A COMPARISON OF THE GRIEVING PROCESS BETWEEN HOSPICE AND NON-HOSPICE PRIMARY CAREGIVERS

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ABSTRACT

Forty-one men and women between the ages of 28 and 88 who had lost a close relative to cancer in the previous 13½ to 26 month period were interviewed. They represented 22 caregivers involved with a hospice program before and after death of their relative and 19 caregivers who had no such involvement. Two questionnaires, the Texas Revised Inventory of Grief and the Modified Bereavement Questionnaire, were administered to each subject. Scores for members of the two groups were compared using Chi Square and Student's t-test to determine significant differences. Responses were categorized into grief reactions, factors affecting bereavement and manifestations of grief. Hospice and non-hospice subjects showed more similarities than differences in all response categories. They were about equally distributed among the four grief reactions, absent, resolved, delayed and prolonged. Four of the 19 factors affecting bereavement showed significant differences. These occurred in the age of the subjects, where the patients' died, who helped most during bereavement and discussion of funeral arrangements. Five of the 29 manifestations of grief showed significant differences. Hospice subjects were far more likely to "still feel the need to cry for the person who died" and have difficulty "getting along with certain people after the death" than non-hospice subjects. However, non-hospice subjects were more likely to "have difficulty sleeping after this person died". The study did not find significant differences between the groups in the use of alcohol, pills, weight change, social withdrawal, anger or irritability. The conclusion was drawn that although there are significant differences in some areas, overall it has not been shown that involvement with a hospice program is associated with a reduction in the nature and extent of grieving symptoms. The reasons for these findings and their implications are discussed and suggestions are offered for the direction of further research.

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Table of Contents

List of Tables

Table

List of Appendices

Appendix

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This dream is dedicated to
my husband, LOU
whose belief in me
gave me the courage to
to believe in myself

Chapter 1

Statement of the problem

In our modern technological society most of us will die in a hospital concerned with curing disease and prolonging life (Fulton, Markusen, Owen & Scheiber, 1978; Kubler-Ross, 1975). The hospital hierarchy is designed to look after those suffering an acute illness, chronic illness or terminal illness in that order. The needs of the dying are at odds with the goals of a general hospital, which include diagnosis and cure rather than palliation (Lepine, 1982; Ryder & Ross, 1978). When medical intervention directed towards cure is no longer appropriate, traditional health care breaks down (Mount & Scott, 1983). Hospice and other palliative care facilities have increased over the last 20 years in an effort to fill the void left when cure is no longer considered a reasonable possibility.

Hospice adherents believe the transition from life to death need not be a lonely agonizing experience. It is possible to pass from this life free of pain, lucid and aware of the presence of caring family members and friends. In our society there is little doubt that "the hospice movement, with its emphasis on support for patients and families and its methods of symptom control, has had a worldwide influence on the care of the dying since the inception of St. Christopher's Hospice, Sydenham in 1967" (Parkes, 1984, p. 120). The word hospice has become synonomous with palliative care over the last 20 years. Palliative comes from the root word palliate meaning "to alleviate disease without curing" (Fowler & Fowler, 1964, p. 875). Hospice, originally a place for pilgrims to rest when travelling from one place to another (Stoddard, 1978) is, today, associated with a place where people who are dying may be cared for. More importantly it is a concept of health care that focuses on the physical, emotional and spiritual needs of the patient and his family during the terminal phase of illness and includes bereavement follow-up (Bonham, Gochman & Burgess, 1987; Mount & Scott, 1983).

Dr. Cicely Saunders, the founder of the modern hospice movement, was motivated by a desire to alleviate the symptoms of terminal illness such as agonizing pain, intense loneliness and fear. This desire provided the foundation for the first modern hospice, St. Christophers (duBoulay, 1984). Since 1967 hospices have proliferated in North America, with an estimated 1,200 or more in the United States alone (Casperson, 1985; Greer & Mor, 1986; Kastenbaum, 1986).

The first palliative care unit in Canada was opened in 1974 at St. Boniface Hospital, St. Boniface, Manitoba, followed quickly in 1975 by the opening of Royal Victoria

Palliative Care Unit at Royal Victoria Hospital, Montreal. According to Elma G. Heidemann, President of the Palliative Care Foundation of Canada, there are now 359 hospices in Canada, a 200% increase since 1981. Of this total, 150 are hospital based, 84 are community based and 125 are both hospital and community based. Eighteen percent have been in operation less than 1 year, 51% between 1-5 years, 18% between 6-10 years and only 12% have been in operation longer than 10 years (Heidemann, 1987).

In spite of this proliferation, the effectiveness of the hospice concept has not been firmly established (Wales, Kane, Robbins, Bernstein, & Krasnow, 1983; Parkes, 1984) particularly in Canada where little formal research has been published. The degree to which participation in a hospice program influences the bereavement of close relatives is an important research topic.

The writer's interest in this area combined with the desire of Hospice Victoria to have research conducted into their program led to the present study. It explores the overall grief reactions, factors affecting bereavement and the manifestations of grief of hospice and non-hospice subjects. All subjects experienced the death of a close family member 13½ to 26 months prior to participation in this study.

Hospice Program Overview

Hospice Victoria is both hospital and community based. It is well established and has been in operation since 1981. It is the only hospice on Vancouver Island that has in-patient beds and one of only four in the province that includes in-patient facilities.

Hospice Victoria is an independent registered charitable society, governed by a board of directors and basically funded by the British Columbia Ministry of Health. Its physical connection to a large acute-care hospital provides easy access to surgical and technical services. The medical director oversees a staff which includes doctors, nurses, counsellors, administrative staff and active volunteers (see Table 1). This team serves people in the Greater Victoria Regional District in their homes, at other facilities in the community or at the hospice unit itself. Team members work in conjunction with home care nurses, homemakers, clergy, the family physician and other community members. At any one time there may be as many as 47 terminally ill patients and their families enrolled in the program.

The in-patient unit consists of seven beds. The 47 patients on the program are rotated through these beds for assessment, symptom control and patient or family relief. These beds are not available for long term assignment as hospice patients are encouraged to stay at

Table 1

Hospice Victoria Staff Allocation

Position	Full-time equivalents
Medical director	1.00
Clinical doctors	2.00
Nurses	12.20
Co-ordinator of care	1.00
Nurse clinician	0.50
Counsellors	3.16
Administrative assistant	1.00
Office staff	2.39
Volunteer co-ordinator	1.00
Hospice Society Staff	1.20
Active volunteers	85.00

home in familiar surroundings as much as possible. The hospice team is also available for consultation with patients, families, staff and doctors in acute care hospitals within the capital regional district.

The primary focus of hospice programs is to assist patients to relieve the symptoms associated with terminal illness and to support their families during the time before and after the patient's death (Godkin, Krant & Doster, 1983; Greer, Mor, Sherwood, Morris & Birnbaum, 1983; Kane, Klein, Bernstein, & Rothenberg, 1986; Parkes, 1985). These services are offered at the hospice under study beginning with an intake assessment interview by a doctor, nurse or counsellor. The decision whether or not to admit the patients is reached in consultation with the family and their physician. A plan of care is established and upon admission particular areas of concern are noted for follow-up. Assessment is on-going. A counsellor is assigned to each family and he or she in turn solicits the assistance of volunteers who help to meet the needs of the patient and family. Continuity of care is assured by a follow-up program to assist family members after the death of their relative.

Support for the family members after death of the patient takes a number of forms. Each family is sent a sympathy card which is closely followed by a letter of information and an invitation to attend support groups and memorial services. Programs offered to the bereaved include individual counselling, family counselling, one-on-one volunteer support and a monthly drop-in support group. In addition a 'walking group' has been established in the last year to involve the bereaved in regular outdoor activity. The participants meet each week, walk for an hour and then socialize over coffee. An eight-week children's support group along with a concurrent parent's group is also offered on a weekly basis two or three times a year.

The bereaved are telephoned 3 weeks, 6 weeks, 3 months, 6 months and 12 months after the death of their relative. On the anniversary of the death a letter is sent acknowledging the anniversary and formally ending the hospice program. However, in some cases hospice involvement with family members continues beyond one year.

Clarification of Terms and Variables

The loss of a loved one, particularly the loss of a spouse, is considered a major life stressor (Lieberman & Videka-Sherman, 1986; Parkes, 1985; Raphael, 1977; Windholz, Marmar, & Horowitz, 1985; Worden, 1982; Zisook, & Schucter, 1985). When a loved one dies; be it a spouse, parent, or sibling, the survivor is required to make many adjustments. These adjustments begin with the diagnosis of the terminal illness and continue in a variety of ways for years after the death.

There are a number of factors which affect the grieving process. These include age, sex of the bereaved, relationship and degree of closeness to the deceased, spiritual and social factors (Davidson, 1981; Vachon, Roberts, Lyall, Lancee, Sheldon & Freeman, 1982) and the "death surround" (Rando, 1984, p. 50). Rando's use of the term "death surround" relates to the immediate circumstances surrounding the death such as: reason for the death, type of death, where it occurred and the amount of death preparation that has taken place. "To the extent that the death surround can be accepted by the griever, the grief will be more amenable to management and resolution" (Rando, 1984, p. 50). Hospice, with its commitment to the whole person and family may be able to exert a positive influence on the social, spiritual and death surround factors influencing the grieving process.

The terms grief and bereavement are used interchangeably in this paper and other research (Rando, 1984) as they refer to the process of adjustment to the loss of a loved one. Manifestations of normal grief that appear in the literature again and again include: crying, inability to sleep, anger, feelings of loneliness and helplessness, preoccupation with thoughts of the deceased and social withdrawal (Fulton, 1987; Parkes, 1985; Worden 1982; Zisook & DeVaul, 1984). These manifestations are numerous and varied, but generally fall into four categories: (a) feelings, (b) physical sensations, (c) cognitions and (d) behaviors (Rando, 1984; Worden, 1982). Unresolved grief may be classified into three categories: (a) absence of grief, (b) delayed grief and (c) prolonged grief (Faschingbauer, 1981; Rando, 1984). Normal and unresolved grief are discussed in more detail in Chapter 4. These categories provide a convenient framework within which to discuss a complex and complicated process.

Purpose of the Study

Some writers contend that hospice produces a very positive outcome for caregivers during the bereavement period (Kastenbaum, 1986; Lamertaon, 1983; Stoddard, 1978). Researchers have attempted to validate these claims (Cameron & Parkes, 1983; Godkin et al., 1983; Greer et al., 1983; Kane, Wales, Bernstein, Leibowitz, & Kaplan, 1984; Parkes, Part I and II, 1979, 1985) and have discovered contradictory evidence. With the exception of the Cameron & Parkes study, little has been published with respect to Canadian hospices and the effects of their programs.

The main purpose of this study was to determine if participation in a hospice program has an effect on the overall grief reaction, factors affecting bereavement or on the grieving symptoms manifested by surviving relatives.

The responses of hospice and non-hospice subjects on two questionnaires, the Texas Revised Inventory of Grief and the Modified Bereavement Questionnaire were analyzed to determine if differences between the two groups could be attributed to the influence of a hospice program. Respondents were men and women between the ages of 28 and 88.

Chapter 2

Review of related literature

In October, 1979, a symposium sponsored by the Hospice Institute for Education, Training and Research, Inc., New Haven, was held which brought together well over 500 delegates concerned with the planning development and implementation of hospice programs (Parks, 1979). This symposium included such notable leaders in the hospice movement as Dr. Cicely Saunders and Dr. Colin Murray Parkes, who, along with their colleagues, stressed the need for research and evaluation of hospice care. At that time very little empirical data had been collected to substantiate the claims made by proponents of hospice as to the benefits of hospice care. Since then a number of studies have been conducted, varying in size and scope (Cameron & Parkes, 1983; Godkin, et al., 1983; Greer, et al., 1983; Kane et al., 1984; Parkes, 1979, 1984). Two major studies, the National Hospice Study and the University of California Los Angeles Randomized Control Study, have provided the majority of research literature to date.

Dr. Colin Murray Parkes initiated the first hospice evaluation study in 1979. He studied 34 spouses of patients who had died from cancer at St. Christopher's Hospice, London, England and compared them with a matched group of spouses of similar patients who had died in other hospitals in the vicinity (Parkes, 1979). The surviving spouses were interviewed approximately 13 months after bereavement. A standard interview schedule was used which involved self-assessments by the caregiver regarding their involvement with the patient before death and the caregiver's emotional state before and after death. Scoring on various scales was used to determine intensity of anxiety and emotional symptoms of bereavement.

The only item, the responses to which reached significance, was "loss of appetite" (Parkes, 1979, Part I, p. 525) which occurred for 70% of non-hospice spouses and only 36% of hospice spouses. "Other sources of anxiety do not distinguish the groups to a significant degree but all show trends favouring the St. Christopher's group" (Parkes, 1979, Part II, p. 525).

The overall findings indicated that the service provided by St. Christopher's was superior in many respects to that provided in other hospitals, particularly in care of the patient and spouse before death. Nonetheless, the study revealed no significant difference between hospice and non-hospice spouses on the Post-Bereavement Adjustment Scale. However, the author was quick to point out that at the time of the study no systematic attempt was being made to support bereaved families at St. Christopher's and it was left to the initiative of family members to ask for help if they needed it. It is well known that bereaved individuals are often listless and apathetic and do not have the energy to initiate new contacts or seek outside help (Parkes, 1975; Rando, 1984; Worden, 1982). Most hospices, including St. Christopher's now offer follow-up support to families of patients who have died (Parkes, 1986).

In another study, Parkes & Parkes (1984) used death registration forms to identify surviving spouses of patients who had died of cancer. Spouses of 64 patients who had died at nearby hospitals were matched with spouses of 64 patients who had died at St. Christopher's. The primary caregivers were interviewed 13 months after the death of their spouse and were asked to estimate the maximum and minimum intensity of a number of symptoms such as anxiety, worry, stress and post-bereavement grief. Significant differences were apparent only for anxiety. "Very great anxiety" (Parkes & Parkes, 1984, p. 123) was found to be significantly less for the spouses at hospice than for those of other programs.

The 1984 study also provided a comparison of the differences in terminal cancer care in 1967-69 with care in 1977-79 by comparing the views of surviving spouses of patients who had died in local hospitals in and around St. Christopher's Hospice and at St. Christopher's. The authors concluded that pain and distress among the patients were no longer a major problem in the hospitals or hospice and attributed this change to education and training provided by St. Christopher's to the staff of the other facilities on how to care for the terminally ill. Hospice was seen as having a major influence on the improved care of the terminally ill over this 10 year period (Parkes & Parkes, 1984).

Kane, Bernstein, Wales, Leibowitz and Kaplan (1984) report on the evaluation of a hospice program using a randomized control design, which included 56 hospice caregivers and 40 controls. It was carried out at the Veteran's Administration Hospital Wadsworth Medical Centre, Los Angeles. Patients were randomly assigned to either the hospice program or to another ward within the same hospital. Patients and familial caregivers were followed from the time of referral until the patient's death. The caregivers were followed for an additional 18 months. No clear pattern of differences emerged in anxiety or depression between hospice caregivers and control subjects. There were no significant differences in smoking or drinking behaviors, social participation, or contacts with friends or relatives.

Services offered to the caregivers after the death of a loved one included condolence letters, announcements of meetings and social functions and a routine questionnaire sent every three months for two years. It is important to note that only 20% of the questionnaires were returned.

These questionnaires were intended to alert the social worker or nurse involved in bereavement support. Any implied or stated problems on the questionnaires were responded to by a phone call and additional counselling and support was offered. However, fewer than 25% of the subjects participated in counselling or support groups (Kane, Klein, Bernstein, & Rothenberg, 1986). These authors suggest that due to unpleasant associations many caregivers found it too difficult to return and felt supportive telephone contact initiated by hospice staff was inappropriate given that there was no longer a patient in the unit.

Kane et al., (1986) also suggest that the telephone contacts made during this study and the interviews themselves may have provided sufficient outlet to both groups to reduce any differences. "The interviewers often reported sad stories, tearful conversations, expressions of depression and other signs of grief" (Kane et al., 1986, p. 741).

The only published report of a Canadian study the writer has been able to locate is one undertaken at Royal Victoria Hospice, Montreal (Cameron & Parkes, 1983). Twenty close relatives of patients who had died in the Palliative Care Unit were compared with 20 relatives of patients who had died of cancer in other wards of the same hospital. These people were interviewed by telephone two weeks and one year after the death of their loved one. The measurement scale used was an extensive bereavement anniversary questionnaire, developed specifically for this purpose.

Services offered the patients and their families included opportunities to discuss their concerns with staff, permission to communicate their grief and receive support, and encouragement of family members to be present at the time of death. Support offered to relatives after death included telephone contacts and informal counselling sessions.

All the subjects were interviewed by telephone one year and two weeks after their relatives' death. Questions were designed to elicit information pertaining to areas such as appetite, sleep disturbance, use of sleeping pills and more specific manifestations of grief such as pining, irritability and anger.

Considerable differences were found between hospice and non-hospice subjects in a number of areas. Fifty percent of non-hospice subjects were taking sleeping pills compared to 20% of hospice subjects. In addition, the non-hospice subjects were more likely to be irritable and angry a year later.

A recent study of major proportions is the National Hospice study (Greer et al., 1983) which was a multi-site, quasi-experimental study in which researchers compared the experiences of terminal cancer patients and their families in hospice with those of similar patients and families receiving conventional care.

Seventeen hundred and fifty-four families from 40 hospices and 14 conventional cancer care settings were studied. The study was intended to follow families for approximately six months before the death of a family member but 50% of the population admitted to the hospice program died within 35 days of admission and 20% survived less than one week in hospice. Nonetheless, from the time of referral, the caregiver was involved in assessment interviews approximately every 14 days until the death of the patient and then received one follow-up interview approximately four months after the death. An average of six interviews were conducted with each person, with a minimum of 2 and a maximum of 20 if the patient lived 4-6 months after referral. It is very possible, again, that this much opportunity to talk about the process affected the outcome.

The findings were similar to those delineated in the Randomized Control Study previously referred to. That is, little or no difference was found between the groups on anxiety and depression or the use of medications for anxiety and depression. Nor did any significant differences emerge between the groups in the use of alcohol, which did not show any overall increase. No differences were reported between the groups on hospitalizations or physician visits after the death of the patient (Greer, Mor, Morris, Sherwood, Kidder & Birnbaum, 1986).

Godkin, et al., (1983) conducted a study on the Palliative Care Service of the University of Massachusetts, Medical Centre. Of 100 living spouses of deceased patients who were sent a questionnaire 58 returned the questionnaire after follow-up phone calls. Questions covered five areas: perceptions of palliative care services, perception of emotional support and impact on family functioning, psychological well-being, families preparedness for death and bereavement problems.

Palliative care was perceived as significantly better than prior care. Seventy percent of the spouses felt supported and 84% felt post-death support was an important feature. Seventy-two percent felt their family had become closer during the time the patient was in hospice. Sixty-one percent felt it was very important to be able to return to the hospice unit after their spouse had died. Many reported feeling better able to cope with feelings of distress, anxiety, depression, helplessness and fear while in hospice than in prior care settings. Eighty percent felt they were emotionally prepared for death and the subsequent consequences.

Overall, spouses who felt emotionally prepared for death experienced less difficulties during the bereavement period. The authors concluded that, "hospice mode of care, with its support of families during terminal and bereavement stages, impacts significantly on families' abilities to cope with the terminal phase and adapt afterwards" (Godkin, et al., 1983, p. 153).

In summary, the research includes large and small studies, some of which took years to design and carry out. One very large study involved 1,754 subjects across 54 different programs. In another study which involved 96 participants pre-selection bias was addressed by using random assignment to either a hospice or non-hospice program. The smaller studies contributed valuable information obtained from hospice and non-hospice subjects who were well matched for age, socio-economic status and relationship to the deceased. In at least two of the smaller studies hospice subjects were involved in programs that have led the way in the field of palliative care.

The data are inconclusive and the amount of research relative to the growing numbers of hospices is small. However, a number of authors (Cameron & Parkes, 1983; Casperson, 1985; Godkin et al., 1983; Kastenbaum, 1986; Lamerton, 1983; Parkes, 1979; Parkes & Parkes, 1984;

Stoddard, 1978) contend that association with a hospice program produces positive benefits for the bereaved. This lends support for the research hypothesis.

Therefore, this current study replicated in part, the Cameron & Parkes (1983) study. The 41 subjects were randomly selected. The writer conducted one face-to-face interview with each subject well after bereavement. At this interview two questionnaires were administered, the Texas Revised Inventory of Grief and the Modified Bereavement Questionnaire, in an attempt to produce more conclusive results and shed some further light on the subject.

Hypothesis

Relatives of patients who died while attending the hospice program will show differences in overall grief reactions, the factors affecting bereavement and show significantly fewer manifestations of grief one to two years after the death of the patient than will a comparable group of control subjects.

Chapter 3

Methodology

Subjects

The subjects in this study were 16 male and 25 female family members who had lost a close relative to cancer in the preceeding 13½ to 26 month period. Of this group 22 subjects were involved with hospice Victoria before and after death of their relative. These hospice subjects ranged in age from 26 to 67 years (see Table 2). Non-hospice subjects (N=19) had no such involvement with a hospice program and ranged in age from 30 to 88 years (see Table 2).

Chi square was used to compare the groups according to sex and no significant difference emerged (see Appendix A). The age of the two groups was then compared by two-way analysis of variance which showed a significant difference, $F(1, 35) = 4.887$, $p < .05$.

The majority of the subjects were spouses of the deceased and they rated their relationship as "closer than any before or since" (see Table 3). No signficant differences between the two groups were found in type of relationship or degree of closeness. Nor was any significant difference found in religious orientation (see Appendix A).

Table 2

Age Means and Sex Distribution of Sample According to Group

Group	Frequency	Mean age
Hospice		
Males	6	49
Females	16	47
Totals	22	47
Non-hospice		
Males	10	64
Females	9	53
Totals	19	59

Table 3

Relationship and Religious Factors According to Group

Variable	Hospice (N=22)	Non-Hospice (N=19)
Relationship to deceased		
Wife	12	4
Husband	6	9
Mother	1	2
Father	0	1
Daughter	2	2
Sister	0	1
Fiancé	1	0
Degree of closeness to deceased		
Closer than any before or since	13	12
Closer than most	5	5
About as close as most	0	2
Not as close as most/not very close	4	0
Religion		
Protestant	11	13
Catholic	3	4
Other	8	2

The majority of subjects in both groups were Protestants and Catholics (see Table 3). However eight of the hospice group marked 'other' for religion. This included four without religious affiliation, 1 Mormon, 1 Buddhist, 1 Quaker and 1 Ismalie. The two non-hospice subjects who marked 'other' had no religious affiliation.

The subjects were aware of the impending death for varying lengths of time. The majority became aware about six months prior to death while a few indicated knowledge of impending death for as long as two to six years before the actual death (see Table 4). No significant difference emerged between the groups (see Appendix A).

As would be expected for terminal patients, the subjects indicated the deaths were mostly expected and slow (see Table 4). No significant difference between the groups was apparent (see Appendix A).

All of the hospice subjects lived in the Greater Victoria Regional District while the non-hospice subjects were scattered throughout the southern region of Vancouver Island, including Nanaimo (2), Ladysmith (2), Duncan (1), Cobble Hill (1) and Sooke (1).

Procedure

The writer obtained information pertaining to age and date of death of 159 patients who died while attending the Hospice Victoria program in 1986 from the hospice

Table 4

Death Surround Factors According to Group

Variable	Hospice (N=22)	Non-Hospice (N=19)
Length of time between subjects impending death and actual death.		
1 - 6 months inclusive	9	10
7 - 12 months inclusive	7	7
over 12 months	6	2
Death was?		
expected	10	6
slow	7	2
expected and slow	4	6
sudden and/or unexpected	1	5

bereavement records. Of these 45 were between the age of 30 and 62 at the time of their death.

The writer assumed that a more homogeneous age group of patients would produce a more homogeneous age group of subjects. This assumption was not borne out, however, as the subjects ultimately selected for the study ranged in age from 28 to 88 years.

Letters were sent in early February, 1988 to the 45 hospice subjects requesting their participation (see Appendix B) and including a Participant's Consent Form for them to read and sign (see Appendix C). A phone call was made one week later. Of the 45 possible subjects, 10 could not be contacted and 13 declined to participate. Sixteen females and six males agreed to participate, representing a 50% participation rate.

The questionnaires were administered to the subjects by the writer, at a place and time convenient to them and each meeting took approximately 45 minutes.

After the hospice data were collected an attempt was made to match hospice subjects with those at the Victoria Cancer Clinic, using the computer records. This comparative group was selected because the deceased in the hospice program had died of cancer.

Insufficient numbers would have occurred in the comparative group if rigorous matching criteria were established. Therefore, non-hospice subjects were chosen using the same criteria used for choosing the hospice subjects, that is, the deceased died of cancer 13½ to 26 months ago and was between the age of 30 and 62 at time of death.

One hundred and forty-four people met the above criteria. Of this number 38 were immediately disqualified because they had been involved in the hospice program and a further 53 were deemed inappropriate because they either had no next of kin or the potential subject now lived too far away to be interviewed.

Letters to 53 non-hospice subjects were sent under the signature of Dr. Peter Coy, Director, Victoria Cancer Clinic, along wtih a Cancer Clinic Consent form and a Participant's Consent form, in early March, 1988 requesting their participation. This letter was followed by a phone call one week later. Of the 53 potential subjects, 17 could not be contacted and 17 declined to participate. The 10 males and 9 females who agreed to participate represent a 35% participation rate. Interviews were arranged and conducted in the same manner as the hospice interviews.

Measurement Tools

The measurement tools were selected because both of them were designed specifically to elicit information from individuals who had experienced a recent bereavement.

Answers to the questions provide substantial information about the factors affecting the grieving process and the manifestations of grief.

Texas Revised Inventory of Grief. Zisook & DeVaul (1984) initially developed a 14-item self report scale to measure grief, called the Texas Inventory of Grief. "Based on the literature of normative and atypical grief reactions, as well as the clinical experience of the authors, the original 14-item inventory was expanded to 58 items" (Zisook & DeVaul, 1983, p. 248), referred to as The Texas Revised Inventory of Grief.

This inventory was the primary outcome measure used in this study. It has two scales, one which is comprised of eight items and measures past behavior and the other comprising 13 items and measuring present feelings. The eight items measuring past behavior have a test re-test reliability of .77 and a split half reliability of .74 (Faschingbauer, 1981). The 13 items on the present feeling scale produced a co-efficient alpha of .86 and a split half reliability of .88 (Faschingbauer, 1981).

Responses are indicated on a Likert-type scale. The subjects are required to mark each question in a column headed either completely true, mostly true, true & false, mostly false or completely false. These columns were summed down and across and the five scores totalled into one score for past behavior for each subject and one score for present feelings for each subject.

All scores for past behavior (N=41) were combined to produce a median score for the two groups. The same was done for present feelings. The 41 scores for past behavior, along with the 41 scores for present feelings were compared to median scores and subsequently placed in one of four grief reaction categories; (a) low/low (absent grief) where both scores fell below the median; (b) high/low (resolved grief) where the past behavior score fell above the median while the present feeling score fell below the median; (c) low/high (delayed grief) which indicated the past behavior score fell below the median while the present feeling score fell above the median; and (d) high/high (prolonged grief) where both scores fell above the median.

The four grief reaction categories, absent, resolved, delayed and prolonged are used in the test manual (Faschingbauer, 1981). They generally correspond to grief reaction categories discussed in the literature (Rando, 1984; Worden, 1982) and are described in more detail in Chapter 4.

Additional questions elicit demographic data, relationship factors and death surround information. It takes approximately 20 minutes to administer and is examiner scored.

The Modified Bereavement Questionnaire. In 1981, researchers at the Royal Victoria Hospice in Montreal undertook a retrospective bereavement anniversary study. They developed their own questionnaire called The Bereavement Anniversary Questionnaire. It was developed specifically to elicit information regarding an individual's overall state of adjustment one year after death of a loved one due to terminal illness (Ajemian & Mount, 1982; Cameron & Parkes, 1983). This questionnaire asked for demographic information in addition to 80 other questions. The format was simple question and answer.

The objective of the present study is to elicit similar information from a similar population, but at a later date in the bereavement process. Therefore, permission was sought and received from Dr. B. Mount, Director of Royal Victoria Hospice to modify their questionnaire accordingly.

The modification eliminated the demographic and anniversary questions as they are covered in the Texas Revised Inventory of Grief and consolidated the remaining questions. The Modified Bereavement Questionnaire has a total of 20 questions, 17 of which may be answered either yes or no, with a place for comments where appropriate. The original questions were retained where applicable to the purpose of this study. It takes approximately 15 minutes to administer. Responses to each item were tabulated, with no subtotals or totals computed.

Data Analysis

Chi square was applied to the overall grief reaction categories, the demographic information and factors influencing bereavement.

The two Likert-type scales were analyzed two ways. Student's t-test for independent groups was applied and then the response categories were collapsed into true, true & false and false, after which Chi square was used.

Level of significance required for statistical significance in all cases was .05 or less.

Chapter 4

Results and Discussion

Overall it has not been shown that involvement with a hospice program is associated with a reduction in the nature and extent of grieving symptoms. As indicated in Table 5, patterns across the four grief reaction categories do not support the hypothesis that relatives of patients who died while attending the hospice program will show differences in their grief reaction, the factors affecting bereavement and will show significantly fewer manifestations of grief one to two years after the death of the patient than will a comparable group of control subjects.

The writer intended to use the comparison of grief reaction categories as the definitive outcome measure. Due to the surprising results, that is, no statistically significant differences between groups, the decision was made to analyse each factor and item individually. For discussion purposes the following headings will be used to categorize the data: (a) grief reactions, (b) factors influencing outcome of bereavement and, (c) manifestations of grief.

The Texas Revised Inventory of Grief provided data primarily on the manifestations of grief and the Modified Bereavement Questionnaire addressed primarily the factors

Table 5

Subject's Grief Reaction According to Group

	Group	
Grief Reaction	Hospice (N=22)	Non-Hospice (N=19)
Absent	8	6
Resolved	3	4
Delayed	4	4
Prolonged	7	5

Note. X^2 (3) = .54 ns

influencing bereavement. Some overlap does exist between these questionnaires.

Grief Reactions

The four grief reaction categories are: absent, resolved, delayed and prolonged grief (Faschingbauer, 1981). Each subject was placed in one of these categories (see Table 5) combining the past behavior score and the present feeling score as related to the median score for all subjects. The scores of all hospice subjects are reported according to grief reaction category in Appendix D and E and the same is done for all non-hospice subjects in Appendix F and G.

Faschingbauer (1981) does not describe the four grief reaction categories in detail in the manual nor are they elaborated on in further writings of the test authors (Zisook, et al., 1982; Zisook & DeVaul, 1984). Therefore the writer has relied on Worden (1982) and Rando (1984) for clarification of these categories.

Absent grief. This category corresponds most closely to "abbreviated grief" (Rando, 1984, p. 62) and does not imply that the griever has denied the death and, therefore, has not grieved. On the contrary; the death has been accepted and fully grieved but the grieving period was relatively short. Rando (1984) and Parkes (1986) suggest this abbreviation may have occurred for a number of reasons

The period from diagnosis to the eventual death of the patient may have allowed sufficient time for the griever to adjust and provided an opportunity for intense grieving before the actual death occurred. Five of the eight hospice subjects falling into this category were aware of impending death for well over six months before the actual death. Another reason suggested by Rando and Parkes is that the relationship may not have been very close and the deceased was quickly replaced. In two of the cases in this study the relationship was not particularly close and the subjects have since established new long-term permanent relationships.

Religious convictions about death and after life might also influence the grieving process and five of the eight reported spiritual beliefs had helped them during bereavement.

Six of the non-hospice subjects were placed in this absent grief category. They all had close relationships and awareness of impending death ranged from 3 months to 12 months. Four of the six reported spiritual beliefs had helped, and this, in conjunction with a lengthy terminal phase may have facilitated a healthy amount of grieving before death occurred. All of the subjects in the absent grief category had attended the funeral and felt they had really grieved.

Resolved grief. Resolved grief implies that the deceased has been truly grieved and the griever has begun to re-invest his or her energies into his or her changed circumstances. The four non-hospice subjects falling into this category knew about impending death from 3 to 12 months before the death. Two relationships were "closer than any" and two were "about as close as most".

The hospice subjects who had resolved their grief knew about impending death for over six months. One has since re-married and one reported their relationship had not been very close. Again, all the subjects attended the funeral and all but one felt they had really grieved.

Delayed and prolonged grief. Delayed grief may be the result of an ambivalent or overly dependent relationship and is more often than not related to the type of person the mourner is and his or her past experience with loss (Kastenbaum, 1986; Parkes, 1986; Rando, 1984; Worden, 1982). As with delayed grief, the type of relationship and personality of the griever seem to have the most bearing on prolonged grief. No clear pattern of similarities or differences emerged between the four hospice subjects and the four non-hospice subjects in the delayed grief category nor for the seven hospice and five non-hospice subjects in the prolonged grief category (see Table 5). Research pertaining to delayed and prolonged grief indicates it is very difficult if not impossible to put a time limit on grief (Parkes, 1986; Rando, 1984; Worden, (1982).

The relationships varied for hospice and non-hospice subjects in the delayed grief category. The hospice subjects included three spouses and one sister and they rated their relationship as "closer than any" in three cases and "closer than most" in one case. The non-hospice subjects also included three spouses and one mother. Two of the relationships were described as "closer than any" one "closer than most" and one "not as close as most".

More subjects exhibited prolonged grief than delayed grief, however, the difference was not statistically significant (see Table 5). The hospice group included six spouses and one daughter while the non-hospice group included four spouses and one mother. The relationships were either "closer than any" or "closer than most" for both groups. All of the delayed grievers attended the funeral and felt they had really grieved and all but one of the prolonged grievers answered likewise. The one exception was a non-hospice subject who could not attend a service because none was held.

Factors Influencing Bereavement

It is generally acknowledged that there are a number of factors influencing bereavement (Parkes, 1986; Rando, 1984; Worden, 1982). The research hypothesis suggested there would be differences between the groups on these factors.

There are demographic and relationship factors, as discussed in Chapter 3, which people bring to the situation and other factors that are subject to influence prior to death. Typical examples include: where the person is to die, discussion of the will and funeral, type of service etc. The factors subject to influence have been categorized under three headings (a) death surround factors, (b) spiritual/ceremonial factors and, (c) social factors.

Each category has an accompanying table which illustrates the responses to each item according to group. There is also an appendix for each category which reports the statistics for non-significant differences. The statistics for significant differences are reported in the text of this chapter.

The information for the factors influencing bereavement was obtained from The Modified Bereavement Questionnaire. However, one item came from the Texas Revised Inventory of Grief, (Did you attend the funeral?) which is discussed under spiritual/ceremonial factors.

Influenceable death surround factors (see Table 6). As noted in Chapter 1, death surround refers to the immediate circumstances surrounding the death, in particular, where the death occurred and the amount of preparation that has taken place. Death occurred in acute care hospital for 7 of the hospice subjects and for 15 of the non-hospice subjects and at home for 3 of the hospice subjects and 4 of the non-hospice subjects.

Table 6

Influenceable Death Surround Factors According to Group

Variable	Hospice (N=22)	Non-Hospice N=19)
Where did this person die?		
In acute care hospital	7	15
In hospice	12	0
At home	3	4
Had the deceased made a will?		
Yes	19	14
No	3	5
Had funeral arrangements been discussed?		
Yes	19	10
No	3	9

Twelve of the hospice subjects died in hospice, which may reflect the hospice subjects' preference for the safety and security they have come to know and desire at the time of death or may simply reflect the overall trend for death in an institution which is evident throughout North America (Adams, 1984; Fulton, et al., 1978; Kastenbaum, 1986; Rando, 1984). Where the person died proved to be significantly different X^2 (2) = 14.91, $p < .05$.

Hospice fosters open communication between patient and family members in the belief that this will ease the patients dying process and contribute to a less complicated bereavement period. Patients are encouraged to make a will and discuss funeral arrangements with their relatives in order to share the responsibility for these decisions and alleviate undue pressure and confusion after death. Nineteen of the 22 hospice patients had made a will and discussed funeral arrangements with their relatives. Fourteen of the 19 non-hospice patients had made a will but only 10 discussed funeral arrangements (see Table 7). The difference between the groups concerning the will did not reach significance (see Appendix H). However non-hospice subjects were found to be less likely to have discussed funeral arrangements X^2 (1) = 4.09, $p < .05$.

Spiritual/ceremonial factors (see Table 7). In our increasingly secular society many people have drifted

Table 7

Spiritual/Ceremonial Factors According to Group

Variable	Hospice (N=22)	Non-Hospice (N=19)
Have your religious/spiritual convictions helped you during bereavement?		
Yes	14	9
No	8	10
Did you receive support from a religious person such as a rabbi or priest etc?		
Yes	8	10
No	14	9
Did you attend the funeral?		
Yes	22	18
No	0	1
Did you have cremation or burial?		
Cremation	17	11
Burial	5	8
Do you visit the grave?		
Yes	12	11
No	10	8

away from organized religion and in some cases develop their own belief system to help them understand their world. A belief system allows them to put death in a broader context and make sense out of an otherwise overwhelming event. The clergy have traditionally played a major role in supporting patients and their families at the time of death and their role still seems to be significant in today's society.

Fourteen of the hospice subjects reported their spiritual convictions helped them during bereavement but only eight had received support from a religious person (see Table 7). Only 9 of the non-hospice subjects felt their spiritual convictions helped although 10 reported help from a religious person. Neither of these factors proved to be significantly different (see Appendix I). It is, nevertheless, interesting that proportionately fewer hospice subjects relied on help from the clergy though they reported a higher rate of religious convictions. Could it be that hospice provided the surrogate?

As noted earlier, all the hospice subjects and non-hospice subjects attended the funeral except for one non-hospice subject where there was no service. This factor did not lend itself to statistical analysis by Chi Square due to the distribution of numbers, that is, cell sizes were too small (see Table 7).

Cremation was the preferred mode of disposition of the body for 17 hospice subjects and 11 non-hospice subjects, the remainder chose burial. Twelve hospice and 11 non-hospice subjects visit the grave. None of these factors approached statistically significant differences (see Appendix I).

Social factors (see Table 8). Social support is believed to buffer the individual during times of intense stress (Cobb, 1976; Jacobson, 1986; Pearson, 1986; Turner, 1981). It is defined "as information leading the subject to believe that he is cared for and loved, esteemed and a member of a network of mutual obligations" (Cobb, 1976, p. 301).

This type of support, whether within the family or community, is believed to contribute to successful bereavement (Parkes, 1986; Raphael, 1977; Vachon et al., 1982). Hospice subjects primarily received support from hospice and secondarily from their family and friends, while non-hospice subjects received support overwhelmingly from family and friends. It may be that hospice subjects have fewer family and friends to draw on or simply did not need to due to the support received from hospice. This factor showed a highly significant difference between the groups, X^2 (3) = 14.38, $p < .0024$ (see Table 8).

Family relationships became closer or remained unchanged after the death for 20 of the hospice subjects and 15 of the non-hospice subjects. This difference was not statistically significant (see Appendix J).

Table 8

Social Factors According to Group

Variable	Hospice (N=22)	Non-Hospice (N=19)
Who or what helped most?		
Family and friends	6	15
Hospice counselling and support.	10	0
Work and keeping busy	2	2
My faith	4	2
Relations with other family members now are?		
Closer	8	10
Unchanged	12	5
More distant	2	4
Have you returned to the hospice or hospital?		
Yes	9[a]	6
No	12	13
Did you attend any support functions?		
Yes	6	2
No	16	17

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[a] One subject did not answer this question

Manifestations of Grief

The manifestations of grief are generally discussed under four headings; feelings, physical sensations, cognitions and behaviors (Rando, 1984; Worden, 1982). For purposes of this study they were grouped under three headings; feelings, cognitions and behaviors because the measurement tools did not elicit any information pertaining to physical sensations.

The two scales on the Texas Revised Inventory of Grief relate to past behavior and present feelings, for a total of 21 items. The Inventory also has a section for related facts, three of which pertain to manifestations of grief. With the addition of four items from the Modified Bereavement Questionnaire there are a total of 28 items distributed among the feelings, cognitions and behaviors.

Each category has an accompanying table which illustrates the responses to each item according to group. Those items of particular interest or showing significant differences are discussed below. The response to each item was analyzed by Chi Square and Student's t-test for independent groups according to group. Significant differences are reported in the text of this chapter, while non-significant differences are reported in Appendices K, L, M, N, O, P and Q.

Feelings (see Table 9). "Sadness is the most common feeling found in the bereaved" (Worden, 1982, p. 20) and is often expressed by crying. Hospice subjects are far more likely to feel the need to cry when they think of

Table 9

Frequency of Responses to "Feeling" Items for Hospice and Non-Hospice Groups

Item	Group	Response		
		True	True & False	False
I still cry when I think of the person who died.	H	9	7	6
	NH	7	4	8
At times I still feel the need to cry for the person who died.	H	13	2	7
	NH	5	2	12
I was angry that the person who died left me.	H	8	1	13
	NH	4	0	15
I feel it's unfair that this person died.	H	13	1	8
	NH	8	2	9
Sometimes I very much miss the person who died.	H	19	0	3
	NH	17	1	1
I feel that I am now functioning about as well as before the death.[a]	H	16	-	6
	NH	15	-	4
No-one will ever take the place in my life of the person who died.	H	15	1	6
	NH	16	2	1

Note. H = Hospice group, NH = Non-hospice group.

[a] This question was only answered yes or no.

the deceased than non-hospice subjects. This proved to be significantly different when analyzed by Student's t-test $t(36) = -2.12$, $p < .04$.

Almost an equal number of hospice (15) and non-hospice (16) subjects said that no-one will ever take the place in their life of the person who died. Six hospice subjects indicated this was not true for them compared to only 1 non-hospice subject. This item also proved to be significantly different when Student's t-test was applied $t(34) = 2.13$, $p < .04$. None of the other feeling items were statistically significant using Student's t-test (see Appendix K). No statistically significant differences emerged for the feeling items when Chi Square was applied (see Appendix L).

Cognitions (see Table 10). In the process of grieving it is not unusual for mourners to be preoccupied with thoughts of the deceased as they reflect over their relationship roles and the changes death has brought. Eleven of the hospice subjects and 14 of the non-hospice subjects reported that they cannot avoid thinking about the person who died, although fewer (5 hospice and 9 non-hospice) said they were preoccupied with thoughts about the person who died.

About an equal number for both groups still get upset when they think about the person who died. However, half the hospice subjects were ambivalent on this item, compared to only two for non-hospice. This proved to be the only cognition item that showed a statistically

Table 10

Frequency of Responses to "Cognitions" Items for Hospice and Non-Hospice Groups

Item	Group	Response True	 True & False	 False
I am preoccupied with thoughts (often think) about the person who died.	H	6	5	11
	NH	9	2	8
I can't avoid thinking about the person who died.	H	11	2	9
	NH	14	0	4[a]
I cannot accept this person's death.	H	5	1	16
	NH	2	1	16
I am unable to accept the death of the person who died.	H	3	1	18
	NH	1	1	17
Things and people around me still remind me of the person who died.	H	16	2	4
	NH	12	2	5
Even now it's painful to recall memories of the person who died.	H	8	5	9
	NH	7	4	8
I still get upset when I think about the person who died.	H	8	11	3
	NH	9	2	8

Note. H = Hospice, NH = Non-Hospice

[a] One subject did not answer this question

significant difference when Chi Square was applied X^2 (2) = 8.38, $p < .05$ (see Appendix M). However, no significant difference was found when using Student's t-test (see Appendix N).

Behaviors (see Table 11 and 12). Behaviors commonly associated with normal grief are many and varied and include identification with the deceased, social withdrawal, inability to sleep, weight change and increased consumption of tranquilizers and alcohol (Parkes, 1986; Rando, 1984; Raphael, 1977; Windholz, et al., 1985; Worden, 1982). These behaviors generally lessen with time (Worden, 1982).

Social withdrawal manifests itself in different ways, some withdraw socially, others withdraw at work or from family and friends. Almost an equal number of hospice (9) and non-hospice (10) subjects found it hard to work after this person died, although very few in either group lost interest in their family, friends or outside activities. Nine of the hospice subjects found it hard to get along with certain people compared to only 3 non-hospice subjects. This was the only behavioral item which proved to be significantly different when student's t-test was applied $t(38) = -1.99$, $p < .05$.

Very few hospice (6) and even fewer non-hospice (2) subjects take sleeping pills, although more in both groups consume alcohol and most have experienced weight change. No consistent pattern emerged for the subjects related to

Table 11

Frequency of Responses to "Behaviors" Items for Hospice and Non-Hospice Groups

Item	Group	Response True	 True & False	 False
I felt a need to do things the deceased had wanted to do.	H	4	4	14
	NH	10	2	7
Sometimes I feel that I have the same illness as the person who died.[a]	H	3	-	19
	NH	1	-	18
I was unusually irritable after this person died.	H	6	4	12
	NH	3	4	12
After this person died I found it hard to get along with certain people.	H	9	4	9
	NH	3	2	14
I found it hard to work well after this person died.	H	9	4	8[b]
	NH	10	0	9
After this person's death I lost interest in my family, friends and outside activities.	H	4	6	12
	NH	4	2	13
I couldn't keep up with my normal activities for the first three months after this person died.	H	7	3	12
	NH	11	0	8

Note. H = Hospice, NH = Non-Hospice

[a] This question was answered only yes or no.

[b] One subject did not answer this question

Table 12

Frequency of Responses to "Behaviors" Items for Hospice and Non-Hospice Groups

Item	Group	Response: True	Response: True & False	Response: False
I hide my tears when I think about the person who died.	H	6	2	14
	NH	6	3	10
I seem to get upset each year at about the same time as the person died.	H	8	-	14
	NH	10	-	9
I have made alterations in my living arrangements since the person died.	H	13	-	9
	NH	6	-	13
I am currently taking sleeping pills.	H	6	-	16
	NH	2	-	17
I consume alcohol	H	11	-	10[a]
	NH	14	-	5
My weight has changed	H	12	-	10
	NH	8	-	11
I found it hard to sleep after this person died.	H	10	4	8
	NH	15	0	4

Note. H = Hospice, NH = Non-Hospice

Note. All items with a dash under the true & false heading were answered only yes or no.

[a] One subject did not answer this question

alcohol or weight change, some were drinking less than before the death while two were drinking more, and, in some cases, the weight had gone up while in others it went down. Almost half the hospice subjects and three quarters of the non-hospice subjects found it hard to sleep after this person died. This was the only behavior which showed a statistically significant difference when Chi Square was applied $X^2(2) = 6.14$, $p < .05$ (see Appendix O and P).

Thoughts on the findings of this study are offered in the next chapter.

Chapter 5

Summary, Conclusions and Implications

Summary

Two questionnaires, the Texas Revised Inventory of Grief and the Modified Bereavement Questionnaire, were administered to 22 hospice and 19 non-hospice subjects by the writer. Their responses were statistically analyzed using Chi Square and Student's t-test to determine differences. For ease of discussion, the responses were categorized into grief reactions, factors affecting bereavement and manifestations of grief.

Hospice and non-hospice subjects showed far more similarities than differences in all response categories. They were about equally distributed among the four grief reactions: absent, resolved, delayed and prolonged. This was the primary overall measure which was made up of the factors affecting bereavement and the manifestations of grief.

There are 19 factors affecting bereavement and 4 show significant differences. These are: age of the subjects, where the patient's died, who helped most during bereavement and discussion of funeral arrangements.

Hospice subjects ranged in age from 28 to 67 while the non-hospice subjects ranged in age from 30 to 65 except for one female age 85 and one male age 88.

Except for these two much older subjects the age range of the two groups is virtually identical.

Twelve of the hospice subjects died in hospice, seven died in an acute care hospital and three died at home. Fifteen of the non-hospice subjects died in an acute care hospital and four died at home. Hospice encourages people to die in their homes whenever possible. When this is not a reasonable possibility they may die at hospice. It is surprising, therefore, that seven died in an acute care hospital and only three died at home.

The subjects were asked "who or what helped most during bereavement?" The majority (15) of non-hospice subjects said family and friends helped the most. Six hospice subjects indicated their family and friends while 10 said that hospice counselling and support had helped them the most. This finding is a confirmation of the supportive role played by hospice during bereavement.

Nineteen hospice subjects compared to 10 non-hospice subjects discussed funeral arrangements with the patient. This finding is also a confirmation of Hospice Victoria policies which include directions to staff to ensure discussion of funeral arrangements early on in the terminal phase.

Although these four factors reached significance no clear pattern emerged that would account for this nor did these factors have a noticeable effect on the manifestations of grief or the grief reactions.

The 29 manifestations of grief have been discussed under the headings of feelings, cognitions and behaviors. Two items from each of feelings and behaviors and one from cognitions, for a total of 5 manifestations, reached statistical significance. One from each category is discussed below.

The item "no-one will ever take the place in my life of the person who died" came under feelings. Almost an equal number of hospice (15) and non-hospice (16) subjects indicated this was true for them. What proved to be significant was the false response, that is, 6 hospice subjects compared to 1 non-hospice subject responded with "false" to this item, indicating that they did not feel that "no-one will ever take the place" in their life of the person who died.

"I still get upset when I think about the person who died" was discussed under cognitions and again almost an equal number of hospice (8) and non-hospice (9) subjects indicated this was true for them. However, half (11) of the hospice subjects compared to only 2 non-hospice subjects responded "true & false" for this item indicating this was sometimes true for them also.

More non-hospice (15) than hospice (10) subjects responded "true" to the behavorial item, "I found it hard to sleep after this person died." However, four hospice as compared to zero non-hospice answered this item "true & false" indicating, again, that this was sometimes true for them also.

Considering that only 5 of 29 manifestations of grief reached statistical significance, it is difficult to attribute the differences to any one influence.

These data are generally consistent with the findings of the National Hospice Study (Greer et al., 1986) the Randomized Control Study (Kane et al., 1984) and the Parkes Study (1979). These researchers did not find any differences on the various measures used to assess such areas as anxiety, depression, use of alcohol, social withdrawal and overall post-bereavement adjustment.

The current study did not find significant differences in the use of alcohol, pills, weight change, social withdrawal or overall post-bereavement adjustment. However, it did not specifically measure anxiety and depression.

The data are inconsistent with the findings of the Cameron & Parkes Study (1983) which found significant differences in a number of areas such as use of sleeping pills, anger and irritability, and the Godkin et al., Study (1983) which found significant differences in perceptions of support and perceived ability to cope with feelings of distress, anxiety, depression etc.

Again, the current study did not find significant differences in the use of sleeping pills, or anger and irritability, nor in general support or ability to cope.

The Parkes (1979) and Cameron & Parkes (1983) studies both interviewed caregivers approximately 13 months after death of their relative. Parkes interviewed his subjects in their homes while Cameron conducted her interviews over the phone. Parkes found no differences on the Post Bereavement Adjustment scale while Cameron found significant differences on the Bereavement Anniversary Scale used in her study. At the time of the Parkes study St. Christopher's did not offer counselling or bereavement support services, while counselling and support were offered at Royal Victoria Hospice where the Cameron study took place.

The current study replicated in part the Cameron & Parkes (1983) study. Each study contained interviews of approximately 20 hospice and 20 non-hospice subjects conducted after the loss of a close relative to cancer. The writer modified the Bereavement Anniversary Questionnaire used in the Cameron & Parkes study and added an additional inventory of grief to provide further quantifiable data. The questionnaires were administered in person to overcome the distancing effect of telephone contacts.

Conclusions

The hospice program studied is a comprehensive program offering home based and hospice based care. It has a large medical component in conjunction with professional counsellors, support staff and a very active volunteer contingent. Service is provided to the patient and family throughout the terminal phase and ongoing counselling and support is offered to the family in the bereavement phase.

Why then are there so few differences between the hospice and non-hospice subjects? Are we missing the essence of hospice in our desire to produce scientifically valid, replicable and generalizeable research? Are we looking in the wrong place and using the wrong tools?

Based on extensive reading in this area, personal and professional experience and this research study the writer believes that we are not able to capture the nature of the hospice influence by using quantitative measurement tools, however sophisticated and numerous, in isolation from qualitative, personal data.

"Each person's grief will be idiosyncratic, determined by a unique combination of psychological, social and physiological factors" (Rando, 1984, p. 43). If this research has highlighted a single theme for the writer, it is that the grieving process is a uniquely individual and personal process.

Due to the nature of the subject matter, at the end of each interview, after the questionnaires were filled out and pen and paper put away, the writer asked each subject "how was that for you"? There were 41 different replies, all with their own story, reflecting each person's unique life experiences.

In most cases this question elicited stories of general restlessness and difficulty adjusting to changed circumstances. In a number of instances people talked about being afraid to go outside after dark, drinking too much alcohol and being intensely lonely. Initially, the writer religiously recorded this information shortly after leaving the subject. However, this soon seemed inappropriate. The subjects had agreed to participate in an interview that involved filling out two short questionnaires so that when this was done, for all intents and purposes, the interview was over. The stories were not by prior agreement, were not for the record, and are not for publication.

Implication for further research

Hospice and palliative care services have mushroomed throughout North America in recent years, but evaluation of their effectiveness has not kept pace. Further research is clearly needed to light the way and harness these new resources.

The research to date has been of a quantitative nature involving a broad range of measurement instruments and, yet, has not produced conclusive results.

The fundamental question remains unanswered, casting doubt on whether it can be answered conclusively through quantitative research alone.

Mount and Scott (1983) speak eloquently to this concern.

> Consider the rose. You can weigh it, photograph it, categorize it, measure its height, petal size and number of thorns, not to mention the ratio of thorns to height. The mean and standard deviation of the measures can then be determined. We may go further and do content analysis on a random selection of descriptions of the flower by persons representing both sexes, with samples from cleverly determined age cohorts established so as not to prejudice the data too greatly along any particular experimental bias. The color may be measured by spectroscopic analysis; the chemical composition defined, the light refraction from the dew drop on the petal measured and aroma quantified....
>
> Although we would all like to measure the beauty of a rose or to quantify the sense of fulfillment of a dying person, we do not yet have the appropriate tools (p. 735).

Indeed, in the writer's opinion the most interesting and illuminating aspect of this current study was the off-the-record human experiences of the subjects, told candidly and sincerely. The themes and patterns of personal experiences must be identified in order to capture the essence of the hospice experience and understand the healing effect this program can have. A deeper insight into feelings is needed to fill in the gaps and give meaning and clarity to previous research.

Hospice ideology, as expressed by Hospice Victoria, is a gentle force for good in our society, the essence of which is being missed due to inadequate measurement instrumentation. An in-depth qualitative study involving more subjects, and including the use of one comprehensive grief experience inventory might accomplish this objective and shed further light on the elusive elements of palliative care, hospice and other similar programs.

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Appendix A

Statistics for Non-significant Demographic factors

Variable	Df	X^2	p
Sex	1	1.79	.18
Relationship; spouse, parent, sibling etc.	5	6.41	.27
Degree of closeness	4	5.85	.21
Religious orientation	2	3.70	.15
Length of time between subjects impending death and actual death.	2	1.84	.39
Death was, expected, slow, expected and slow, sudden and/or unexpected.	4	6.79	.14

Appendix B

Letter to Hospice Participant's

February 3, 1988

Dear

Hospice Victoria and the Victoria Cancer Clinic are cooperating with me in conducting a study of the manner in which people who have suffered a recent bereavement adapt to their new situation. I am a graduate student in the counselling program at the University of Victoria and have also worked as a Hospice counsellor.

Would you consider meeting with me to answer two short questionnaires? This meeting would take approximately 60 minutes and all information obtained will be held in strictest confidence.

In addition you will be requested to sign a Participant's Consent Form before we proceed. This is enclosed for your perusal.

Please give this your thoughtful consideration. I will call you in a couple of days to arrange an appointment should you wish to participate.

Sincerely

Gail Boulanger

Appendix C

Participant's Consent Form

I, , consent to being part of this Adaptation to Loss study.

I understand that my involvement in this study is completely voluntary and that I may decide to withdraw at any point.

I am aware that I will be asked to fill out a written questionnaire and participate in an interview with the researcher.

I understand that my involvement in this project will be kept strictly confidential by the researcher and that results of the study, published or unpublished will in no way identify me.

Signed: ________________

Date: ________________

Appendix D

Hospice Scores on the Texas Revised Inventory of Grief According to Grief Reaction Category

Category	Subject	Score Past Behavior (Md=21)	 Present Feelings (Md=39)
Absent grief low/low (n=8)			
	3	17	39[a]
	4	8	25
	7	21[b]	29
	10	16	17
	14	18	24
	16	11	24
	17	14	27
	21	21[c]	39[d]
Resolved grief high/low (n=3)			
	12	26	36
	19	27	34
	22	27	34

Note. Md = Median

[abcd] Scores which equalled the median score were arbitrarily designated low

Appendix E

Hospice Scores on the Texas Revised Inventory of Grief According to Grief Reaction Category

Category	Subject	Score Past Behavior (Md=21)	 Present Feelings (Md=30)
Delayed grief low/high (n=4)			
	5	11	45
	6	19	46
	8	14	54
	11	16	44
Prolonged grief high/high (n=7)			
	1	26	54
	2	24	43
	9	28	52
	13	27	63
	15	22	47
	18	32	47
	20	27	65

Note. Md = Median

Appendix F

Non-Hospice Scores on the Texas Revised Inventory of Grief According to Grief Reaction Category

Category	Subject	Score	
		Past Behavior (Md=21)	Present Feelings (Md=39)
Absent grief low/low (n=6)			
	2	14	28
	5	21[a]	34
	8	19	29
	14	8	22
	15	16	29
	19	11	28
Resolved grief high/low (n=4)			
	6	22	37
	9	28	39[b]
	12	27	31
	17	28	32

Note. Md = Median

[ab] Scores which equalled the median score were arbitrarily designated low.

Appendix G

Non-Hospice Scores on the Texas Revised Inventory of Grief According to Grief Reaction Category

Category	Subject	Score	
		Past Behavior (Md=21)	Present Feelings (Md=39)
Delayed grief low/high (n=4)			
	4	14	40
	7	19	60
	11	18	43
	13	20	53
Prolonged grief high/high (n=5)			
	1	22	41
	3	28	54
	10	24	47
	16	34	61
	18	24	51

Note. Md = Median

Appendix H

Statistic for Non-significant Influenceable Death Surround Factor

Variable	Statistic
Had the deceased made a will?	X^2 (1, N=41) = .39, p=.53

Appendix I

Statistics for Non-Significant Spiritual/Ceremonial Factors

Variable	Df	X^2	p
Have your religious spiritual convictions helped you during bereavement?	1	.53	.46
Did you receive support from a religious person such as a rabbi or priest etc.?	1	.53	.46
Did you have cremation or burial?	1	.98	.32
Do you visit the grave?	1	.00	1.00

Appendix J

Statistics for Non-Significant Social Factors

Variable	Df	X^2	p
Relations with other family members now are?	2	3.57	.17
Have you returned to the hospice or hospital?	1	0.16	.68
Did you attend any support functions?	1	0.91	.34

Appendix K

Statistical Analysis of Feelings by Item Using Student's t-test

Item	Df	t	p
I still cry when I think of the person who died.	37	- .91	.36
I was angry that the person who died left me.	38	- .83	.41
I feel it's unfair that this person died.	38	- .69	.49
Sometimes I very much miss the person who died.	38	1.13	.26

Appendix L

Statistical Analysis of Feelings by Item Using Chi Square

Item	Df	X^2	p
I still cry when I think of the person who died.	2	1.140	.56
At times I still feel the need to cry for the person who died.	2	4.670	.09
I was angry that the person who died left me.	2	2.260	.32
I feel it's unfair that this person died.	2	1.370	.50
No-one will ever take the place in my life of the person who died.	2	3.730	.15
Sometimes I very much miss the person who died.	2	1.900	.38
I feel that I am now functioning about as well as before the death.	1	.009	.92

Appendix M

Statistical Analysis of Cognitions by Item Using Chi Square

Item	Df	X^2	p
I am preoccupied with thoughts (often think) about the person who died.	2	2.150	.34
I can't avoid thinking about the person who died.	2	3.920	.14
I cannot accept this person's death.	2	1.070	.58
I am unable to accept the death of the person who died.	2	0.810	.66
Things and people around me still remind me of the person who died.	2	0.460	.79
Even now it's painful to recall memories of the person who died.	2	0.017	.99

Appendix N

Statistical Analysis of Cognitions by Item Using Student's t-Test

Item	Df	t	p
I am preoccupied with thoughts (often think) about the person who died.	36	.58	.56
I can't avoid thinking about the person who died.	38	1.94	.06
I cannot accept this person's death.	37	- .78	.44
I am unable to accept the death of the person who died.	38	- .62	.54
Things and people around me still remind me of the person who died.	35	- .80	.43
Even now it's painful to recall memories of the person who died.	37	.08	.94
I still get upset when I think about the person who died.	34	- .48	.63

Appendix O

Statistical Analysis of Behaviors by Item Using Chi Square

Item	Df	X^2	p
I felt a need to do things the deceased had wanted to do.	2	5.38	.06
Sometimes I feel that I have the same illness as the person who died.	2	0.14	.70
I was unusually irritable after this person died.	2	0.78	.67
After this person died I found it hard to get along with certain people.	2	4.50	.10
I found it hard to work well after this person died.	2	4.02	.13
After this person's death I lost interest in my family, friends and outside activities.	2	1.80	.40
I couldn't keep up with my normal activities for the first three months after this person died.	2	4.49	.10

Appendix P

Statistical Analysis of Behaviors by Item Using Chi Square

Item	Df	X^2	p
I hide my tears when I think about the person who died.	2	0.65	.72
I seem to get upset each year at about the same time as the person died.	1	0.53	.46
I have made alterations in my living arrangements since the person died.	1	2.00	.14
I am currently taking sleeping pills.	1	0.91	.34
I consume alcohol	1	1.12	.28
My weight has changed	1	0.23	.63

Appendix Q

Statistical Analysis of Behaviors by Item Using Student's t-Test

Item	Df	t	p
I felt a need to do things the deceased had wanted to do.	37	1.78	.08
I was unusually irritable after this person died.	39	-0.85	.40
I found it hard to work well after this person died.	36	0.39	.69
After this person's death I lost interest in my family, friends and outside activities.	37	-0.60	.55
I couldn't keep up with my normal activities for the first three months after this person died.	35	1.31	.20
I hide my tears when I think about the person who died.	37	0.39	.70
I found it hard to sleep after this person died.	38	1.58	.12

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Title of Thesis

A Comparison of the Grieving Process Between Hospice and Non-hospice Primary Caregivers.

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[redacted]

GAIL BOULANGER

July 21, 1988