>Karuna’s Beginnings</td>
</tr>
<tr>
<td>DW04</td>
<td>Hospice website</td>
<td>Karuna’s Vision and Values</td>
</tr>
<tr>
<td>DW05</td>
<td>Hospice website</td>
<td>The Organisation</td>
</tr>
<tr>
<td>DW06</td>
<td>Hospice website</td>
<td>Information</td>
</tr>
<tr>
<td>DW07</td>
<td>Hospice website</td>
<td>Care with</td>
</tr>
<tr>
<td>DW08</td>
<td>Hospice website</td>
<td>Frequently Asked Questions</td>
</tr>
<tr>
<td>DW09</td>
<td>Hospice website</td>
<td>Knowledge Base</td>
</tr>
<tr>
<td>DW10</td>
<td>Hospice website</td>
<td>Knowledge Base: Death, Dying and Buddhism</td>
</tr>
<tr>
<td>DW11</td>
<td>Hospice website</td>
<td>Community Program</td>
</tr>
<tr>
<td>DW12</td>
<td>Hospice website</td>
<td>Volunteers Wanted</td>
</tr>
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<td>DW13</td>
<td>Hospice website</td>
<td>Monday Meditation</td>
</tr>
<tr>
<td>DW14</td>
<td>Hospice website</td>
<td>Secure Online Donation</td>
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<tr>
<td>DW15</td>
<td>Hospice website</td>
<td>Downloads</td>
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<td>Blog</td>
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<td>Hospice website</td>
<td>Jobs at</td>
</tr>
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<td>DW20</td>
<td>Hospice website</td>
<td>Privacy Statement</td>
</tr>
<tr>
<td>DW21</td>
<td>Hospice website</td>
<td>Contact Us</td>
</tr>
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<td>DW22</td>
<td>Bookstore website</td>
<td>Home page</td>
</tr>
<tr>
<td>DW23</td>
<td>Bookstore website</td>
<td>About Us</td>
</tr>
<tr>
<td>DW24</td>
<td>Bookstore website</td>
<td>Who are the books for?</td>
</tr>
<tr>
<td>DW25</td>
<td>Bookstore website</td>
<td>How to order</td>
</tr>
</tbody>
</table>
## Appendixes

| DW26 | Book list            |
| DW27 | Recommended reading list |
| DW28 | Lothian Books        |
| DW29 | Cards                |
| DW30 | CDs                  |
| DW31 | Posters              |
| DW32 | Children’s Books     |
| DW33 | Latest Catalogue     |
| DW34 | Call Centre          |
| DW35 | Website              |
| DW36 | A helping hand       |
| DW37 | About Us             |
| DW38 | Callers’ Stories     |
| DW39 | Goals                |
| DW40 | Palliative care can assist |
| DW41 | Events               |
| DW42 | Downloads             |
| DW43 | Health Professional Area |
| DW44 | The Palliative Care Partner Network |
| DW45 | Contact Us           |
## Appendix 7: Document Summary Form

### DOCUMENT SUMMARY FORM

<table>
<thead>
<tr>
<th>CODE:</th>
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#### A: DETAILS

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<table>
<thead>
<tr>
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<th>Time to</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Accessed by</th>
</tr>
</thead>
</table>

#### B: NAME / DESCRIPTION OF DOCUMENT

-...

#### C: CONTACT / EVENT PROMPTING DOCUMENT REVIEW

-...

#### D: KEY ISSUES

<table>
<thead>
<tr>
<th>Issue</th>
</tr>
</thead>
</table>

#### E: SALIENT POINTS FOR DATABASE MATRIX

<table>
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</tr>
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</table>

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#### G: ACTION PLAN

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<td>✓</td>
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</table>

(Adapted from Miles & Huberman, 1994, p.55)
**Appendix 8: Prompt Questions – In-depth Interviews**

<table>
<thead>
<tr>
<th>Subunit of Analysis</th>
<th>Key informant / staff / volunteer focussed questions</th>
<th>Consumer focussed questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Building public policy</strong></td>
<td>◦ How does this organisation participate in the development of public policies relating to palliative care?</td>
<td>◦ What services do you receive from [ ]?  (clinical care / information and advice / counselling / spiritual care / etc)</td>
</tr>
<tr>
<td></td>
<td>◦ Can you describe any research project this organisation has participated in that has/could influence how palliative care is organised?</td>
<td>◦ In what ways do these services support you in your current situation?</td>
</tr>
<tr>
<td></td>
<td>◦ Does this organisation liaise with other sectors outside of health care? How?</td>
<td>◦ Are these services available to you when you need them? Can you give an example?</td>
</tr>
<tr>
<td></td>
<td>(Not targeted)</td>
<td>◦ Are there ways in which [ ] better support you here at home? What are they?</td>
</tr>
<tr>
<td><strong>Creating supportive environments</strong></td>
<td>◦ How does your organisation circulate information about death and dying to the wider community?</td>
<td>◦ Do you feel you are listened to by [ ] staff and volunteers? Can you give an example?</td>
</tr>
<tr>
<td></td>
<td>◦ In what ways does this organisation provide support to patients in the areas of relationships and home life?</td>
<td>◦ Do you see your family members being supported by [ ]? How?</td>
</tr>
<tr>
<td></td>
<td>◦ What sorts of strategies does this organisation use to prevent or minimise social difficulties for patients and their families during the palliative care period? When are they implemented?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>◦ What does the term ‘advocacy’ mean to you? Can you give an example of how this organisation advocates for its patients? What barriers exist in providing advocacy for your patients?</td>
<td></td>
</tr>
<tr>
<td><strong>Strengthening community action</strong></td>
<td>◦ Imagine a service club came to you and asked you to help them understand the demands of terminal illness upon family members. How might you go about meeting their need?</td>
<td>(Not targeted)</td>
</tr>
<tr>
<td></td>
<td>◦ Describe some ways in which this organisation promotes the family members’ participation in decision-making about the care provided to their relative?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>◦ Imagine you have been asked to recruit a palliative care consumer representative for the Board. How might you go about achieving this?</td>
<td></td>
</tr>
</tbody>
</table>
## Subunit of Analysis

### Developing personal skills
- How have you learned about death and dying? Think about both formal and informal ways.
- How has this past learning about death and dying prepared you for palliative care work? Where are there gaps in your learning?
- If you needed to know more about death and dying, where would you go? Again, think about both formal and informal ways.
- Do you believe this organisation has changed people’s thinking about death, dying and palliative care? In what ways?

### Reorienting health services
- How do you evaluate your clinical staff’s skills and performance in the practice of palliative care?
- How do you support your staff’s learning in the practice of palliative care?
- Describe some ways in which this organisation promotes the patients’ participation in decision-making about their care.
- What procedures are in place to evaluate the effectiveness of the organisation’s palliative care work?
- Are there policies or other statements which reflect the patients’ place in the organisation? How is this concretely implemented in the organisation’s activities?

## Key informant / staff / volunteer focussed questions

### Developing personal skills
- How have you learned about death and dying? Think about both formal and informal ways.
- How has this past learning about death and dying prepared you for palliative care work? Where are there gaps in your learning?
- If you needed to know more about death and dying, where would you go? Again, think about both formal and informal ways.
- Do you believe this organisation has changed people’s thinking about death, dying and palliative care? In what ways?

### Reorienting health services
- How do you evaluate your clinical staff’s skills and performance in the practice of palliative care?
- How do you support your staff’s learning in the practice of palliative care?
- Describe some ways in which this organisation promotes the patients’ participation in decision-making about their care.
- What procedures are in place to evaluate the effectiveness of the organisation’s palliative care work?
- Are there policies or other statements which reflect the patients’ place in the organisation? How is this concretely implemented in the organisation’s activities?

## Consumer focussed questions

### PATIENTS:
- How prepared were you for the situation you find yourself in now?
- Has Karuna helped you to adjust to these changed circumstances? How?

### CARERS:
- What practical skills do you need to as a carer?
- What emotional / coping skills do you need as a carer?
- Has Karuna helped you to gain these skills you need to be a carer? How?
- What are the best ways for carers like you to gain these skills?

(Not targeted)
## Appendix 9: Contact Summary Form

### A: CONTACT DETAILS

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Type</th>
<th>Individual</th>
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<th>Site</th>
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<td></td>
<td></td>
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</table>

### B: KEY DISCUSSION ISSUES

- [Blank lines for additional discussion issues]

### C: SALIENT POINTS FOR DATABASE MATRIX

<table>
<thead>
<tr>
<th>Issue</th>
<th>Units of analysis</th>
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<tbody>
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### D: ACTION PLAN

<table>
<thead>
<tr>
<th>Follow up action required</th>
<th>Date</th>
<th>Done</th>
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<td></td>
</tr>
</tbody>
</table>

(Adapted from Miles & Huberman, 1994, p. 53-54)
Appendix 10: Prompt Questions and Guidelines

– Focus Groups

GUIDELINES FOR FOCUS GROUPS

Format:

1. Introduction:
   a. The **aim** of this focus group is to determine your perceptions of the personal skills needed for palliative care work and the nature of the engagement of **Karuna** with the wider community.
   b. We'll be attempting **to do this** by spending about an hour looking at what **HPPC** is and how **Karuna** might already show a HPPC approach, what issues would help it fully integrate HPPC, and what issues might present barriers to HPPC being integrated. We’ll do this by clarifying what HPPC is, and discussing elements of it in concrete terms.
   c. **Ground rules** for this discussion are based on respect:
      i. All opinions are welcomed
      ii. Differences of opinions are welcomed
      iii. Each person will have an opportunity to have their say
      iv. Only one person speaking at a time
   d. **Consent**: if you agree to this arrangement, please sign the consent form in front of you. Remember, your participation is voluntary and you are free to withdraw from this focus group if you wish, without explanation or penalty.

2. Who’s who? You know each other but I don’t know you – tell me your name, role at **Karuna**, and one thing you’d like to achieve before you die.

3. Discussion
   a. Orientation to HPPC
      i. What do you already know about it? [ask for individual comment]
      ii. **Summary sheet – definitions, components, examples**
      iii. Questions?
      iv. If you had to summarise in one or two short sentences what HPPC is, how would you do it? OR Can you name one or two key messages from our discussion so far?
   b. Specific questions (see table) – use SWOT format on whiteboard
   c. What factors might advance or impede these activities becoming part of **Karuna**’s work?
**Appendixes**

**Discussion**

Consider these questions in a SWOT format.

- How does this organisation participate in the development of public policies relating to palliative care?
- Can you describe any research project this organisation has participated in that has/could influence how palliative care is organised?
- Does this organisation liaise with other sectors outside of health care? How?
- How does your organisation circulate information about death and dying to the wider community?
- In what ways does this organisation provide support to patients in the areas of relationships and home life?
- What sorts of strategies does this organisation use to prevent or minimise social difficulties for patients and their families during the palliative care period? When are they implemented?
- What does the term ‘advocacy’ mean to you? Can you give an example of how this organisation advocates for its patients? What barriers exist in providing advocacy for your patients?
- Imagine a service club came to you and asked you to help them understand the demands of terminal illness upon family members. How might you go about meeting their need?
- Describe some ways in which this organisation promotes the family members’ participation in decision-making about the care provided to their relative?
- Imagine you have been asked to recruit a palliative care consumer representative for the Board. How might you go about achieving this?
- How have you learned about death and dying? Think about both formal and informal ways.
- How has this past learning about death and dying prepared you for palliative care work? Where are there gaps in your learning?
- If you needed to know more about death and dying, where would you go? Again, think about both formal and informal ways.
- Do you believe this organisation has changed people’s thinking about death, dying and palliative care? In what ways?
- How do you evaluate your clinical staff’s skills and performance in the practice of palliative care?
- How do you support your staff’s learning in the practice of palliative care?
- Describe some ways in which this organisation promotes the patients’ participation in decision-making about their care.
- What procedures are in place to evaluate the effectiveness of the organisation’s palliative care work?
- Are there policies or other statements which reflect the patients’ place in the organisation? How is this concretely implemented in the organisation’s activities?
FOCUS GROUP INFORMATION - later groups

Thanks for agreeing to join this focus group for staff.

I now have only a short time remaining to finalise data collection for my PhD study and my interim analysis enables me to focus in on a few key issues that emerged from earlier data.

There are a few issues I’d like to hear your views on during our focus group. I’ve put some questions in each section to prompt your thinking about these issues.

1. **CHANGE CHANGE AND MORE CHANGE**

   It's very clear that organisations are in a constant state of change, and in some ways [redacted] is more changeable than other organisations. This has its pros and cons, but the issue raised by many in this study relates to how those changes are communicated to those they effect.

   *How well do you think organisational change is being communicated to you at the moment? What's going well and what could be improved?*

2. **SUPPORTIVE ENVIRONMENTS FOR STAFF**

   Different people need different kinds of support to do this sort of work. There have been some changes in the past six to twelve months in how [redacted] offers this.

   *How suitable are current support structures and processes for you? What's going well and what could be improved?*

3. **A NEW NAME FOR WHAT WE DO, OR A NEW WAY OF DOING WHAT WE DO?**

   Health promoting palliative care has been explicitly identified by [redacted] as an approach to palliative care that drives its strategic direction. Here’s a summary of what each of the elements of HPPC is focussed on:
<table>
<thead>
<tr>
<th><strong>KEY ACTION AREAS</strong></th>
<th><strong>DESCRIPTIONS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Building public policy</td>
<td>Concerned with the participation of [blank] in the development and/or uptake of public policy relating to palliative care and the support of dying people.</td>
</tr>
<tr>
<td>Creating supportive environments</td>
<td>Concerned with the ways in which [blank] contributes to the creation of supportive environments to enhance well-being for consumers and employees of the palliative care service.</td>
</tr>
<tr>
<td>Strengthening community action</td>
<td>Related to the nature of the engagement of [blank] with the wider community, beyond the recipients of palliative care services, to promote community action towards improved support of people at the end of life.</td>
</tr>
<tr>
<td>Developing personal skills</td>
<td>Concerned with [blank]'s participation in the development of personal skills to assist individuals to deal with issues around death and dying. Includes both health care professionals and primary caregivers.</td>
</tr>
<tr>
<td>Reorienting health services</td>
<td>Related to the activities of [blank] in reorienting its members to a health promoting approach, and has a particular focus on the holistic needs of its client population, and changes in organisation attitudes.</td>
</tr>
</tbody>
</table>

Here are two quotes from earlier data that demonstrate opposing views of health promoting palliative care:

- **FACILITATOR:** “Do you think there are barriers to health promotion being integrated into this palliative care organisation?”
- **RESPONDENT:** “I think that all we are doing is putting a name to what we have been doing for a long time. I don’t think we will be doing anything different to what we are doing now.”

- **FACILITATOR:** “So there’s a whole reform agenda for preparing health professionals for working with dying people that needs addressing?”
- **RESPONDENT:** “Yes, but it’s [about] cost. There are things...in every on of those five areas [of health promotion] there’s lots of work that needs to happen ...great concept though! [laughs]”

**Do you think health promoting palliative care is simply a new name for existing ways of providing palliative care, or is it more than that?**

**Is it just a good idea or can it capture the intent of a palliative care organisation like [blank]?”**

Have think about these before we meet on Monday. I’ll need to ask you to sign another consent form, which I’ll bring with me.

The stenographer, Anne Isdale, will be joining us as before.

You can call me on 0423 211 743 if you wish.

Thanks again,
John Rosenberg
Appendix 11: Carer Questionnaire

[Researcher’s note: formatting has been altered to enable ease of inclusion in Appendices]

Carer Questionnaire
A study of the integration of health promotion principles and practices in palliative care organisations.

Thank you for completing this brief questionnaire.

I’m interested in your experiences of being a carer receiving support from [REDACTED].

◦ Please complete the questionnaire yourself.
◦ You must be 18 years of age or older.
◦ It should take about 15 minutes to complete.
◦ Please answer as honestly as possible – I’m interested in both your positive and negative experiences.

REMEMBER, YOUR ANSWERS ARE ANONYMOUS AND CONFIDENTIAL and will not put the support you receive from [REDACTED] at risk.

When you have completed the questionnaire, please place it in the envelope provided and return it to me at Queensland University of Technology.

Thank you.

JOHN ROSENBERG
### How often is each of the following kinds of support available to you if you need it?

*Circle one number on each line*

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<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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</thead>
<tbody>
<tr>
<td>1 Someone you can count on to listen to you when you need to talk</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2 Someone to give you information to help you understand a situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3 Someone to give you good advice about a crisis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4 Someone to confide in or talk to about yourself or your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5 Someone whose advice you really want</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6 Someone to share your most private worries and fears with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7 Someone to turn to for suggestions about how to deal with a personal problem</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8 Someone who understands your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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### Tangible support

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<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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</thead>
<tbody>
<tr>
<td>9 Someone to help you with caregiving if you were confined to bed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10 Someone to take you to the doctor if you needed it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11 Someone to prepare your meals if you were unable to do it yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12 Someone to help with daily chores if you were sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</table>

### Affectionate support

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<tr>
<th>Affectionate support</th>
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<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 Someone who shows you love and affection</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14 Someone to love you and make you feel wanted</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
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<td>15 Someone who hugs you</td>
<td>1</td>
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### Positive social interaction

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<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 Someone to have a good time with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17 Someone to get together with for relaxation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18 Someone to do something enjoyable with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Additional items

<table>
<thead>
<tr>
<th>Additional items</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>19 Someone to do things with to help you get your mind off things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
## Appendixes

### To what extent does [the hospice service] offer this sort of support to you?

<table>
<thead>
<tr>
<th></th>
<th>Circle one number on each line</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td>20</td>
<td>Think for a moment about Items 1 to 8 in <strong>Emotional/informational support.</strong> To what extent does [the hospice service] offer this sort of support to you?</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>21</td>
<td>Think for a moment about Items 9 to 12 in <strong>Tangible support.</strong> To what extent does [the hospice service] offer this sort of support to you?</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>22</td>
<td>Think for a moment about Items 13 to 15 in <strong>Affectionate support.</strong> To what extent does [the hospice service] offer this sort of support to you?</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>23</td>
<td>Think for a moment about Items 16 to 18 in <strong>Positive social interaction.</strong> To what extent does [the hospice service] offer this sort of support to you?</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>24</td>
<td>Think for a moment about Item 19 in <strong>Additional item.</strong> To what extent does [the hospice service] offer this sort of support to you?</td>
</tr>
<tr>
<td></td>
<td>1</td>
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</tbody>
</table>

### How satisfied are you with the care provided by [the hospice service]?

<table>
<thead>
<tr>
<th></th>
<th>Circle one number on each line</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>VS = very satisfied</td>
</tr>
<tr>
<td>How satisfied are you with:</td>
<td>VS</td>
</tr>
<tr>
<td>25</td>
<td>The patient’s pain relief</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>26</td>
<td>Information provided about prognosis</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>27</td>
<td>Answers from [the hospice service]’s health professionals</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>28</td>
<td>Information given about side effects by [the hospice service]’s staff</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>29</td>
<td>Referrals to specialists / other services by [the hospice service]</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>30</td>
<td>Availability of a hospital bed for home use</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>31</td>
<td>Family conferences held by [the hospice service] staff to discuss the illness</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>32</td>
<td>Speed with which symptoms are treated by [the hospice service]’s staff</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Question</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>33</td>
<td>Attention to the patient’s description of symptoms by [the hospice service]’s staff</td>
</tr>
<tr>
<td>34</td>
<td>The way tests and treatments are performed by [the hospice service]</td>
</tr>
<tr>
<td>35</td>
<td>Availability of [the hospice service]’s doctor to the family</td>
</tr>
<tr>
<td>36</td>
<td>Availability of [the hospice service]’s nurses to the family</td>
</tr>
<tr>
<td>37</td>
<td>Coordination of care by [the hospice service]</td>
</tr>
<tr>
<td>38</td>
<td>Time required to make a diagnosis of new problems</td>
</tr>
<tr>
<td>39</td>
<td>The way the family is included in treatment and care decisions by [the hospice service] staff</td>
</tr>
<tr>
<td>40</td>
<td>Information given by [the hospice service]’s staff about how to manage pain</td>
</tr>
<tr>
<td>41</td>
<td>Information given about tests by [the hospice service]</td>
</tr>
<tr>
<td>42</td>
<td>How thoroughly [the hospice service]’s staff assess the symptoms</td>
</tr>
<tr>
<td>43</td>
<td>The way tests and treatments are followed up by [the hospice service] staff</td>
</tr>
<tr>
<td>44</td>
<td>Availability of [the hospice service]’s staff</td>
</tr>
</tbody>
</table>


**FOLLOW UP PHONE INTERVIEW**

If you are prepared to participate in a follow up interview, please provide your name and contact details here. If you do not wish to participate in an interview, leave this section blank.

REMEMBER, YOUR DECISION TO PARTICIPATE OR NOT IN THIS INTERVIEW WILL NOT PUT THE SUPPORT YOU RECEIVE FROM KARUNA AT RISK.

**NAME:**

**PHONE:**

I will contact you shortly to arrange with you a suitable date, time and place for interview.
### Appendix 12: Sample Descriptive Matrix – Strengthening Community Action

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>ENABLERS</th>
<th>BARRIERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ Vol program: community can learn from the work of vols about the human journey inc death and dying (F02V)</td>
<td>◦ Community activities in which vols play an essential part – Market Day, Art and Craft Market, Christmas Market, public speaking (I06V)</td>
<td>◦ Funding constraints – therefore limited resources to implement community education programs represents “The biggest test for...” in implementing HPPC (I23S:88)</td>
</tr>
<tr>
<td>◦ Palliative care services have a role in normalising issues around death and dying; sometimes formalised but sometimes through serendipity (F01S)</td>
<td>◦ These activities play a part in raising community awareness and promoting a sense of belonging to [ ] and its work (F01S)</td>
<td>◦ Difficult strengthen larger communities when one is a small palliative care place, hence great need for collaborative approach to this. (I20K)</td>
</tr>
<tr>
<td>◦ However, the nature of palliative care is such that when people need the service, they are vulnerable with limited options (I07S)</td>
<td>◦ Clinical focus on whole family promotes their involvement in the dying process (F01S)</td>
<td>◦ Difficult in urban communities to defining communities and what can and can’t be done; in rural communities this is less of a problem. (I20K)</td>
</tr>
<tr>
<td>◦ Reception (front desk) is an important function in the organisation – it is the public persona of [ ] but also builds relationships within the community (I03S)</td>
<td>◦ Bookstore on site as one of [ ] activities that strengthens community action – not a shop front but a book distributor (I08K)</td>
<td>◦ Some activities are still clinical support eg children’s bereavement – sand therapy – rather than community action per se. (I20K)</td>
</tr>
<tr>
<td>◦ [ ] as a “living example of compassion in action” with [ ] [bookstore] as an extension of that compassion; it is this activity that strengthens community action towards acts of compassion to the dying (I08K:9)</td>
<td>◦ [ ] [call centre] is an activity of [ ] that provides information and support about palliative care through provision of a call centre. (I09K)</td>
<td>◦ Constrained by small size and limited resources to address activities viewed as non-core business or “airy-fairy”. (I20K:142)</td>
</tr>
<tr>
<td>◦ Two pronged approach – [ ] [bookstore] is both an act of compassion AND a business (I08K)</td>
<td>◦ Appointment of a consumer representative to the Board to help plan and evaluate services to meet required standards. (I14K)</td>
<td>◦ Needs dedicated role to address this element to avoid getting swallowed up in day to day running. (I20K)</td>
</tr>
<tr>
<td></td>
<td>◦ Building social networks eg: bereavement group meets for craft weekly. (I20K)</td>
<td>◦ Resources are an enormous limitation to community strengthening activities – only so much can be asked of volunteers. (I22K)</td>
</tr>
</tbody>
</table>
### FACTORS
- [In] Buddhism, you cannot escape the discussion of and the consideration and the need to consider the concept of death because it's intrinsic to Buddhist philosophy. It's what karma revolves around, surrounds the whole concept of the meaning of life. Why are we here? And one cannot escape the discussion of and understanding of death.” *(I08K:141-144)*
- “The evidence is saying that if the community or the consumer is involved in their care, you’ve got better outcomes” *(14K:9-10)*

### ENABLERS
- Utilise skill, expertise and contacts of board members to promote support for Karuna too. *(I20K)*
- Defining community is important step in strengthening it. *(I20K)*
- Scheduling free public talks to raise awareness of death and dying issues. *(I22K)*
- [death education] program for community and corporate clients which aims to educate re life skills as a preparation for death. “Normalising the fact that death is a part of life cycle.” *(I22K:194; I32K)*
- [call centre] for information about palliative care. *(I22K)*
- Volunteering as a form of involvement. *(I22K)*
- Media coverage. *(I22K)*
- Public speaking and senior representation. *(I22K)*
- Informal and formal ambassadors who represent Karuna in various forums. *(I22K)*
- Remuneration was no problem in non-clinical role, coming from public sector to NGO. *(I26K)*

### BARRIERS
- Respondent doubtful the core management individuals have insight into the impact of their negative behaviour on others. *(I29V)*
- “The chronically ill don’t get a fair deal from palliative care.” *(F04S:314-315)* due to lack of resource, political factors.

### STRUCTURES
- Community participation can be to groups of people with like interests, perhaps but not necessarily disease-specific, or to a community. They are the client, not simply the recipients of services. *(I14K)*
- “We have to involve consumers in planning and evaluating our services...what does the community out there, the wider community, think of this?” *(I14K:21;27-28)*
- “The wider community needs to be doing something so that...dying doesn’t belong to a hospice service...it belongs to the community.” *(I29K:8-10)*
### FACTORS
- Social barriers to strengthening communities in regard to issues of death and dying, culturally bound, long term view needed, strategic direction from board, operational planning, resourcing. (I20K)
- Desired outcome that KHS is thought of as leaders in issues of death and dying, and sought when crisis (I20K)
- Breaking down the barriers is all about change, change management principles. Community development is a business that needs running like any other. (I20K)
FACTORS

- “I think [Karuna’s mission is to give that care and education to build a sustainable community is the overarching health promoting palliative care thing...building a sustainable community is the overall mission...at the moment we’re building a palliative sustainable community, but it’s not gone into the wider...” (I20K:222-226)
- Development of programs within systems driven by consumer identified needs. (I20K)
- “Well you know I really believe that the act of dying is something that people don’t want to talk about...And I think that people need to talk about it. You know we’ve got like everybody keeps telling us, an ageing community and so I think the more people know about [Karuna] then maybe other organisations might model themselves on [Karuna] or, we might have more support out there for the community and take the pressure off hospitals and people can die in an environment that...is known to them.” (I26K:417-418; 420-424)
- “...the feedback we’ve had from GPs that they’d actually have a phone number or whatever that they could give to client and say...‘I know this must be really traumatic for you but you could call these people and they may be able to help you work through some of these issues.’” (I10K:46-49)

ENABLERS

- Give control to patients and carers regarding how they want dying to be and how [Karuna] can provide PC: “They have a huge input into the decision making” (F01S:381)
- Raise community awareness, respond to community concerns; “I was on the radio a while back and some said, ‘We’ve always died, why do we need you?’ I said, ‘Very good question! A lot of people die in pain, emotional, physical or spiritual. Do you want that to happen to you?’” (I02K:417-419)
- Bookstore provides information for coping strategies for life generally; internet advertising and promotion, plus some Buddhist-specific print media; about to embark on local promotion (I08K)
- Learn from what others are doing to strengthen communities, particularly evidenced in other cultures. (I20K)
- Need to do community assessment and analysis, develop strategies, outsource it. (I20K)
- Identifying partners amongst stakeholders, eg Queensland Health. (I20K)
- “…what we’re all becoming much more aware of now is there are so many more possibilities of what we can do...with the [death education] Program and Books [bookstore] and the use of the community wing...some of the things that I would like...to see are things like free public talks on things like grief and loss, preparing for a funeral, emotional resilience, bereavement support groups. You know, things that are much more publicly available.” (I22K:57-63)
- Fluid role allocation offers reassurance that should personal circumstances change, will be supported. (I28K)
- “Sometimes audiences of [Karuna] talks (eg: services clubs) don’t want to listen to discussion of death and dying, rather keeping things practical and pragmatic – not receptive to issues (F01S)
- Use social marketing research to identify needs, not service providers who feel obligated to do it themselves. (I20K)
- Prioritising; “I think organisations like [Karuna] need to balance out between what they can’t see and what they can see...if they want long term sustainability, if they want to be leaders here, they need to think bigger and more visionary. The only tension there is to commit them to it, but if you can’t think bigger than this you won’t be able to find the funding for it...if it’s important enough, you will find it.” (I20K:160-161, 163-164, 167-168)
- Need to nail down leadership commitment. (I20K)
- FACILITATOR: “Do you think it’s sufficiently on the agenda to remain part of [Karuna] direction even if you were to withdraw completely?” RESPONDENT: “Can’t answer that...I don’t really know.” (I20K:236-238, 240)
- High staff turnover has meant that knowledge of HPPC amongst staff varies. (I20K)

BARRIERS

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- High staff turnover has meant that knowledge of HPPC amongst staff varies. (I20K)
<table>
<thead>
<tr>
<th>FACTORS</th>
<th>ENABLERS</th>
<th>BARRIERS</th>
</tr>
</thead>
</table>
|         | ◦ Participant in education program observing personal skills of other more experienced palliative care nurses. (I28S)  
◦ Participant in education program has had productive sessions with counsellor to address issues of grief and bereavement. (I28S)  
◦ Educate the public via print media publications. (I32K)  
◦ “The re-orienting health services as part of the health promotion, I think this health education project is a part of that process. It’s like everything. You have to find the niche to get in to start the changes and it’s taken - we have been working on doing this for three years. Because [organization]’s director started wandering around a couple of years ago, talking about health promoting palliative care, when the book came out it became our bandwagon two and a half, three years back now, which is why the shift into community education, community input and community contact - and for the clinical team, this has been our first opportunity to get that shift into health care. That is my perception. We have always done education. It has been on specific things.” (F04S:294-302) | ◦ “Then we are fighting cultural perceptions as well because we are a culture which doesn’t want to talk about death and dying as a general rule. Strengthening community action with that makes it really hard. Our core business is that. Our shift - [organization]’s shift into [death education program] stuff and making people’s lives better - it is a program of community education, covering a lot of different things, getting people ready for death. It is the background to it. We are teaching them to live.” (F04S:281-285) |
<table>
<thead>
<tr>
<th>FACTORS</th>
<th>ENABLERS</th>
<th>BARRIERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ Normalising of death and dying demonstrated in serendipitous conversations where relaxed, positive discussions of death are evident (F01S)</td>
<td>◦ Some former carers have ended up volunteering, on staff or on the board and demonstrate KHS’s ability to flexibly find a place for them in the work of palliative care (F01S)</td>
<td>◦ No needs analysis of wider community to identify how to strengthen and empower them. (I20K)</td>
</tr>
<tr>
<td>◦ Use of resources from Mandala [bookstore] may influence people’s experiences of death and dying (I08K)</td>
<td>◦ “Palliative Care at Home” booklet has received very positive feedback from carers and patients (I09K)</td>
<td>◦ Need to develop indicators of strengthened communities to confirm outcomes of strategies. (I20K)</td>
</tr>
<tr>
<td>◦ “Palliative Care at Home” booklet has received very positive feedback from carers and patients (I09K)</td>
<td>◦ Art Market and Christmas Market do promote questions from strangers to enquire aboutKaruna’s work. (I20K)</td>
<td>◦ Humanistic benefit of Mandala [bookstore] cannot be measured (unlike the commercial benefits) although the sorts of titles indicate the level of interest in issues of death and dying (I08K)</td>
</tr>
<tr>
<td>◦ “Palliative Care at Home” booklet has received very positive feedback from carers and patients (I09K)</td>
<td>◦ Meeting room facilities is raising profile of Karuna outside of palliative care. (I20K)</td>
<td>◦ No evidence available that the benefits of “Palliative Care at Home” booklet is being passed on once its use is completed (I09K)</td>
</tr>
<tr>
<td>◦ Art Market and Christmas Market do promote questions from strangers to enquire about Karuna’s work. (I20K)</td>
<td>◦ More media profile about death and dying would be indicator of raised community awareness and perhaps strength; eg: radio talk, mentions in the paper, etc. (I20K)</td>
<td>◦ “...so any opportunities that arise to bring Karuna forward into the public arena, we're now, I think, much more consciously trying to do that and that's an interesting one because,...sometimes the results of that is that we get a lot more referrals to our patient service. So we've always historically been a little bit careful about what media we actually promote because what we don't want to end up with is a long waiting list because one of the things we've always prided ourselves on is a pretty quick response time when people actually need the service.” (I22K:236-242)</td>
</tr>
</tbody>
</table>

◦ No needs analysis of wider community to identify how to strengthen and empower them. (I20K)
"The other day, someone who was from an organisation of a different religion who supports financially - a representative of that organisation was recently at a retiree adventure program and happened to bump into a young journalist and the journalist is just turning to him and this person who's involved in supporting us with fundraising started telling him about and that journalist then immediately came and wanted to do a story with us. So just things like that. I mean, sometimes we find out about it and sometimes we don't. I mean, other people have conversations with other people and we don't even know what's happening out there in the ether." (I22K:290-298)

"...a PhD thesis like this is - as we all know, it is putting evidence out there that this is a valuable thing to do. We have to hit them with evidence and evidence and evidence. You are becoming part of our evidence that this is a valuable thing - not to us. We are the converted. It's hitting that policy maker. The action areas are - yes, we do them all." (F04S:328-332)
# Appendix 13: Record of Analysis Form

<table>
<thead>
<tr>
<th>ISSUE:</th>
<th>CODE:</th>
<th>DATE:</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOAL OF ANALYSIS:</td>
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<table>
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<th>DATA SOURCE</th>
<th>PROCEDURAL STEPS</th>
<th>DECISION RULES</th>
<th>ANALYSIS PROCEDURES</th>
<th>CONCLUSIONS DRAWN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Data reduction</td>
<td></td>
</tr>
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<td></td>
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<td></td>
<td>Conclusion drawing</td>
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</tr>
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<td></td>
<td></td>
<td></td>
<td>Verification</td>
<td></td>
</tr>
</tbody>
</table>

(Adapted from Miles & Huberman, 1994, p.283)
Appendix 14: Superseded Organisational Chart
Appendixes
Appendix 15: Call Centre Downloadable Information


The following resources are available for free download. Most files are in Adobe PDF format. Click title or cover image to download the document.

Palliative Caring at Home

_Palliative Caring at Home_ is a guide for carers who are caring for a person with life-limiting illness at home. This 62 page booklet addresses various aspects of the practical caring role, as well as providing information about looking after yourself and how and where to get help if you need it. If you are caring for a loved one who has made the decision to die at home, this book is a must to read. If you would like to order a free hard copy of this booklet, please e-mail your request with a return address to info@pcis.org.au, or call 1800 [number] during business hours.

_Palliative Care Information Service Brochure_

This brochure explains the services provided by the Palliative Care Information Service for individuals suffering from life-limiting illnesses, their family, friends and carers. More copies of this brochure can be obtained by e-mailing your request with a return address to info@pcis.org.au, or call 1800 [number] during business hours.

Connecting Doctors and Nurses with Palliative Care Specialists

This brochure outlines the specialist linkage service provided by the Palliative Care Information Service, a service that connects Queensland doctors and nurses to Specialist Palliative Care doctors and nurses for clinical support and advice. More copies of this brochure can be obtained by e-mailing your request with a return address to info@pcis.org.au, or call 1800 [number] during business hours.

_Palliative Care Fact Sheets_

Palliative Care Queensland (PCQ) has developed a series of fact sheets that provide information on a range of palliative care related issues including:
- the process of dying
- nutrition in palliative care
- nausea and vomiting
- fatigue and exhaustion
- loss of appetite in advanced illness
- pain and pain management
- confusion and terminal restlessness
- making a will
- advanced health directives and appointing an enduring power of attorney
- refusing treatment
Appendixes

- helping children when someone has a life threatening illness
- resources for helping children cope with bereavement
- planning a funeral ahead of need
- looking after yourself.

These resources can be downloaded free of charge from the resource section of PCQ’s website.

**Understanding Grief**

This booklet has been developed by the Queensland Cancer Fund to help you understand more about the feelings experienced when someone close to you dies. *Understanding Grief* can help answer questions about the process of grief, how you can help yourself if you are bereaved and what resources are available to help in your bereavement. To download a free copy of this booklet, please follow the link above.

**Palliative Care - Your Next Treatment Option**

*Coming soon*

This booklet has been designed to empower individuals who have been newly diagnosed with a life-limiting illness with the knowledge required to achieve quality of life with their remaining time. The booklet outlines the role of Palliative Care in relation to life-limiting illness, the types of services available and where, as well the cost of receiving palliative care in Queensland. If you or someone you know has been referred to palliative care, then reading this booklet could be of tremendous benefit. If you would like to order a free hard copy of this booklet, please e-mail your request with a return address to info@pcis.org.au, or call 1800 772 273 during business hours.
Appendix 16: Christmas Market Advertisement

Join us! Nov 25, 26 & 27

Christmas Market invites you to visit our very own special Christmas Market.

The display of our exquisitely handmade items will definitely create “THE WOW FACTOR”

- Designer trimmed Christmas Trees
- Fabulous front door wreaths and swags
- Beautifully created Christmas gifts
- Decorated jars of jams & jellies
- Famous Cranberry Sauce
- Amazing centre pieces
- Uniquely hand made Christmas Decorations
  - Art Prints and Jewellery
  - Christmas themed wine bottle holders and ham bags

Food and refreshments will also be on sale.

So make a night and day of it at

Support — free home hospice care service.
— Nov 25th, 26th & 27th
Friday & Saturday 4pm — 9pm • Sunday 9am — 4pm
### Appendix 17: Carer Questionnaire Frequency Tables

#### EMOTIONAL/INFORMATIONAL SUPPORT

<table>
<thead>
<tr>
<th>Someone you can count on to listen to when you need to talk</th>
<th>Frequency</th>
<th>Percent</th>
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<table>
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<th>Valid Percent</th>
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<tr>
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<td>41.7</td>
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<tr>
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</table>

<table>
<thead>
<tr>
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<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
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<td>4.2</td>
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<tr>
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<td>8.3</td>
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<td>16.7</td>
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<tr>
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<table>
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<td>4.2</td>
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<td>25.0</td>
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<tr>
<td>most of the time</td>
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<tr>
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<td>29.2</td>
<td>29.2</td>
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<td><strong>Total</strong></td>
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### Appendixes

**Someone to turn to for suggestions about how to deal with a personal problem**

<table>
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<tr>
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<tr>
<td>some of the time</td>
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<tr>
<td>most of the time</td>
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**Someone who understands your problems**

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**To what extent does [the hospice service] offer this sort of support to you?**

<table>
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<tr>
<td>a little</td>
<td>2</td>
<td>8.3</td>
</tr>
<tr>
<td>to some extent</td>
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<tr>
<td>greatly</td>
<td>8</td>
<td>33.3</td>
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<tr>
<td>totally</td>
<td>6</td>
<td>25.0</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>95.8</td>
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<td>4.2</td>
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<tr>
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</table>

**TANGIBLE SUPPORT**

**Someone to help you with caregiving if you were confined to bed**

<table>
<thead>
<tr>
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</tr>
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<tbody>
<tr>
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<td></td>
<td></td>
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<tr>
<td>none of the time</td>
<td>4</td>
<td>16.7</td>
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<td>20.8</td>
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<tr>
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<td>33.3</td>
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<td>4.2</td>
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<tr>
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<td>100.0</td>
</tr>
<tr>
<td>someone to take you to the doctor if you needed it</td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>-----------</td>
<td>---------</td>
</tr>
<tr>
<td>Valid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>none of the time</td>
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<td>12.5</td>
</tr>
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</table>
a little of the time                           | 1         | 4.2     | 4.3           |
some of the time                               | 7         | 29.2    | 30.4          |
most of the time                               | 4         | 16.7    | 17.4          |
all of the time                                | 8         | 33.3    | 34.8          |
Total                                          | 23        | 95.8    | 100.0         |

|Missing                                        | 1         | 4.2     |               |

|Total                                          | 24        | 100.0   |               |

<table>
<thead>
<tr>
<th>someone to prepare your meals if you were unable to do it yourself</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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<tbody>
<tr>
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<td></td>
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<tr>
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<td>4</td>
<td>16.7</td>
<td>17.4</td>
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</table>
some of the time                                               | 7         | 29.2    | 30.4          |
most of the time                                               | 5         | 20.8    | 21.7          |
all of the time                                                | 7         | 29.2    | 30.4          |
Total                                                          | 23        | 95.8    | 100.0         |

|Missing                                                      | 1         | 4.2     |               |

|Total                                                        | 24        | 100.0   |               |

<table>
<thead>
<tr>
<th>someone to help with daily chores if you were sick</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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<td>3</td>
<td>12.5</td>
<td>12.5</td>
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</table>
a little of the time                              | 3         | 12.5    | 12.5          |
some of the time                                  | 5         | 20.8    | 20.8          |
most of the time                                  | 5         | 20.8    | 20.8          |
all of the time                                   | 8         | 33.3    | 33.3          |
Total                                             | 24        | 100.0   | 100.0         |

<table>
<thead>
<tr>
<th>To what extent does [the hospice service] offer this sort of support to you?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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<tr>
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<tr>
<td>not at all</td>
<td>3</td>
<td>12.5</td>
<td>13.6</td>
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</table>
to some extent                                                            | 9         | 37.5    | 40.9          |
greatly                                                                   | 6         | 25.0    | 27.3          |
totally                                                                   | 4         | 16.7    | 18.2          |
Total                                                                     | 22        | 91.7    | 100.0         |

|Missing                                                                   | 2         | 8.3     |               |

|Total                                                                     | 24        | 100.0   |               |
### AFFECTIONATE SUPPORT

<table>
<thead>
<tr>
<th>Someone who shows you love and affection</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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<table>
<thead>
<tr>
<th>Someone to love you and make you feel wanted</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
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<tbody>
<tr>
<td>Valid</td>
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<tr>
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<td>12.5</td>
<td>13.0</td>
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<td>4.3</td>
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<td>33.3</td>
<td>34.8</td>
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<tr>
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<td>33.3</td>
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<table>
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<tr>
<th>To what extent does [the hospice service] offer this sort of support to you?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
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<tbody>
<tr>
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<td></td>
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<tr>
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## POSITIVE SOCIAL INTERACTION

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<td></td>
<td></td>
</tr>
<tr>
<td>someone to have a good time with</td>
<td></td>
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</tr>
<tr>
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<td>4</td>
<td>16.7%</td>
<td>17.4%</td>
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<tr>
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<td>4</td>
<td>16.7%</td>
<td>17.4%</td>
</tr>
<tr>
<td>some of the time</td>
<td>5</td>
<td>20.8%</td>
<td>21.7%</td>
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<td>17.4%</td>
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<td>100.0%</td>
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### Someone to get together with for relaxation

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<td>4</td>
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<td>17.4%</td>
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<tr>
<td>a little of the time</td>
<td>4</td>
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<td>17.4%</td>
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<tr>
<td>some of the time</td>
<td>5</td>
<td>20.8%</td>
<td>21.7%</td>
</tr>
<tr>
<td>most of the time</td>
<td>5</td>
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<td>21.7%</td>
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<tr>
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<td>21.7%</td>
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### Someone to do something enjoyable with

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### To what extent does [the hospice service] offer this sort of support to you?

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<td>26.1%</td>
</tr>
<tr>
<td>greatly</td>
<td>4</td>
<td>16.7%</td>
<td>17.4%</td>
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<tr>
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<td>1</td>
<td>4.2%</td>
<td>4.3%</td>
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### ADDITIONAL ITEMS

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### SATISFACTION

#### How satisfied are you with the patient's pain relief?

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<td>4.5</td>
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<td>9.1</td>
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#### How satisfied are you with information provided about prognosis?

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### How satisfied are you with answers from [the hospice service]'s health professionals?

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<td>26.1</td>
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### How satisfied are you with information given about side effects by [the hospice service]'s staff?

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### How satisfied are you with referrals to specialists / other services by [the hospice service]?

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### How satisfied are you with availability of a hospital bed for home use?

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### How satisfied are you with family conferences held by [the hospice service] staff to discuss the illness?

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<th>Valid Percent</th>
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<table>
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## Appendixes

**How satisfied are you with coordination of care by [the hospice service]?**

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</tbody>
</table>

**How satisfied are you with time required to make a diagnosis of new problems?**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
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</table>

**How satisfied are you with the way the family is included in treatment and care decisions by [the hospice service] staff?**

<table>
<thead>
<tr>
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<th>Frequency</th>
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</tbody>
</table>

**How satisfied are you with information given by [the hospice service]'s staff about how to manage pain?**

<table>
<thead>
<tr>
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<th>Frequency</th>
<th>Percent</th>
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<tbody>
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**How satisfied are you with information given about tests by [the hospice service]?**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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<tr>
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</tr>
<tr>
<td>How satisfied are you with how thoroughly [the hospice service]'s staff assess the symptoms?</td>
<td>Frequency</td>
<td>Percent</td>
<td>Valid Percent</td>
</tr>
<tr>
<td>---</td>
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<tr>
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</tr>
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<td>41.7</td>
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<td>4.2</td>
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</table>

<table>
<thead>
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<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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</thead>
<tbody>
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<td>33.3</td>
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<td>4.2</td>
</tr>
<tr>
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<td>87.5</td>
<td>100.0</td>
</tr>
<tr>
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<td>12.5</td>
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<tr>
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</table>

<table>
<thead>
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<th>How satisfied are you with the availability of [the hospice service]'s staff?</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
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<td>79.2</td>
</tr>
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<td>12.5</td>
</tr>
<tr>
<td></td>
<td>undecided / uncertain</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td></td>
<td>very dissatisfied</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0</td>
<td>100.0</td>
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</table>
### Appendix 18: Interpretive Matrix

<table>
<thead>
<tr>
<th>Theme</th>
<th>CONCEPTUAL CONGRUENCE</th>
<th>CORE BUSINESS</th>
<th>MANAGEMENT OF ORGANISATIONAL CHANGE</th>
<th>ANTICIPATED OUTCOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building public policy</td>
<td>Conceptual link between PC and HP</td>
<td>Existing involvement in public policy development Integration of public policy documents Ongoing review of participation in developing public policy</td>
<td>Limited organisational capacity</td>
<td>Overcoming systemic barriers in government and other stakeholders Benefits beyond organisation Focus upon illness, not wellness</td>
</tr>
<tr>
<td>Creating supportive environments for staff/volunteers</td>
<td>Support of staff/volunteers is fundamental to palliative care Alignment of personal and organisational values</td>
<td>Support strategies must be concrete Provision of formalised support</td>
<td>Organisational stability Effective communication of organisational change Strategic inconsistency Inadequate communication of organisational change</td>
<td>Personal development opportunities, meaningful work</td>
</tr>
<tr>
<td>Creating supportive environments for consumers</td>
<td>Holistic support of consumers in fundamental to palliative care Organisation’s philosophy and values counter death-denial</td>
<td>Provision of formalised support Provision of wide-ranging support Emphasis upon providing psychosocial support HPPC activities: extra work or core business?</td>
<td>Responsive and flexible staff Outcome measurement Provision of quality resource information</td>
<td>Counter low public awareness of ‘Good death’ experiences Effective pain and symptom control Balanced attention to non-physical needs</td>
</tr>
</tbody>
</table>
| **Strengthening community action** | ▪ Death belongs to the community  
  ▪ The community is death-denying  
  ▪ □ Buddhist foundation promotes HPPC uptake | ▪ Existing involvement in strengthening community action  
  ▪ Death education programs  
  ▪ Programs strengthening community capacity  
  ▪ Are non-clinical activities core business? | ▪ Resources for non-clinical activities  
  ▪ Consumer involvement | ▪ Humanistic outcome measurement  
  ▪ Raising □ profile  
  ▪ Death education programs  
  ▪ Increased community resilience |
| **Developing personal skills** | ▪ Linking palliative care to personal skills development | ▪ Existing involvement in developing personal skills  
  ▪ Concrete strategies targeting skill development  
  ▪ Personal development  
  ▪ Consumers’ preparedness  
  ▪ Death education programs | ▪ Adequate support of staff and volunteers | ▪ The community is death denying  
  ▪ Individuals are death denying  
  ▪ Identification of personal values to underpin encounters with death and dying |
| **Reorienting health services** | ▪ Conceptual congruence  
  ▪ Linking organisational vision to strategic goals  
  ▪ Nomenclature – understanding the language of HPPC | ▪ Consumer engagement  
  ▪ Existing strategies for reorienting health services  
  ▪ Is HPPC core business?  
  ▪ Systemic barriers within PC profession  
  ▪ Is HPPC just the latest trend? | ▪ Management of organisational change – single or incremental implementation?  
  ▪ Organisational stability | ▪ Alignment of organisational values with identified consumer need  
  ▪ Governance of individual palliative care services to promote clear strategic direction to HPPC  
  ▪ Effective, relevant evaluation of end of life care |
Appendix 19: Policies of Compassionate Cities


<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 1 Has local health policies that recognise compassion as an ethical imperative. | 1A Fosters and supports education initiatives linking health and compassion. | • Community consultations.  
• Public forums. |
| | 1B Fosters and supports compassion in the workplace, school and aged care facility. | • Written policies and practices.  
• Collective discussion.  
• Information about supportive services.  
• Debriefing practices.  
• Peer networks.  
• Buddying/mentoring systems. |
| | 1C Fosters and supports health-promotion messages to incorporate death and loss. | • Information regarding patterns of morbidity and mortality in community.  
• Education campaigns regarding social and personal impacts of losses.  
• Local government policies regarding localised community responses to death and loss. |
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 2 Meets the special needs of its aged, those living with life-threatening illness and those living with loss. | 2A Fosters and supports the community awareness of the special needs of the aged, those living with life-threatening illness, and those living with loss. | • Continuity of social relations through maintenance of existing networks including family, friends and animal companions.  
• Provision for privacy, flexible visiting, meaningful work and animal companionship.  
• Learning programs/information about living with life-threatening and chronic illnesses. |
| 2B Fosters and supports positive ageing, positive aspects of chronic illness and positive aspects of loss. | 2B Fosters and supports positive ageing, positive aspects of chronic illness and positive aspects of loss. | • Values clarification strategies to educate regarding positive ageing.  
• Peer network support.  
• Facilitation of creativity as an expression of experience.  
• Honouring legacies – support of charities, establishment of foundations for education and awareness, advocacy for reform. |
| 2C Fosters and supports media recognition of their presence and experience. | 2C Fosters and supports media recognition of their presence and experience. | • Programs to raise community awareness of special needs and positives of ageing, serious illness and loss (eg: PC week; participation in community events such as festivals).  
• Maintain sense of compassionate purpose through media feedback. |
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 3 Has a strong commitment to social and cultural difference. | 3A Fosters and support anti-racist laws and inclusive policies; discourages religious discrimination based on class, gender, race and sexual preferences. | • Public health requires community tolerance of difference.  
• Link between communities’ failures to be tolerant and loss and grief amongst marginalised community members.  
• Public discussion about difference and social inclusion in matters of death and loss. |
|                                                    | 3B Fosters and supports social and cultural differences in public education and school curricula. | • Integration of cultural difference and experiences of death and loss into programs of education.  
• Participation of representatives of marginalised groups in community events (such as festivals and commemorative events). |
|                                                    | 3C Fosters and supports practices that recognise social and cultural influences in ageing, serious illness and loss in different groups. | • Groups are not homogenous.  
• Education and information strategies must include reflection upon differences within groups and in self. |
<p>|                                                    | 3D Any implementation, policy or planning committee must include members chosen for their combination of skills, expertise AND social and cultural diversity. | • Committee membership includes those it seeks to support. |</p>
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 4 Involves the grief and palliative care service in local government policy and planning. | 4A Any implementation, policy or planning committee should include a member of the local hospice/palliative care AND bereavement (sudden death) care team. | • Committee membership includes those with expertise in death and loss.  
• Targets sudden death including suicide, accidents, homicide. |
| | 4B Any implementation, policy or planning committee should include members with direct personal experience of ageing, living with a life-threatening illness or loss. | • Committee membership includes those with personal, first hand experience in death and loss. |
| | 4C Develops a local government policy to address loss and grief matters in the local community. | • Identify community needs on an ongoing basis using participatory research methods.  
• Local government funding of local programs addressing issues of death and loss (eg: community hospice; loss and grief programs).  
• Education and information programs targeting community development.  
• Cross reference to 1C. |
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| Offers its inhabitants access to a wide variety of supportive experiences, interactions and communication. | 5A Fosters and supports media attempts to compare and contrast experiences of death and loss for its viewers and readers. | • Lobby for more organised media coverage of issues of death and loss.  
• Cross comparisons of experiences. |
| | 5B Fosters and supports voluntary social services that assist people to maintain a preferred lifestyle in the face of death and loss. | • Promoting volunteer service participation in existing charity organisations.  
• Promoting new networks of voluntary support. |
| | 5C Fosters and support special social support programs for people in need. | • Promote contribution to and/or participation of people in need in community and social action (eg: visiting schools, workplaces, churches, festivals). |
| Promotes and celebrates reconciliation with indigenous people and the memory of other important community losses. | 6A Fosters and supports national, state and local government initiatives and policies towards indigenous reconciliation. | • Local policy of reconciliation. |
| | 6B Fosters and supports an inclusive approach to Remembrance Days and festivals, including members for ALL sides of former conflicts and former victims and workers of wars. | • Foster inclusion of all sides to march and acknowledge losses incurred by all people.  
• Promote healing (ie: health) through compassionate approach. |
| | 6C Has an annual day of remembrance for death and loss in peace times | • Working with local organisations concerned with death loss, commemorate losses incurred in peace time.  
• Festivals, commemorative events. |
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 7 Provides easy access to grief and palliative care services | 7A Promotes and supports a single telephone referral service for loss and palliative care. | • Prioritise access to loss and palliative care services.  
• 1800 dedicated phone line, website, with advertising support from local businesses, churches, community groups. |
| 7B Promotes and supports local grief and palliative care service by facilitating access to schools and workplaces. | • Goal is to mainstream grief and palliative care services to address ignorance and fear in wider community and build community resilience.  
• Partnerships between organisations. |
| 7C Promotes and supports public education and awareness campaigns about the existence of nature of these services. | • Sponsorship of festivals or other community events.  
• Encourage and promote involvement of community members in grief support and palliative care services in their local area. |
| 7D Promotes and supports community initiatives from these services. | • Promote reciprocal and participatory nature of engagement between services and the communities they serve.  
• Moves services away from solely a service orientation to a social orientation and promote social relevance as well as clinical services. |
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 8 Has a recognition and plan to accommodate those disadvantages by the economy, including rural and remote populations, indigenous peoples and homeless. | 8A Has a research-based understanding of the role of death and loss in the health and illness patterns of these communities. | • Apply global knowledge to local context.  
• Research development promoted in partnerships between communities, services and researchers (including universities). |
| 8B Has a plan to address the death and loss issues for these communities. | 8C Promotes and supports grief and palliative care services for rural and remote areas, indigenous populations and the homeless. | • Identify local issues relating to death and loss.  
• Consideration of resource requirements to address local needs.  
• Develop, provide and maintain culturally and socially appropriate services related to death and loss for marginalised community members. |
| 8D Involves schools, police, churches, workplaces and businesses in the formulation and design of these understandings and plans. | | • Involvement of non-clinical service providers.  
• Promote ownership of local policies. |
<table>
<thead>
<tr>
<th>POLICY VISION for a compassionate community which:</th>
<th>OPERATIONAL POLICIES that:</th>
<th>ISSUES AND STRATEGIES include but are not limited to:</th>
</tr>
</thead>
</table>
| 9 Preserves and promotes a community’s spiritual traditions and storytellers. | 9A Fosters and supports inclusive religious politics, including ecumenist and multifaith initiatives, but eschews the proselytisation of tribal or medieval prescriptions. | • Participation in festivals.  
• Representatives of religious groups present in communities on policy and planning committees or service provider boards. |
| 9B Fosters and supports ‘festivals of the spirit’ in an inclusive context, which embraces religions and spiritual traditions both old and new. | | • Provide information and narrative about the variety of approaches to making meaning of death and loss. |
| 9C Fosters and supports the role of multifaith chaplaincy, pastoral care and humanist dialogue in their community role of comforting those living with life-threatening illness and loss. | | • Contribute to development of locally relevant curricula in pastoral care training.  
• Sharing information of such services at festivals and other community gatherings, plus through localised advertising and promotion. |
| 9D Fosters and supports the value and importance of spiritual beliefs and meanings in the development and support of healthy and compassionate lifestyles. | | • Develop relationships between community and religious institutions and the providers of support services around death and loss. |
REFERENCES


References


Palliative Care and Public Health Network. (2003a) News from the Hunter Region Palliative Care Service, NSW. *Social Networks, 1*, 3-4.


Palliative Care Australia. (2004b). *Policy Consultation Paper: meeting the needs of people who are dying through population based service planning*. Canberra: Palliative Care Australia.


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


References


