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# The Coping Strategies of Hospice Patients with Life-Threatening Illnesses

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27.05.04

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## Abstract

The principal research aim was to investigate whether spirituality played a role in the coping strategies of patients (N = 120) undergoing palliative care over a six month period within 2 specialised hospice units (Hospices A & B). Using an adapted version of the McGill Quality of Life Questionnaire (Cohen et al, 1995), the self-assessed scores of “Believing & Practising Church Members” (BPCM), “Believers but Non-practising Church Members” (B-NPCM) and “Non-Believers” (NBNP) were compared in an attempt to determine “Quality of Life” (QOL) differences between each hospice.

Two-way Between Groups ANOVA results indicated significant main effects for all 5 McGill Quality of Life Questionnaire-Scottish Version (MQOL-SV) hypotheses, 2 of which were qualified by significant interaction effects. One-way ANOVA results indicated that although BPCM & B-NPCM in Hospice A attained higher score levels than NBNP patients, all 5 hypotheses were statistically non-significant. For Hospice B however, 4 of the 5 hypotheses achieved statistically significant results. Findings implied that QOL assessments for BPCM & B-NPCM in Hospice B were attained because of the influence and “bolstering effect” caused by spirituality and holistically centred policy programmes operating within that hospice. Overall MQOL-SV findings suggested that the existence or non-existence of spirituality based hospice policies affected the QOL of 5 of the 6 groups involved in the “Patient Research” study.

A secondary aim was to determine whether staff with “High”, “spirituality measurement scores” (SMS) were more favourable towards the introduction / maintenance of spirituality issues within hospice policy programmes than staff with “Low” SMS. The study also investigated staff depression concerning occupational duties and overall QOL levels. Staff (N = 100) completed a “Staff Questionnaire” (CPCD, Caddell, 2002). Two-way Between-Groups ANOVA tests indicated non-significant results for all 4 hypotheses intimating that staff with Low SMS were as favourable as staff with High SMS towards spirituality policies within all hospices. Findings also suggested however, that Hospice B staff with “High” SMS experienced higher emotional upset regarding occupational duties than the same staff grouping within Hospice A.

# Chapter 1

## Introduction

In stressful circumstances, individuals cope in a variety of different ways, most often employing cognitive or behavioural strategies as a means of alleviating the stress. Coping is generally viewed as a process through which individuals try to understand and deal with significantly personal or situational life events. In order to adequately cope, people have to appraise the situation and the degree to which it is perceived as harmful or life threatening. Researchers have distinguished among a variety of coping activities for example problem focused, emotional-focused, rational action, religious belief, spiritual well-being, social networking, positive thinking, seeking help, withdrawal, self-blame and denial (Koenig, 1992, Pargament, 1992, Lazarus and Folkman, 1984, Billings and Moos, 1984, Taylor 1983, Paloutzian and Ellison 1979).

Anna Freud was the first researcher to mention the word “cope” in her work investigating the effects of stress encountered by children due to bombing of London during World War 2. However it was not until the 1970’s that the first mention of “coping” was used in the work of Lazarus and his colleagues. In 1977, Lazarus and Cohen, both leading researchers into the field of coping with stress, described the coping process as follows,

“Most persons utilize a variety of coping strategies, anticipating and evaluating what might happen and what has to be done, planning and preparing, changing the environment, retreating when necessary, postponing action for maximum effect, tolerating frustration and pain and even deceiving themselves in order to feel better and to maintain hope and a sense of self-worth” (p.112).

Interest in the concept of coping began to grow out of a number of studies in which it was found that stressful events were not very good predictors of how individuals behave. Different people were shown to respond differently to the same situation. For example, some were devastated, some were able to survive and put it behind them, while others possessed the capacity to grow from the stressful experience. Some individuals appraised a stressful situation as a threat, while others appraised it as a challenge. In 1984, Lazarus and Folkman emphasised that “coping” was the key element to whether an outcome was successful or unsuccessful. This overall appraisal also extended to self-appraisal and to whether the stressful situation could be managed successfully by the individual or whether it would result in the person being taxed beyond their resources. Subsequent to this study, Lazarus and Folkman defined coping as,

"...constantly changing cognitive and behavioural efforts to meet specific external and / or internal demands that are appraised as taxing or exceeding a person's resources" (p. 141).

These efforts may consist of overt / covert behaviours and responses, which are designed to overcome, reduce or tolerate these demands. Lazarus and Folkman (1984c) proposed two general categories of coping strategies –

1. "Instrumental" - problem-solving efforts.
2. "Palliative" - strategies aimed at the regulation of emotion.

The instrumental technique focused on information gathering, problem solving, communication and social skills and mobilising support. The palliative techniques on the other hand included denial, diverting attention, searching for meaning, emotional distancing, and relaxation techniques.

Lazarus and his colleagues concluded that coping was initiated by an appraisal process secondary to the assessment of circumstances as harmful, threatening or challenging. To this end, an individual judges their own resources such as effort, time, coping abilities and skills and then determines whether or not they will be sufficient to overcome the challenge posed by the stressful event.

Many of life's occurrences in the 21<sup>st</sup> century are significantly stressful for the whole of humanity. Disasters such as earthquakes, floods, tornadoes, wars and acts of terrorism are obvious examples, but for individuals caught up in specific events, personal feelings and reactions are intensified. Following the attack on the World Trade Centre in New York (September 2001) for example, many inhabitants of Manhattan experienced fear when going into public buildings, anxiety concerning another attack and inability to sleep adequately due to stress associated with an unknown enemy. Although psychological distress emerges fairly frequently following catastrophes (Totman 1990) it could be argued that to a degree, human beings also encounter stress in ordinary day to day occurrences. Studies in Britain have shown that stress and depression account for a large percentage of the reasons given for work absenteeism (Busfield, 1996). Interestingly the same conditions figure highly in a long list of drawbacks to being unemployed (Muchinsky 1990). Consequently, during periods of employment and unemployment, individuals often struggle to find a means of coping with their own unique circumstances, fearful that a failure to do so may produce psychological or physical ill health.

This present research study concerns an examination of the coping mechanisms adopted by patients following the diagnosis of a “life-threatening illness”. Specific interest centres on patient’s spirituality / religious belief. It is hoped that results of the empirical research will help determine whether spiritual / religious orientated patients choose to employ their beliefs as coping strategies throughout their end-of-life care and whether they derive physical or psychological benefits from doing so in comparison to non-spiritually / non-religiously orientated patients. This may indicate whether spirituality / religiosity should be more widely recognised as an additional category of coping strategy, worthy of inclusion alongside more established coping mechanisms.

One of the earliest researchers in the field of spirituality was Moberg (1971), whose now classic work established “spiritual well-being” as an area for scientific inquiry. Using traditional research methods, Moberg’s instrument was an 82-item Likert type questionnaire that was the product of extensive instrument development work and testing. Questionnaire items were related to seven factors of spiritual well-being and included Christian faith, self-satisfaction, personal piety, optimism, elitism, religious cynicism and subjective spiritual well-being. As this instrument is restricted to the Christian faith, it has a limited research value although it has to be noted that the vast majority of studies within this area of investigation are conducted from a Christian perspective. It is also important to point out that “spiritual well-being” is a concept related to spirituality and faith. Although an individual does not need to believe in a particular religion to encounter spiritual well-being, it is most often the case that religion is the source of spiritual well-being for the majority of people.

From the 1970’s onwards, other researchers began to take an interest in “spiritual well-being” and its eligibility as a coping aid. In 1979, Paloutzian and Ellison development a later instrument. Based on that of Moberg, it contained a smaller 20-item Likert-type questionnaire. Two dimensions of spiritual well-being were conceptualised, each of which underlined a separate sub-scale of the instrument. The religious well-being sub-scale (RWB) measured the sense of well-being derived from a person’s conceived relationship with God. The existential well-being sub scale (EWB) measured the sense of well-being related to a person’s personal conception of the meaning and value to life and existence. Ellison argued that the RWB could be interpreted to fit Eastern conceptions of God although its main focus is most definitely towards Western cultures. Known as the “Spiritual Well-Being Scale” (SWBS), this research instrument produced some interesting findings. In 1987, for example, Fehring, Brennan and Keller’s research with students recorded that spiritual well-being correlated with indicators of self-esteem and assertiveness and

that it was negatively correlated with indicators of depression and loneliness. The findings (above) were similar to the 1989 study into mental health by Crawford, Handal and Weiner. Of course overall reviews of empirical research have not revealed consistent findings. With reference to the previously mentioned studies, Ellis (1980) claimed, for example, that religiousness was accompanied by irrational thinking and emotional disturbance, whereas Bergin (1991) proposed that there was no support for the view that religiosity was a counterpart of psychopathology. Indeed Bergin (1991) claimed that the dominant classes of values in therapy, precluded religious values and has urged therapists to become more conversant about the spiritual and religious values which their clients hold. (He would like to see religious issues and beliefs included more systematically in psychological theories, research and techniques). A number of other studies found benevolent religious interpretations of negative life events to be associated with indices of better mood, fewer psychological symptoms and more favourable event outcomes (Jenkins & Pargament 1988, Pargament, 1992 and Koenig, 1992). The latter is again contrary to earlier research in which it had been argued that religion, with its focus on sacred explanations and influences, may discourage the development of a sense of personal control and efficacy (McIntosh, Kojetin and Spilka, 1985). Other research has suggested that religion can operate effectively as a mechanism of tension reduction. High levels of religious commitment and involvement have been associated with lower levels of anxiety and depression among a variety of groups such as the bereaved, (Gray 1987) the elderly, (Koenig 1988) and the terminally ill (Koffman & Higginson, 2002). Conversely, various measures of religious involvement were correlated with higher levels of worry and anxiety among some groups in a study by Pressman, Lyons, Larson and Garter (1992).

In 1990 Pargament et al introduced the proposal that religion / spirituality may be decisive factors in maintaining a successful coping outcome. For Pargament, religious or spiritual acts such as church attendance and personal prayer were integral to the maintenance of successful coping strategies. Pargament et al extended the coping theory by arguing that religion may enter the coping process in a number of ways, with critical events, appraisals of outcomes, coping activities and outcomes, to which religion may be integral or external to these occurrences.

It has been suggested that the distinction between different aspects of religious orientation (i.e. Intrinsic / Extrinsic, Allport & Ross, 1967) can give insight into the relationship between religion and mental health. Gorsuch (1988) for example argued that the distinction between the two different orientations has been the most useful to research on the relationship between religiosity

and psychological health. Recent research by Krivohlavy (2001) has shown that there is a relationship between faith and psychological health and research by Schnoll, Harlow & Brower (2000) indicated that psychosocial variables may mediate the emotional and social impact of serious illness.

Recent studies investigating association between religiosity and psychological well-being have been conducted most frequently in the United States but in 1999, Maltby, Lewis and Day conducted a British study with 474 students (251 males, 223 females) aged between 18 and 29 years. The aim was to examine the role of religious acts and the relationship between measures of religious orientation and psychological well-being. Results illustrated distinct similarities with those of Pargament's (1997) study. Psychological well-being was influenced by the frequency of personal prayer. Interestingly the researchers found that the act of prayer itself rather than religious orientation may be the dominant factor producing a coping strategy against depression and anxiety. Personal prayer, they concluded, may be an important variable to consider within the theory of religious coping.

In 2000, the present researcher conducted a study based on the Maltby, Lewis and Day (1999) investigation. The study consisted of 30 religious and 30 non-religious members of the general public aged between 20 and 70 years. Results concurred with those of Maltby, Lewis and Day, i.e. that there was significant correlation between frequency of prayer and other religious ritual, (such as church attendance), and psychological and personal well-being. Using the Paloutzian and Ellison (1979) "Spiritual Well-Being Scale", scoring in the Extrinsic section demonstrated a strong association between satisfaction in religious belief and life in general. A similar pattern of results emerged in this study for scores in the Beck's Depressive Inventory test. Subjects who took part in religious ritual produced significantly lower scores in this test (thereby indicating fewer tendencies towards depressive symptoms). Overall, frequency of personal prayer seemed to be a significant factor in psychological as well as spiritual well-being (Caddell 2000). It should be noted however that while prayer in response to stressful life circumstances had previously been associated with active coping attempts in some factor analysis (Gill, Abrams & Phillips 1989), an earlier study by Keefe et al (1987), had conversely found it to be associated with escapism and diversionary strategies.

One of the suggestions for further research recommended by the Paloutzian & Ellison study (1979), presented challenging possibilities for researchers interested in spiritual well-being and



health. As a conclusion to their research, the authors recommended that all seriously ill patients should be tested using their “Spiritual Well-Being” scale. This would give interested health care workers a validated and reliable measurement of the patient’s mental state concerning not only their religiosity but also their ability to cope with their current situation. It would also provide good indications of levels of depression and loneliness. In addition, the SWBS, could also determine patient’s psychological state with regard to spiritual and personal well-being which could provide additional information when assessing quality of life and coping ability.

The subjects of spiritual well-being, illness and coping were of particular interest to the present researcher and presented exciting and challenging areas for a new research project. Focusing on the areas of terminal illness, palliative care, quality of life, coping strategies and spirituality, prominent questions within the research were formulated as follows, -

1. Do patients choose a coping strategy during terminal illness?
2. If so, is this choice determined by personal attitudes or beliefs?
3. What are the most frequently employed coping strategies?
4. Are “coping strategies” analogous to “well-being” and “quality of life”?
5. Are policies in operation, which encourage assessment of patient’s depression or anxiety symptoms?
6. Do staff consider religion or spirituality issues worthy of inclusion within the category “coping strategies of patients with life-threatening illness”.

Literature relating to these points has proved to be scant. It is only in recent years that there has been an increase in research and clinical studies designed to determine whether religious belief / spirituality contribute to the coping strategies of patients suffering from life threatening illness. Most of these have been conducted in the United States rather than Great Britain, where (according to opinion polls) scores on religious belief scales are significantly higher than in the United Kingdom. In 1995, Paloutzian expressed the view that Gallup Poll data consistently show that approximately 90% of the American population believe in God; that 50% are active in religious organisations on at least a weekly basis and that 71% believe in life after death (Gallup and Castelli 1989). Similar views and percentages were reflected in a more recent opinion poll. (CNN/USA Today 1997) whose results were based on telephone interviews with 1,009 adults. Within the United Kingdom, the Christian percentage was cited in “Religious Trends” (2000) as 64% of the total population, with total religious percentage totalling 71%. Consequently it can be stated that religious belief (whether nominal or practising) constitutes a significant part of both

British and American cultural attitude and opinion and is therefore worthy of consideration as a coping strategy during times of stress, particularly ill health and terminal illness. Moreover researchers who study religious belief and practice are of the opinion that these subjects are essential to the understanding of current cultural attitudes since religion and religiosity are part of traditional, historical cultural background.

Interestingly, in a recent publication, Brierley (1999) reported that only 8% of the population of the United Kingdom worshiped weekly but that this finding did not necessarily mean a drastic deterioration in faith. Instead it may signify a shift in cultural practices from outward shows of religious ritual (i.e. church attendance) towards a more intrinsically orientated perspective. Paradoxically, as extrinsically orientated religious practices seem to be declining, interest in “spirituality” appears to be increasing, with 7 out of 10 adults reporting a belief in God (Gower, 1992/93). However it should also be pointed out that there is often confusion between the terms “spirituality” and “religiosity” and that, as Percy (2000) proposed, official religion exists against a background of innate spirituality which has become intertwined with popular cultural events and happenings. This “folk spirituality”, Percy proposed was evident in recent tragedies such as Zeebrugge, Hillsborough and the death of Princess Diana. (Defining spirituality and religious belief is a difficult but necessary task, which will be attempted in Chapter 2).

Within Western societies, people die from a variety of causes, for example heart disease or cancer, but according to Katz (1995) most people die in old age, often in hospitals, residential care centres or hospices. Because of economic, social and cultural changes, social organisation of death and religious attitude, are very different today than at the beginning to middle of the twentieth century. Consequently many terminally ill patients are no longer cared for in their homes, surrounded by extended family. Katz suggested that,

“Death and dying have become medicalised, insofar as they have been seen as requiring the intervention of health professionals in institutional settings. Hence the person’s home environment was no longer seen as the appropriate venue for birth and death” (p.43/44).

One of the salient question within this present research is whether spirituality or religious belief merit consideration as a coping strategy by medical practitioners in their work with patients with non-curative illnesses. Throughout most of modern human development, history has recorded medicine and religion to be closely linked. Indeed Kuhn 1988 proposed that the former evolved out of the latter. In the past, because hospitals within Europe were also religious institutions, the acceptance of death or healing was physically and spiritually embraced by both patient and healer

(the physician). Interestingly, Benson (1996), proposed that in former times when the patient regarded the healer as having both clinical expertise and also as being an instrument of a higher healing power; a placebo effect was often generated thereby enabling some patients to, in effect, heal themselves.

Because this present research will be based within 2 specialised care hospice units, a brief mention of the origins of the hospice movement is worthy of mention. This can be traced back to the fourth century, to a time when Christianity became the official religion of the Roman Empire. Originally catering for pilgrims and travellers, it gradually took on the responsibility of caring for the sick. According to Saunders (1986),

“For a thousand years, Christian charitable institutions carried the burden of the sick and the poor the indigent, orphans and others – amounting almost to a general national health and welfare service” (p.41).

Yet up until the 19<sup>th</sup> century there was no separation of care for the dying from care for the living. The first institutions to cater specifically to the care of the dying were established in London between 1885 and 1905 (Phipps 1988). They were predominantly religiously orientated, operated in the main by religious orders (for example St. Joseph’s, founded by Mother Aikenhead of the Irish Sisters of Charity), whose prime objective was to guide their patients towards what they regarded to be an appropriate Christian death. Phipps recorded that although spiritual and religious aspects of patient care were of primary consideration, alleviation of patient’s bodily suffering was also regarded as important. Nevertheless it was not until the late 1950’s that the now acknowledged founder of the modern hospice movement, Cicely Saunders, began to initiate her goals of alleviating both physical and mental pain, in new homes based on her personal (Christian) ideals of care at the end of life (Saunders, 1958). In a recently recorded Radio Scotland interview (6<sup>th</sup> July 2001), Saunders reminisced that her early hopes and aspirations grew out of the significant relationship she had experienced while administering to a Jewish émigré in a London hospital after World War 2. This relationship further strengthened her growing convictions in a holistic approach, which combined recognition of spirituality and religious needs with the administration of the most up to date pain relieving analgesics.

In 1948, the U.K. National Health Service (Ministry of Health) advised local health authorities to provide spiritual care for their patients by appointing paid chaplains of different (Christian) traditions. Thus within medical administrative policy of the time, a recognition of patient’s

spiritual needs was in fact present. However as Davie (1994) pointed out, by that time, formal religious adherence for many members of society within the United Kingdom had already begun to decline (although many continued to maintain faith with the idea of a God and life after death, while having no association with church denominations). Consequently many health sector hospital employees regarded the objectives of a hospital chaplain as being unfamiliar and unrelated not only to their personal lives but to their professional duties also.

Interestingly, in the recent radio interview, Saunders (2001) acknowledged spirituality rather than religiosity to be the term most often accepted within palliative care today. But it was obvious that her personal religious beliefs and convictions had remained as strong as they had been in the 1950's. Saunders had striven to revive an attitude towards death as being part of life at a time in the 20<sup>th</sup> century when (as Aries 1976 argued), the desire was to hide death away. It had become policy not to disclose to the patient their imminent death in order to spare the dying person from the extra stress such a disclosure would promote. As Aries pointed out,

“One dies in hospital because the doctor did not succeed in healing..... Death is a technical phenomenon obtained by a cessation of care” (P.88).

This can result in “dissimulation” particularly to the patient’s relatives who feel unable to broach the subject of death as people are now no longer culturally confident in life after death. Added to this is the fact that many hospital / hospice staff feel uncomfortable discussing death, spirituality or religious belief.

Acknowledging that the hospice movement now administers to the faith of every individual and to those with none, Saunders (2001) stated that in her opinion many terminally ill patients embark on a strategy of contemplation concerning the meaning and purpose of their life and death. Many also take solace in their religious practices and welcome visits by the hospice chaplain and visiting clergy of all faiths and denominations. Saunders also made the significant statement that at this point in time, society on the whole, is less comfortable with topics such as dependency, death and dying than it was in the 1950's. Culturally, society now views these issues as a threat to the individual's independence and control. Death, the taboo subject, is thus rarely acknowledged and rarely discussed, even within families where a death has occurred. Interestingly, Bradshaw (1996) stated that death is not so much the taboo subject, but rather, God is –

“We must ask whether palliative care is now in danger of losing its ethos not perhaps because death is a modern taboo, but because God has become the modern taboo, excised from any spiritual understanding of

death. And these changes seem to resonate with a redefinition of the spiritual dimension of palliative care” (p.413).

It must be stated however that some patients will inevitably take solace in different kinds of “spiritual well-being”. These may include acknowledgement of death as finite, or security in the achievement or life goals or relationships. Individuals may find satisfaction in having fulfilled their role as parent, spouse or friend or some other kind of relationship which transcends the limits of self gratification. Others while not acknowledging God as in the Judaic / Christian mode, may experience what Tillich (1952) described as “ontological harmony”. In other words, by inner contemplation, some individuals come to an acceptance of “something greater than themselves” which can produce states of peace, contentment and acceptance of death.

Thus, against this background of information and opinion, the present researcher seeks to conduct an empirical study, the outcomes of which it is hoped will,

1. Help reduce patient’s mental anguish by the recommendation of improved “quality of life” assessments.
2. Increase medical practitioner’s awareness and support of their patient’s spiritual / religious concerns resulting in better medical control of patient’s symptoms.
3. Result in the inclusion of “psychological measuring scales” within healthcare assessment of patients, which may further increase their overall QOL and end-of-life care.

A recent statement issued by the current Minister of Health may help generate more interest and research into the areas of coping strategies adopted by patients with life-threatening illnesses (particularly from a psychological and spiritual perspective). Speaking at a conference in Stirling, Scotland, the minister for Health and Community Care, stated,

“NHS staff, patients and their families are often confronted with serious or life-threatening conditions, injuries and bereavement. Spiritual care can be a great source of comfort for them in these difficult circumstances. Under this new guidance, which will be issued to the NHS in January 2002, each Health Board will be required to develop a strategy for spiritual care to ensure that spiritual care and chaplaincy services in each Trust are adequately managed, staffed, regulated and funded.....Local chaplains will help train and develop the skills of volunteers from a range of organisations to enable them to provide spiritual care services across all faiths or on a secular basis” (Chisholm, 2001).

## Literature Review

Results of several recent research studies consistently indicate that an individual's spirituality or faith can play an important role in coming to terms with clinical prognosis, particularly in the area of terminal illness (Levin, Larson and Puchalski 1997). Interestingly, spirituality and religious belief are often integrated within an individual's belief system. Scobie (1975) stressed the fact that,

"In this area of study it is important to bear in mind not only the content of beliefs, but the manner in which they are held and the consequent effect on behaviour since items of belief in themselves would have little significance if they did not influence the individual to respond in a particular way" (p.9).

The erosion and undermining of religious and spirituality issues within society in general and the medical profession in particular, has had repercussions on how patients and their problems are perceived. An individual's belief system is rarely taken into account when assessments are being considered concerning coping ability or quality of life of palliative care patients. Searle (1991) pointed out that concern may be directed towards a health care system in which physicians consistently hold a "scholarly" perspective on behaviour, when confronted by patients wishing to discuss their health worries and fears within the context of a spiritual or religious perspective. Most religiously orientated patients use aspects of their religion (for example prayer) in times of serious ill health. However when confronted with terminal illness, religious and non-religious patients frequently adopt coping strategies in order to come to terms with the physical discomfort and mental anguish of the trauma. As previously stated, recent investigations have shown that an individual's spirituality or religious belief system, can feature significantly as a coping aid in coming to terms with impending death. Aspects of religion and spirituality are now beginning to be recognised and promoted as coping aids by healthcare chaplains who work within hospice environments (Mitchell & Sneddon 1999). According to the Association of Palliative Medicine, (1993) palliative medicine (exemplified in hospice care) is,

"The appropriate medical care of patients with advanced and progressive disease for whom the focus of care is quality of life and in whom the prognosis is limited (although sometimes it may be several years). Palliative medicine includes consideration of the family's needs before and after the patient's death. Central to the philosophy of palliative medicine is the concept of holistic care, concentrating not only on the physical needs of the patient, but also on emotional, spiritual and social needs. Good palliative care includes, - respecting patient autonomy throughout the illness and discussing treatment options before jointly formulating treatment plans – expert management of pain and other distressing symptoms in the context of holistic care; this may include drug treatment, anaesthetic procedures, psychological or neurosurgical approaches.....The philosophy of the hospice movement and palliative medicine provided a positive alternative to active euthanasia for those afraid of dying in great pain and anguish" (p. 14).

The move from “closed” to “open” awareness in caring for the terminally ill, was promoted by researchers and ethicists who argued that the former practice of “closed awareness” was damaging and morally wrong. Prominent among these researchers was Glaser and Strauss (1965) and Searle et al (1991). The latter reported that in two national surveys conducted in 1969 and 1987, the proportion of dying people reported to have known that they were dying rose from 16% to 44% for those with cancer and from 18% to 22% for those who died from other conditions. The proportions of patients who reportedly did not know that they were dying declined from 38% to 4% for cancer deaths and from 22% to 9% for other conditions. These results are both interesting in general but are specifically important to this present research study because if an individual is fully aware of their terminal state, it will more realistically determine the appropriateness of their choice of coping strategy. This more recent ideology towards openness is seen as the prerequisite of a “good death” in which symptoms are well controlled and managed as patients wish and where, most importantly, death is accepted. An example of proposed outcomes of closed awareness versus open awareness resulting from the Searle 1991 study, can be viewed in Appendices 3. Research outcomes were directed towards patients, relatives, nurses and doctors. It could be argued that results such as these are idealistic rather than practical and it is important to keep in mind the observation by Kubler-Ross (1982) who stated that there are,

“...millions of people who still have the illusion that a patient is better off if surrounded with an air of “all is well”; that is, if we visit terminally ill patients only with a smile on our face and cheerful, superficial conversation or silence. We have no problems getting them the very best in physical care and attention, but most often neglect their more painful emotional and spiritual turmoil” (p.4).

These sentiments were recently supported by Bradshaw (1996) when she contended that the concept of a “good death” had become institutionalised to the extent that it now means the process of dying rather than the actual death itself. Referring to the McNamara, Waddell and Colvin 1994 study in which nurse’s interactions with patients and opinions of patients were observed and recorded, Bradshaw berated the institutionalised expectation of achieving “a good death” on every or most occasions. This attitude, she contended caused a type of “opiate” effect that prevents a “real” death and a freedom to consider ultimate questions of faith” (p.410). In 1997, Searle et al, were able to conclude that,

“A preference for open awareness of dying is now well established in terminal care settings and amongst the general population in the U.K., U.S.A. and other Anglophone countries” (p.477).

In Scotland (where this present research is being carried out) chaplains work closely with doctors and other health staff (Mitchell & Sneddon 1999) and offer patients meditation, prayer, music and

traditional sacred readings. The hospice tradition demonstrates an example of a health care team approach that integrates emotional and relational well-being together with a certain degree of hope. It may be generally assumed that the hospital chaplain is perhaps the most suited to this role, however in a 1991 survey by Maugans and Wadland, it was found that very few patients (whether religious or non-religious) were offended by inquiries into religious beliefs and attitudes. Forty per cent of patients welcomed the idea of having care-staff discuss spirituality issues with them, particularly within the context of chronic or terminal illness. Moreover, in a study by Ehman et al (1999), fifty-one per cent of the study patients described themselves as religious, and ninety-four per cent of the religious patients agreed or strongly agreed that staff (particularly doctors) should ask them whether they have such beliefs if they become seriously ill. Forty per cent of the respondents who denied having religious beliefs nonetheless agreed to an initial inquiry on the subject and only sixteen per cent of all respondents refused a discussion on the subject in the event of becoming terminally ill.

As previously mentioned, recent studies have concluded that aspects of religiosity (particularly prayer) and psychological well-being are significantly related. This is an important area of consideration within palliative care because although the body's physical capacities may be rapidly deteriorating, the same may not be the case with regard to its mental capacities. It therefore becomes vital that terminally ill patients are offered opportunities within the hospice environment which prevent them from becoming depressed or anxious, thus jeopardising personal well-being and quality of life. Within palliative medicine, it has become recognised that this holistic approach to the linkage between mind and body is most beneficial to patients themselves (Mitchell & Sneddon, 1999).

Because some patients often rely on religious conviction during times of serious or terminal illness, health care workers devoid of similar belief systems may nonetheless have to consider how best to respect the patient's beliefs and that of their families. Health care workers may also consider it more appropriate for patient's spirituality issues to be dealt with by chaplains and visiting clergy. They may consider any inquisition into the patient's spiritual needs as an additional work task – that of amateur psychiatrist – to an already busy work schedule. In addition, caring for the terminally ill and dying person within a hospital or hospice situation can be stressful for staff. Vachon (1979) listed several sources of stress within the hospice situation –



"Difficulty in accepting the fact that the patient's physical and psychological problems cannot always be controlled.

Frustration at being involved with a patient's family only after their emotional resources have been drained by the illness.

Disappointment if expectations for patients to die "a good death" (however this may be defined) are not met.

Frustration at having invested large amounts of energy in caring for people who then die, taking this investment with them.

Anger at being subjected to higher than standard performance expectations in prototypal facilities exposed to considerable scrutiny and publicity.

Difficulty in establishing a sense of realistic limitations on what the hospice service, which is expected to be all-encompassing, can provide" (p.182).

Teamwork and attending conferences and workshops appropriate to the needs of the chronically sick and dying not only informs the health care worker of the latest information available, but also generates support for the health care worker among their peers. In 1989, an interdenominational Working Party comprised of mainly doctors, nurses and clergy examined the impact of hospice experience on the church's ministry of healing ("Mud and Stars"). On the subject of support for staff members, the Working Party was unanimous –

"Hospice staff not only have to bear their own feelings, but also the projected fears and anger of others – patients, patient's relatives and colleagues. The injection of negative feelings into staff, results in stress and sometimes illness or breakdown, unless these feelings can be safely discharged or transformed" (p.223).

These objectives are often difficult to attain since society (as previously stated) treats the subject of death and dying as a taboo issue. Health care workers may be criticised as morbid if they try to talk to their own families about their work problems. But for hospice staff there is an unusually high exposure to death, which in turn may produce changes in beliefs, attitudes and values.

Researchers involved with the inclusion of religious belief or aspects of spirituality with regard to health or death rarely have a scholarly background in religious studies. According to Krause (1993) and Williams (1994), they are often not familiar with the long history of attempts to conceptualise and measure multiple dimensions of religiousness. Misunderstandings quite frequently occur between health-care staff and the seriously sick patient because neither can fully comprehend the other's opinions in the area of communication about spirituality or religious belief. Health-care workers may be primarily concerned with physical comfort and pain relief aspects of patient management. However recent research (Cohen et al, 1995) involving patients with life-threatening illness frequently note that many enter a state of shock or depression at the realisation of the seriousness of their condition. Mental health may inevitably deteriorate, and this

coupled with physical decline could herald significant troubling questions and doubts concerning formally held religious convictions. They may become tormented by sudden spells of doubt concerning the existence of God. On the other hand, those who had previously given little thought to, for example, an eternal afterlife, may encounter similar bouts of anxiety on account of having lived their life convinced that death represented the end of all existence. Concepts such as “soul” and “spirit” are irrelevant to the life of the non-religious person during times of good health. However as the inevitability of death impacts upon the mind of the seriously ill patient, previously held convictions may no longer seem as convincing as they once were. The realisation that former health will never be restored, and that death is the inevitable outlook, presents some patients with the additional problem of trying to find someone who will understand their intense mental anxieties. As Doyle (1994) stated, more than 75% of dying people speak of spirituality issues (which may or may not be allied to religious matters). Questions concerning the meaning of life, the meaning of suffering, the existence of God and life after death etc become so common among individuals as they near death (even among those who had never previously shown any kind of spiritual or religious inclination) that,

“... bewildered relatives often ask if it is a feature of the illness, if he (the patient) is mentally disturbed, or even if it is a side effect of his drugs? (p.97).

Traditionally, doctors, psychologists and psychiatrists have had difficulty with spirituality as it interrelates with their patients. Indeed many psychiatrists have followed the psychodynamic Freudian tradition of attributing a good deal of mental ill health to observance of religious doctrine. Most have encountered examples of vulnerable clients who have been the victim of the harmful effects generated by some religious groups. In addition, religious people, who regard faith, religious practice and spirituality as important, may distrust doctors and counsellors, preferring to discuss these anxieties with hospital or hospice chaplains. As previously stated, in times of imminent death, patients may become extremely agitated, and former cultural restraints can become abandoned in the face of despair or panic. Consequently patients may wish to discuss their health problems with the hospital clergy and their mental problems with their physician or nurse. It is equally hard for the non-religious health-care worker to comfort the religious patient as it is for the religious health-care worker to comfort the non-religious patient. Yet recent studies have revealed that the key to emotional coping with serious illness is to be found within the matrix of patient spirituality (Pargament, 1997).

Other researchers such as Koenig (1994) concluded that it is important for doctors and psychiatrists to be aware of their patient's religious beliefs and spiritual aspirations, to understand them and to know about their patient's background. He also pointed out that in practice there has been considerable evidence for the benefit of religious belief in achieving good mental health and recovery from mental illness. Critics of Koenig are quick to point out however, that the university from which he conducts his research (Duke) lies in the heart of the "bible belt" and as such may very well fund some of his research.

When prognosis indicates a poor outcome, is spiritual well-being important? In an effort to determine whether terminally ill patients with AIDS had greater religious and spiritual care needs than other terminally ill patient populations, particularly those with cancer, a study by Pace and Stables (1997), was conducted in a community based hospice in America. Specifically, the study aimed to compare the perceptions of spiritual well-being, loneliness, social support, health hardiness, pain and functional status among terminally ill clients with cancer and terminally ill clients with AIDS. A sample of 55 hospice patients completed the Correlates of Spiritual Well-Being Scale (COSWEB), which included a demographic data sheet and instruments to measure spiritual well-being, loneliness, health hardiness, social support, functional status and pain. Patients with AIDS reported significantly lower S.W.B., than did patients with cancer or other chronic terminal illnesses. Patients with AIDS also reported significantly greater loneliness than other patient populations. The number of social supports for patients with AIDS was significantly lower than for cancer patients and other groups. Moreover patients with AIDS were significantly more dissatisfied with their supports than other patient groups. The best predictors of spiritual well-being in this study were social support and loneliness which explained 47% of the variance in spiritual well-being. Results of this research indicate differences between different groups of hospice patients. Patients with AIDS appeared to be less spiritually well than other patient groups, Pace and Stables (1997) proposed that this may be due to decreased support systems, dissatisfaction with this support; greater feelings of loneliness; younger ages on entry to hospice care and fewer family support. They recommended that future research should investigate whether health care providers should allocate time and resources to various terminally ill patient populations to achieve higher quality care outcomes in general and greater spiritual well-being in particular. A criticism of this particular research could be levelled at its small number of participating subjects. Nevertheless it does highlight an important ingredient in the care of all chronically sick and terminally ill people – that of social support, particularly from family and close friends. During times of severe stress, the family of a terminally ill patient experiences

emotions ranging from fear through to anger and are generally bewildered by their lack of control in the medical diagnosis. Their main contribution to the alleviation of stress in their loved one is in the form of frequent visits. The Pace and Stables study revealed the fact that even in 1997, family members of AIDS victims had considerably more difficulty in maintaining support for them than families of for example cancer sufferers. In general terms, most family members experience a state of shock following news that their sick relative will probably never recover and consequently request the best palliative care for them, while others choose to care for their dying relative at home.

In 1998, Higgins, Astin, and Dolan published a paper revealing a ten-year trend in England of approximately 50% of cancer deaths occurring in hospitals. The year previously, Rogers, Karlsen and Addington-Hall had conducted a study involving a random sample of 431 cancer deaths drawn from death certificates within the city of London between July 1995 and June 1996. The person who registered the death was randomly contacted seven months later, either for interview (one-third) or to receive a postal questionnaire. Fourteen of the 158 questions were open-ended ones, inviting respondents to comment on their experiences. The overall response rate was 53% and 138 respondents commented on the care received by their relative in hospital. The care given by hospital doctors and nurses was rated “excellent” or “good” by 74% and 80% of respondents respectively. Of the 48 respondents who made at least one negative comment specifically about physician or nursing care, 21 (44%) rated hospital doctor’s care as “excellent” or “good” and 23 (48%) rated nurses’ care as “excellent” or “good”. Overall, 22 respondents experienced poor communication with hospital staff, particularly with regard to doctor’s ability to predict when death would occur. There was also a general criticism of the way bad news was given – often occurring when the patient was alone or alternatively in public places. Six respondents reported disclosure of a poor prognosis against the patient’s expressed wishes and five respondents included requests that medical students and junior doctors should not be allowed access to terminally ill patients because they seemed so inept in dealing with such circumstances. Overall it nevertheless seemed to be a very small percentage of the 138 respondents who highlighted negative aspects or complaints concerning hospital staff. However a criticism of these findings may involve the suitability of bereaved relatives in this study and also the fact that only 53% of the random sample number chose to reply to the questionnaire or interview request. Is it feasible to conclude that bereaved relatives could not be bothered to fill in a questionnaire or take part in an interview less than a year following the death of a close relative? The lack of willingness on behalf of approximately 50% of the sample population could be interpreted in two ways. Either

they were totally satisfied with the care given to their terminally ill relative and did not see the need to record their feelings or it may indicate dissatisfaction, severe enough to prevent the relative wishing to formally record their views. Either way the non-respondents were unaware of the fact that taking part in the study would furnish health authorities with information which would eventually lead to improvements or at least comparisons in palliative services between health regions. Rogers, Karlsen and Addington-Hall (1997) concluded their research by proposing that placing more importance on basic nursing care and adopting a more patient-centered approach would improve patients' hospital-based care,

"An emphasis on the individual patient and their family is the basic tenet of the palliative care approach, and its wider implementation would benefit all patients" (p. 54).

Within recent years there has been a dramatic shift in perspectives in many centres of therapeutic care in America by combining into the medical system a respect for the meaning and importance of the spiritual and religious beliefs of patients. This shift may be a reflection of a trend in society at this present time, which displays a fascination with "spirituality" in general. The latter is evident in many books, articles and films, in both America and Europe, which reflect a longing for meaning and purpose to existence and an underlying conclusion that answers must encompass imaginative, symbolic or transcendental exploration. In recent studies religion and spirituality are no longer viewed as illusory and immature. Experiences with spiritual matters such as faith, prayer, belief in God and ritual are beginning to be viewed as an integral and essential part of human existence and development. In 1992, Koenig reported that for every 10-point increase in an individual's intrinsic religiosity, as measured by a scientifically validated questionnaire, there was a 70% increase in the speed of recovery from depression. Recovery time was even faster for older patients whose medical conditions worsened or failed to improve after discharge. For each 10-point rise in religious faith, there was a 100 percent increase in the speed of remission from depression, compared to their non-religious counterparts. The study involved 87 depressed patients hospitalised for medical conditions such as heart disease and stroke. Intrinsic religiosity was defined as a deep, internally motivated type of religious commitment, related to but distinct from organised religious activities and private meditation and prayer. To be considered depressed, patients had to experience at least 3 out of 13 criterion symptoms for two weeks or longer during the month previous to the study in addition to scoring at a certain level on two nationally recognised depression scales. Koenig expressed the view that

"A lot of older people have exhausted their medical treatment options and we can't do a lot to enhance their physical functioning. But we can facilitate coping mechanisms that ameliorate their psychological and mental

distress. This is the first study to show that religious faith by itself, independent of medical intervention and quality of life issues, can help older people recover from a serious mental disorder” (p.170).

This research has strong implications for patients with non-curative illness, as depression is most probably a consistent variable when considering coping levels. Koenig (1992) proposed that religious belief either,

1. Provides a world view in which medical illness, suffering and death can be better understood and accepted or,
2. That it provides a basis for self-esteem that is more resilient than other sources which tend to decline with increasing age and poor health (such as strong physical ability or abundant material possessions).

It must be stressed that all religious / spirituality studies will evoke criticism from those persons who genuinely hold to their conviction that the fundamental authenticity of such topics is unverifiable and ethereal and consequently unable to be validated scientifically. But there is equally no denying that millions of individuals throughout the world follow religious or spirituality based ideologies and doctrines. Therefore, for the purposes of this present research, it is necessary to abandon philosophical questions of authenticity / verification and concentrate on the phenomena of religious belief / spirituality and its psychological impact on personal coping strategies in times of severe stress.

Another criticism of Koenig’s (1992) study may be that it was not so much religious faith which displaced depression, but the phenomena known as “mind / body connection”. The latter has been included in work by Glaser and Glaser (1995) investigating “psychoneuroimmunology” (PNI) which focuses on the relationship between human behaviour, psychosocial factors and the body’s immunity to viruses and infections. Noted psychologists such as Maslow (1962), Rogers (1961), and Laing (1967) promoted the idea that a healthy state of mind (even when achieved by going against current trends within society) will result in good psychological and physical health. Since the 1950’s psychologists within the phenomenological and existential traditions have been interested in investigating the psychological factors which influence the human body’s ability to control the symptoms of ill health and even survive life-threatening diseases. Contemporary phenomenology centres around the problem of making sense of the world and as such has been attractive to some researchers of health care practice who see in it the potential to illuminate otherwise taken-for-granted assumptions which can exist in the process of giving and receiving care. Benner and Wreubel (1989) incorporated these ideas into nursing in an attempt to identify the elements in a “science of caring”. Examples within the literature of palliative care, cancer and

related fields which report on phenomenology and similarly orientated research suggests that, when properly conducted, the approach has a good deal to offer. Recent studies have included an analysis of existential changes in a group of cancer patients (Halldorsdottir and Hamrin, 1996); an examination of perceptions of death among people with chronic illness (Gullickson 1993), and an enquiry into the ethical context of nursing dying patients in critical care (Wros, 1994). According to Seymour and Clark (1998),

“ Phenomenological approaches, particularly those based on hermeneutics, with their strong emphasis on the interpretation of human meaning and actions, have a good deal to offer palliative care research. Such approaches provide opportunities to explore the place of the body, identity and meaning in the experience of illness, disability, dying and bereavement. Phenomenology also offers opportunities to study the role of emotions and values in the work of undertaking palliative care, particularly from the perspective of care givers. It may also cast light on aspects of professional socialization and relationships in multidisciplinary teams, so central to the philosophy of palliative care. Most challenging of all, phenomenological approaches may help us to develop hypotheses regarding the relationship between particular styles of palliative care provisions and the unique experiences of very sick people and those close to them” (pp.130/131).

It should be noted however, that phenomenological approaches are not a substitute for an underlying research question and that with regard to this present research both qualitative and quantitative methodologies will be used.

The newer PNI research may give psychologists a stronger justification for seeking a larger role in society's health care arena. In the past, the efficiency of traditional interpersonal psychology has been difficult to quantify, whereas according to Glaser and Glaser (1995) the application of PNI can demonstrate tangible results to sceptics and critics. They proposed that an infection or disease is either present or it is not present and have investigated the impact of psychological factors upon immunological changes. They have also established that emotions such as anxiety and hope can be factors in illness outcomes. Studies showed that medical students, during stressful examination times, show a decline in the activity of cells that fight off tumours and viral infections. They also established that people caring for a spouse with Alzheimer's disease show decreases in immune activity. As a new development, PNI research has yet to establish consistent and conclusive results, but a more worrying criticism is the fact that this type of investigation may send a message to the seriously ill patient that they are, in essence, accountable for their own prognosis. In other words incorrect thoughts and attitudes will result in poorer medical outcomes.

Within a psychobiological framework, research by Frankenhaeuser (1979) on human stress and coping found that neuroendocrine responses to the psychosocial environment reflect its emotional impact on the individual. Frankenhaeuser pointed out that recent biomedical techniques have

made it possible to monitor how hormones and other neuroactive compounds change during exposure to many stressful situations. Recordings may be possible even while patients are moving, and can register results from almost all organs in the body. According to Frankenhaeuser, individuals consequently,

“...serve as measuring rods, that is, sensitive instruments, which help to identify factors in the environment which increase bodily wear and tear” (p.123).

Inevitably, there are a large number of factors and qualities by which people judge themselves, when faced with life-threatening illness and possible death. They may even compare themselves to others within the hospital or hospice setting which may result in positive or negative self-imaging. Pargament et al (1990) proposed that the choice of coping strategies affected feelings of empowerment and self-esteem. They also proposed that religion plays a major role in determining whether a patient views their current health state with fatalistic pessimism or with the type of optimism found in the religious adherent who views the ending of their life as being part of God’s plan for the universe. Wulff (1991) pointed out that cognitive strategies are somewhat analogous to certain Christian religious practices such as praying, chanting or meditating. Individuals who can master these strategies reported being able to clear their minds and reduce mental discomfort. These conclusions were reiterated and extended by Dull and Skokan (1995) who proposed that religious practises and strategies may be able to reduce physical pain and discomfort in certain circumstances. Dull and Skokan believed that centring cognitive control on religious practises such as meditation and prayer may conceivably affect physical experiences (as had been found in the Ramaswami and Sheik 1989 study).

Some causal modelling studies have shown evidence that appraisal of stress can influence the degree to which stress is experienced in the first place (Lazarus and Folkman 1984). Other studies point out that daily life is fraught with stress and that the same situation may be assessed in different ways depending on the cognitive processes within the individual. Interestingly Christensen 1981 stated that the potential role for cognitions arising from religious beliefs serve as either buffers or intensifiers for stress in health outcomes. Scientific evidence in support of a mind-body connection is sketchy mainly because the topic presents a methodological challenge to researchers and because it violates several traditional boundaries of specialisation. After reviewing the shortcomings of mind-body literature, Pelletier and Herzing (1989) concluded that,



“Speculations concerning the ultimate role of beliefs, positive emotions and spiritual values in organising and transcending biological determinism would seem to be philosophical speculation if the answers to these questions were not so critical to our survival as a species”(p.379).

Within hospice establishments, patients are particularly dependent on care staff and the medicine necessary for the relief of pain. Any suggestion that their pain and suffering may have been a result of their own psychological make-up would present the patient with an almost unbearable burden at a time of intense stress, even although there may indeed be a certain amount of truth in the assertion.

During any serious illness, one of the most important factors is recovery and release from the hospital situation to the home environment. Most patients cope with inconveniences and annoyances and are willing to try any method of healing (including counselling and psychotherapy) especially if it quickens recovery and release from hospital. But within the hospice environment, many patients come to realise that recovery is not an option, although some can maintain a degree of normality by attending the hospice as day-care patients or attaining periodic home treatment periods. Thus the whole area of coping and coping strategies are important and significant to the hospice patient who is not only struggling to come to terms with their illness, but who may also be searching for meaning and purpose to their life-threatening illness. Because of this, “Quality of Life”(QOL) is becoming increasingly important in assessing the impact of disease upon the advanced terminal patient. Krivohlavý (2001) stressed that,

“The issue of “quality of life” may be one of the oldest of philosophical issues. It is also one of the most central to humankind. It is possible to see in the last few decades a revival of the interest of psychologists in this issue” (p.10).

During patient’s end-of-life care, the quality of life experienced serves as testimony to the quality of palliative care services offered by the medical unit. It is therefore vital that patient’s quality of life (QOL) is assessed so that aspects requiring intervention can be brought to the attention of medical administrators.

In 1996, O’Boyle expressed the view that,

“Patients are people first and foremost; the sick and disabled are not merely biological substrates for treatment. Failure to acknowledge their quality of life, is neither good science nor good medicine. Quality of life is a multi-dimensional construct. It is designed to capture all the essential conditions beyond mere survival that have to be fulfilled if the chronically sick and dying are to experience meaning in their lives. Symptom control is obviously important but the great efforts in palliative care to control pain and manage symptoms serve a deeper, existential purpose” (p.38).

In 2002, Lo et al measured the quality of life of 58 palliative care patients recruited from several medical units within hospitals in Hong Kong. They represented 12.6% of 462 patients previously enrolled in an ongoing longitudinal study. Using a modified version of the McGill Quality of Life Questionnaire (Cohen et al, 1995) the researchers evaluated the profile, determinants and longitudinal changes in the quality of life of the patients last few days before death. The McGill Quality of Life (MQOL) measurement scale was an appropriate instrument to use as it had been specifically designed for use in advanced palliative care patients. It contained four sub-scales, one of which included an existential domain, exploring the perception of purpose and meaning in life which the authors considered especially relevant to terminal patients. Results demonstrated that self-rated QOL evaluations were possible even by patients in the very end stage of life. Taking the 4 sub-scale totals into account, mean total QOL scores for the last 2 weeks of life were 7.0 of 10. This result is in keeping with Cohen et al's (1995) original observations that QOL scores need not necessarily deteriorate as end of life approaches even although patient's physical status may be poor. But, as in all studies incorporating self-evaluation scores, results are directly related to the amount of information given by medical practitioners and by the degree of assimilation of this information by patients. If patients are told the truth about their medical condition it at least affords them the opportunity to deal with the consequences in a manner best suited to their individual coping abilities. Inevitably some will choose not to face the reality of the situation and retreat into a state of denial, but others although shocked, will endeavour to accept the prognosis, comforted in the knowledge that relationships with family and friends can be conducted in an honest and realistic manner. With reference to the Lo et al (2002) results, questions must be asked as to why QOL evaluations were fairly high despite the fact that 52% of the cohort complained of pain in the final 2 weeks of life. Personal beliefs regarding meaning and purpose to life may have played a part or it may have been due to personal conviction of hope that despite pain occurrence, eventual recovery would take place. Although these considerations were not explained, the study none the less demonstrated the fact that when high standards of palliative care prevailed, high quality of life evaluations were recorded.

In 1996, Meredith et al conducted interviews with 250 cancer patients in order to assess their needs about information concerning their own illness. This study is of particular interest to the present researcher as it was carried out at two hospitals in the west of Scotland. Results indicated that more than 90% of respondents wanted as much information as possible about their illness, chance of cure and side effects and 60% of these patients wanted this information to be given to them by the hospital specialist. The study stressed that findings such as these would place a good

deal of stress and commitment on hospital doctors who would prefer to delegate such tasks to specialist nurses and counsellors. The study found that doctors had only limited time with each patient and communication often has a lower priority than medical treatment. In addition the researchers found that a substantial minority of doctors tended to avoid using the word “cancer”, preferring to deploy euphemisms such as “tumour”, “growth” or “cyst”. This well intentioned omission was due to the fact that patients may be so shocked, they may enter a state of depression which would inevitably impair their quality of life throughout the length of their illness. However the researchers concluded their study by highlighting that the opposite may be true. Protecting patients from the truth may be counterproductive in that lack of information might produce anxiety, dissatisfaction and uncertainty and ultimately potential psychological distress.

An important point to note is that, if information is concealed from patients – however well intentioned, it deprives individuals from making authentic decisions about their choice of coping strategy. For example, if patients think they have a cyst rather than a cancerous tumour, they may consider their illness to be curable. Irrespective of how painful their condition, or the deterioration of fellow patients with similar symptoms, they may stubbornly persist in a false perception of recovery thus denying themselves an opportunity of preparing for death with integrity.

More recent research in England on the same subject by Fallowfield & Jenkins (2002) reported that well meaning attempts to disguise the truth from patients was still considered justifiable because of the traditional view that patients did not wish to be told the truth if prognosis was bad. This is difficult to comprehend especially following publication of the Bruera et al (2000) report which recorded that 100% of physicians who participated in the postal survey wished to be told the truth about their own terminal illness. Fallowfield & Jenkins presented two possible explanations for the perpetuating of this unacceptable policy. Firstly, some doctors lack the ability to tailor their communicative skills to suit the comprehension levels of individual patients. Consequently, although unintentional on the part of the doctor, language, terminology and facial expressions can all be misinterpreted by patients. Secondly, the authors proposed that other doctors actively promote misguided evasion or frank dishonesty because they,

“expect people with incurable disease to be psychologically distressed and lack the communicative skills to determine how patients are coping” (p. 302).

Assessing the psychological state and coping abilities of patients may add yet another burden to the physician's busy schedule. However, it must be more acceptable than deliberate misrepresentation in order to maintain a conspiracy of silence on the part of health-care staff, family and visitors. As Fallowfield et al concluded, misleading and confusing information only serves to,

"add considerably to a patient's distress and prolong the necessary adjustment process" (p. 301)

From a psychological perspective, serious chronic and terminal illnesses generate feelings of anxiety and depression in most individuals. Faced with life-threatening illness, many patients, although initially engulfed in an aura of depression, may eventually employ their inner resources to the task of coping with the stressful situation. However, as was pointed out in the previous two research studies, realistic decisions about coping can only be made if patients are truthfully informed. Thus for some, the anxiety and lack of control connected with non-curative illness will produce a strategy of denial precisely because there is no problem solving solution to death. Regulation of emotion often includes an element of avoidance or escapist behaviour as the individual struggles to reduce the tension associated with facing death. Yet, to date no study has indicated that patients die happier if the truth is denied to them. In addition it is logical to deduce that there must come a time when patients realise that recovery is not an option due to fatigue and deterioration but are incapable of altering the status quo. Thus, for patients denied truthful diagnosis, opportunities for closure, reconciliation and forgiveness with family and friends are also denied to them. Given the fact that all patients with life-threatening illness are individuals composed of differing genetic make-up patterns and environmental influences; it is difficult for health care professionals to predict how a patient will cope. Moreover, psychological distress is often overlooked due to time restrictions on health-care staff who are often primarily concerned with physical symptoms. In addition, results of clinical studies in the 1970's and 80's suggested that terminally ill patients, who had been truthfully informed, had to cope with physical, social and psychological stress of not only the serious illness but also impending death. Nevertheless, despite the pros and cons associated with this difficult dilemma, it is imperative that patients are, at least, given the chance to opt for truthful diagnosis and prognosis of their illness as an optional clause within their palliative care policy.

In 1979, Greer, Morris and Pettingale found that women suffering from breast cancer who responded with absolute acceptance or who expressed feelings of hopelessness were likely to die sooner than women who expressed either denial or a fighting spirit. The year previously, Holden

(1978) also found that patients who were more despairing and had fewer social contacts died sooner than individuals who expressed more anger towards the disease and their doctors. However contrary to the Greer, Morris and Pettingale findings, Holden's study found that those who died more quickly tended to use denial and repression as coping mechanisms. In 1979 a study by Derogatis, Abeloff and Melisaratos (again investigating breast cancer) found that those who survived the longest were judged to show more mood disorders and alienation than short-term survivors. Moreover in 1985, Cassileth et al. found that no relationship was recorded between survival time and psychological factors such as hopelessness / helplessness, life satisfaction and social ties. It could be cited as a criticism of such research that survival length may not be paramount to the terminally ill patient's priorities and that concentrating on the element of longevity is not necessarily the best criteria for judging the coping mechanisms employed during the last phase of life.

What is certain however, is that disclosure of a life-threatening illness elicits strong emotional reactions (Lazarus and Folkman 1984c) including fear, anxiety, despair, depression, anger and hostility (Hinton 1979). Literature on the subject expresses the view that during such circumstances, family, health professionals, spiritual directors and clergy interact with patients to facilitate a good or appropriate death. Measures applied to achieve the latter concentrate mainly on the alleviation of pain and physical discomfort, followed to a lesser extent by the easing of psychological anxieties. Schultz (1978) proposed that the latter category usually included interventions designed to preserve dignity and self-worth and to provide love and affection. Ultimately however, the degree of success achieved in coping with terminal illness (and thereby attaining "a good death"), depends on the patient's own mental attitude towards death and the coping strategies adopted in order to have the strength of character to accept or reject truthful prognosis of physical status. This important decision must be made solely by the patient.

When patients with non-curable illness adopt a covert or an overt coping mechanism during the last phase of life, literature suggests that they do not in fact cope alone, even although the patient may often feel as if they are doing so. The terminal patient is surrounded by people within a hospice environment (staff, relatives, visitors). This type of social networking may in fact help or hinder the patient's ability to cope with their illness. However that does not mean that coping is determined by cultural or social contexts. Pargament (1997) stated that,

"The most central of all qualities of coping is possibly; the possibility that the person can rebound from difficult circumstances, that a problem can be anticipated, prevented, solved, that something good can be found in hardship, or that devastating loss can be met with some integrity" (p.86).

Within hospital or hospice care, social networking is not something from which the patient can choose to become isolated. To a certain extent they are a "captured audience" within the medical environment in which they find themselves, and that environment includes a range of interactions with a variety of different people. Interestingly, Monet and Lazarus (1991) highlight several studies whose findings suggest that there are gender differences in the ways that males and females relate to their social networks in times of stress. Fischer (1982) for example found that having children restricted the social involvement of mothers rather than fathers, but that age and ill health however restricted the size of men's networks more than those of women. This is possibly because as Booth (1972) and Miller and Ingham (1976) found, men had more acquaintances (mainly in connection with their work) than women had, but that women acquired more friends than men. In addition, male participation in social networks throughout the life cycle tend to be characterised as more "extensive" but less "intensive" than that of females. Males tend to participate in more activity-focused relationships than females, while females of all ages maintain more emotionally intimate relationships than males. Monet and Lazarus (1991) proposed that,

"Throughout the life cycle, females show a greater propensity to mobilize social supports in times of stress. Females are more likely than males to seek out such support, to receive such support, and to be pleased with the support they receive" (p.263).

These findings may have repercussions within hospital or hospice settings as females may take full advantage of social network support and thus attain comfort in so doing. Males on the other hand invariably refrain from seeking help (other than that of their spouse or partner) because of cultural and social pressures. For men, display of emotional weakness (with the exception of anger) was regarded as a sign of incompetence. These themes are very much incorporated into the work of Busfield (1996), who has contended that differences in cultural attitudes towards men and women often lead to gender stereotyping and that it is precisely these differences in society's attitude that lead to the creation of labels such as "abnormal behaviour". Within her own research, Busfield had noticed that (with the exception of Blacks in America), women were more likely to ask for help and assistance (within clinical settings). Men, on the other hand, who feel themselves in need of guidance or counselling are more likely to remain silent, or turn to alcohol for solace. Busfield also made the interesting point that in psychological tests, such as the M.M.P.I. (Minnesota Multiphasic Personality Inventory), men who displayed feminine values (such as

dependency or empathy) were viewed with some suspicion. Weiss (1995) pointed out that in the men studied, these types of behaviour patterns were extended into the home environment so that signs of emotional turmoil were habitually concealed from their spouse / partner and other family members. Monet and Lazarus (1991) concluded their gender discussion by stating that,

"This review has suggested that there are pervasive gender differences in the ways men and women construct their networks and utilize them in times of stress, and that these differences have consequences for men's and women's well-being" (p.272).

A small qualitative study by Leydon et al (2000) at a London oncology clinic highlighted the fact that men, particularly those over 70 years, tended not to want to seek information about their condition beyond that offered by their doctor. During interviews with these patients, the researchers discovered that older men were brought up in an era that placed trust in their doctor's treatment and medical expertise. Silence rather than open discussion was also preferred which supported the "strength in silence" attitude prominent in the Moynihan (1999) study. In general Leydon et al's study showed that in today's "patient centred" era, some patients adopt a non-participatory role in the management of their illness. Often this was brought about by the wish to appear to be a "good customer" but in other instances, it was due to fear of the illness and fear of the inability to cope with the full knowledge of the stages of the illness. An important issue highlighted in this study was that patient's preferences for information derived from the coping strategy they had adopted to manage their illness. Criticism of the findings could be centred on the small population of the study (17 patients) and its interviewing design, which may have skewed the data towards patients who found it easier to talk about themselves. However the researchers asserted that,

"The similarities between some of our core themes and those found in other studies permits confidence in the validity of our data and analysis of the data" (p.911).

According to Pargament (1997), the assumption that responses to crises are not fully determined, but only partially chosen, moreover sets coping apart from defense mechanisms. (However research conducted by Pargament 1997, also led him to the conclusion that the concept of coping embodies a greater appreciation of the capacity for proactive decision making and conscious awareness in stressful situations than for example the concept of defense).

Reviewing the literature dealing with responses of adults to crisis, Silver and Wortman (1980) found evidence of diverse attitudes and feelings among hospitalised patients which affected their

coping choices when dealing with the ongoing crisis. For example, some patients complain and moan, others cry a lot and go into a state of denial, some seem distant and sad while others appear comfortable and unconcerned. It could be argued yet again that these attitudes and feelings are coping mechanisms employed by the individual with life-threatening illnesses. Interestingly, ten years previously, Kubler-Ross (1970) published her now classic book introducing “stages of dying” and “stages of grief” which have since become generally accepted and often quoted in respect to terminal illness. According to these models, the dying person goes through five progression stages, - denial, anger, bargaining, depression, and acceptance. While some critics argue that the stages are too rigid, they are interesting to this present research as they could be presented as representing five progressive coping strategy stages. A study by Achte and Vauhkonen (1971) compared a group of terminally ill cancer patients with non-terminally ill cancer patients. Results revealed that the higher frequency of depression in the terminally ill patients determined the greatest difference between the two groups although anxiety and tension were also common among non-terminal patients. These findings generally concur with those of Kubler-Ross. They also however, identified a subgroup of patients whose illness terminated quickly. The latter openly displayed aggression and most closely resembled Kubler Ross’ patients in the denial and anger stages. For a variety of reasons, their deaths had occurred before they had been able to pass into the later stages of bargaining, depression and acceptance. The work of Kubler-Ross has nevertheless been criticised, notably by Shneidman (1973), Schulz and Aderman (1974), and Kastenbaum (1977) on the grounds of its ambiguity, sampling, investigator bias and the confounding of physical symptoms with psychological responses.

From the 1970’s onwards, social psychologists have investigated strategies adopted by victims of severe accidents and patients who have been diagnosed as having cancer and into how they react to their illness and develop at least a degree of control within the stressful situation. (Bulman and Wortman, 1977; Lichtman, and Wood, 1985, Taylor 1983, Taylor et al, 1984; Gotay, 1985 and Maton, 1989). A general finding has been that many patients in such circumstances are not only involved in questions of attribution, but also in searching for a new purpose. Gotay (1985) found that patients in an early stage of illness use different kinds of attribution than patients in an advanced state. Within the latter stage, religious attribution (e.g. God’s will) was more frequently mentioned. Interestingly, in the Taylor et al 1984 study, cognitive control seemed to be more strongly associated with adjustment than behaviour control or any other type of control or strategy. As Frankl (1963) had proposed, when it is not possible to withdraw from a stress arousing situation, conscious reflection upon a search for ultimate meaning and values may be



necessary to prevent an outbreak of an enduring crisis of meaning. A diagnosis of terminal illness causes cessation and interruption of normal life patterns, thereby weakening the individual's idea of personal identity. The tasks of re-evaluation, re-orientation and coping with the last phase of life, becomes important to an individual's sense of control and ultimately to their achievement of a good death. Van der Lans (1996) proposed,

"At this level, a religious or philosophical symbolic system may help to solve this kind of meaning-problem. The importance of such a system of symbolic ideas is of course not that it takes away the pain, but can make it bearable by giving it meaning. In cultural-anthropological studies, we find a lot of examples of the use of religious symbols and myths as successful therapeutic strategies for people who undergo a transitional crisis" (p.101).

It is interesting to reflect once again upon Kubler-Ross's (1970) proposed five stages of coping attributed to death and dying (denial, anger, bargaining, depression and acceptance). If these are accepted as typical in most cases, then it follows that social networking is of importance within the first four stages only, since during the last phase of "acceptance", the patient no longer needs the help, support and guidance of a variety of people. By this stage, according to Kubler-Ross, the patient will have,

".. been given some help in working through the previously described stages. He will reach a stage during which he is neither depressed nor angry about his fate. He will have been able to express his previous feelings, his envy for the living and the healthy, and his anger at those who do not have to face their end so soon. He will have mourned the impending loss of so many meaningful people and places and he will contemplate his coming to an end with a certain degree of quiet expectation" (p.99).

Kubler-Ross (1970), describes that in this final stage of acceptance, there is no longer the need for intense social relationships. The patient enters a state of peace and detachment from the world, including family, friends and carers. Kubler- Ross continues,

"How could he ever be ready to die if he (the patient) continued to hold onto the meaningful relationships of which a man has so many? When the patient asks to be visited only by a few more friends, then by his children and finally only by his wife, it should be understood that that is the way of separating himself gradually" (p.150).

Later research however questioned this assertion of social disengagement during the last weeks of terminal illness. Baugher et al. (1985) examined the responses of 1,100 terminally ill cancer patients ranging from 20 to 91 years. Both cross-sectional and longitudinal data were collected so as to assess whether or not the process of disengaging occurred. Four areas were examined. These were social concerns, self-concern, focus on "the beyond" and mood states. Results of the study were generally non-supportive of disengagement. The researchers were careful to point to some confounding factors which may have given rise to criticism of the investigation. For example,

only terminally ill cancer patients were studied; the largest majority of the patients did not lack a primary care person and perhaps most critically, for over half of the patients, the primary care person responded instead of the patient with life-threatening illness.

In an earlier study by Greer and Mor (1983) a large-scale study of 1,745 participants were asked, two to eight weeks prior to their deaths, what they considered to be important. Most important to these terminally ill patients at this stage, was having certain people present as sources of support, followed by the strength they obtained from their religious conviction. When asked what they wanted during the last three days of life, the most common responses were having certain people present, being physically able to do things and feeling at peace. Again contrary to Kubler-Ross's earlier research, these patients tended to vacillate between feelings of fear and calm and hopelessness and contentment rather than going from a depressed state to one of acceptance as death approached. Although the Greer and Mor investigation highlighted interesting results, it must be pointed out that they were a fairly selective group of terminally ill cancer patients, educated and articulate and willing to openly discuss their imminent death. These patients were also mostly white, fairly young (mid-sixties) and as in the Baugher et al. (1985) study, generally had a primary or spouse caregiver. Being of significance to the present study, it must also be pointed out that studies such as these (Greer and Mos, and Baugher et al) provide testament to the fact that some individuals choose to cope with dying, by thinking about it and by discussing it openly. However much depends on the disclosure policy operating within care institutions. As was mentioned on p.24, it is not uncommon (in the west of Scotland for example) for hospitals health practitioners to speak to patients in euphemistic terms about their illness.

Kubler-Ross's stages of grief and dying have been fairly widely accepted and although formulated in the 1970's they are still relevant today, at least in their psychological content. What has changed in the last 30 years however, is society's cultural and social values and norms. For example marriage is now only one of a number of family category groupings and as such, there may no longer exist close-knit traditional members to comfort the dying. But for all relatives and friends of patients with non-curative illness, experiencing the last phase of life of a loved one can be extremely harrowing. Studies have shown that relatives also go through stages of grief, generally referred to as anticipatory grief (Welch, 1982, & Sweeting and Gilhooly, 1991/92). Often family members who have cared for sick relative express feelings of guilt about their abilities as carers (Welch 1982) and others express regret for what might have been (Sweeting and Gilhooly). To many older patients, the past is very much in the forefront of their present

perceptions. This is often a source of grief to relatives as it brings home to them the fact that the person with whom they shared so many past experiences will not exist in their future (Gordon, 1994). There is a Heideggerian (1962) view however, which states that time should not be regarded as a linear succession of “nows”, but as a continuous process where the present is both constituted by its links to the past and the influence it will have on making the future.

In an American study by Koenig, Pargament, and Neilson (1998), 600 severely ill hospital patients aged 55 years or over were studied with measures of 47 ways of coping. Some coping measures included religious faith, while others did not. This newer study again confirmed Koenig’s (1994) earlier findings that patients with a strong religious faith, were less depressed and rated their quality of life as higher, despite taking into account the severity of their medical situation. These patients were almost always supported by visits from family, clergy and church members which invariably has the effect of generating high self esteem and co-operation which in turn may even prolong life itself. The researchers also conducted a survey among hospital doctors designed to determine whether they considered religious faith to be an element in the coping strategies of their seriously ill or terminally ill patients. The survey revealed only a 9% measurement in this direction. Within this research, coping strategies that excluded religious beliefs or rituals such as prayer were linked to greater depression and poorer quality of life. The researchers recommended that health care workers dealing with seriously ill patients should make a point of asking them what helps them cope. This information, they then proposed, should be passed on to counsellors or pastoral care workers. Results such as these promote very high ideals. As in every area of investigation however, individuals conducting “hands-on” management and care of subjects under scrutiny may be unable to succeed in all or indeed any of the tasks recommended by researchers. The research study may also not have differentiated between individuals whose religious faith remained constant throughout their lives and those who chose to embrace religion / spirituality as a means of coming to terms with their death.

One of the strongest Christian beliefs is “life after death”. In 1989, a study undertaken by Robins assessed that there were three types of attitude within the general population of the United Kingdom towards the question, “Is there life after death?” namely,

1. “A firm belief in an after-life among those who practice a particular religious faith with a full acceptance of all its tenets. The exact nature of this after-life is recognised by many to be unclear.

2. An open-mind on the subject, not ruling out the possibility but with no definite conviction. Some people in this group may be nominally Christian and in facing their own death when the time comes may seek help in sorting out their own attitudes. Others remain agnostic till the end.
3. Those who are quite clear that for them death is the absolute end of human existence, except for the memories that people leave behind of themselves" (p.10).

She conceded however that the above attitudes may very well change during the last days or months of a person's life, but that,

"Religion has provided a visible framework of support and guidance to human beings in their endeavour to lead a good life and prepare for a life after death.....This rests on a belief in the immortality of the human spirit and the existence of a higher power, namely the deity, or sometimes more than one deity" (p. 65).

In previous centuries, the question of whether there is life after death would not have arisen. Written and oral traditions from every part of the world have almost always reinforced the belief in a spiritual life after death (even although the exact nature of that existence varied from one religion to the other). In recent years, archaeologists have provided material evidence that the dead were provided with articles of everyday living to sustain them on their journey to the next life. Articles found within the Pyramids of Egypt and in the tombs and graves of the Pyramid builders provided proof of a belief in an afterlife – (this being only one example of many which occurred throughout the history of ancient civilisations).

European history, with its Christian roots as a major influence, has consistently shown a belief in immortality and eternal life. The decline in religious belief from the nineteenth century onwards however has produced major changes in attitude to questions such as eternal spiritual life. An interesting recent publication dealing with this topic, (Secularisation in Western Europe, 1848-1914 by Hugh McLeod, 2000) chronicles the decline in religious practice, attitudes and beliefs, brought about mainly by political change (revolutions) and educational reform (e.g. Education Act, 1870) in the 19<sup>th</sup> century. The modern entertainment industry (including sport) of the 20<sup>th</sup>/21<sup>st</sup> century has almost entirely supplanted leisure facilities formerly provided by the churches. According to McLeod (2000),

"The thesis holds that the dwindling social significance of religion is an inevitable consequence of the process of social development in modern societies.....professional specialists take over more and more of the roles previously performed by the clergy. Science replaces theology as the principal source of authoritative knowledge. Growing pluralism leads to a sophisticated relativism, in terms of which the moral absolutes prescribed by the various religions lose their binding force" (p.3).

Nevertheless, McLeod also points out that there are critics of this linear trend of religious decline, most notably Cholvy (1991), who stressed that there had always been cyclical patterns of decline and renewal throughout Western Europe during the past 200 hundred years. On these occasions, religion had not in fact declined, but rather its nature had been changed during these processes. Cholvy expressed the opinion that following the religious “drought” of the “neo-positivist” 1960’s, there has been a religious revival since 1975 (all be it in mainly, though not entirely, among new religions).

Other literature, (for example “The Human Person in Science and Theology” - Gregersen, Drees and Gorman, 2000) discuss the nature of “personhood” as an issue of central importance for both science and theology. Concepts such as “self” and “person” are inevitably connected to the individual’s mind, brain and consciousness. Social psychologists such as Harre (1986) have emphasised that emotions (so much a part of “the self”) could not be viewed without the inclusion of the moral and spiritual dimension. One of the contributors to the book (Watts 2000) discussed the significance of emotional human functioning towards religious experience, stressing that the human brain is involved in religious experience, as it is in experience of every kind. Pointing to D’Aquili and Newberg’s (1998) theory of certain “cognitive operators” having a particular role in religious experience, Watts described it as promising because,

“..it doesn't postulate some completely separate neural basis of religious experience....it doesn't link religious experience to malfunctioning of the brain and it is not necessarily reductionist” (p.45).

Watts (2000) together with some of the other contributors to the publication pointed to neural processes being involved in religious / spiritual experiences while at the same time acknowledging that this type of experience must involve more than the sole functioning of particular neural processes.

The publication must be of interest to any investigation between coping strategies and spirituality as there is now strong implication of neurological functioning involved with issues of spirituality and religious concerns. The latter may be a possible explanation why most researchers dealing with patients with non-curable illness refer to the high percentage who, as end of life approaches, become engrossed in questions of meaning and purpose to life. According to Doyle (1994),

“They ask them (existential questions) when they are ill and their lives are under threat and possibly likely to come to a premature end, with ambitions unfulfilled, relationships strained, differences not resolved, and hopes dashed. In fact, more than 75% of dying people speak of them, given the opportunity” (p.95).

Doyle (1994) questioned whether terminally ill patients are given adequate chance to discuss their social and spiritual concerns. He proposed that as the end of life approaches, patients discover things about themselves that they had never previously realised. They gain insights into their own personality and character which may disturb them. Even their former philosophy, faith or religion may seem inadequate in the face of imminent death. As bodily health fails and pain or discomfort causes less and less mobility, the patient finds more and more of their lucid moments taken up by contemplation which often results in depression and anxiety. By recognising that there is a spiritual dimension within each individual, Doyle urged medical practitioners to help their depressed, lonely or anxious patients whether or not these issues are ever articulated. He proposed that palliative-care practitioners can,

“..train ourselves to recognize spiritual problems in the same way every family doctor or community nurse aims to recognize pain or fear without the patient mentioning them. If not articulated they may present as defeatism ...depression without most of the usual clinical features of a depressive state (particularly hopelessness).....physical symptoms not responding as expected....We must simply be aware of this dimension of life and be as ready to become involved as we would with pain, anxiety or social issues” (p.97/98).

In a recent study in Sheffield, England, Wright (2002) used a phenomenological approach, in order to discover the spiritual essence of palliative care using 16 participants who held a variety of roles linked to the care of the terminally ill. Using semi-structured interviews, Wright was able to compile lists of significant statements in which interviewees described their own experiences of “spiritual care-giving”. Following data analysis, Wright was able to conclude that,

“....the fact that all interviewees were spiritually aware is significant – confirming the view that it appears advantageous for personnel entering the spiritual domain of others to have first addressed the issue of their own spirituality” (p.131).

This particular study could be criticised on its small sample number of participants who, although recording an obvious understanding of the diverse aspects of spirituality, could not be held representative of the majority of health-care staff within palliative care units. In addition some of these 16 “stakeholders” (p.126) did not have daily contact with palliative care patients. As contact with patients is encountered predominantly by nurses and doctors, the question of training in spiritual awareness must therefore arise. Who will make such decisions and will opinions of health-care workers be represented before implementation? The terminology concerning spirituality could also be criticised in so far as it is a concept which seems to have gained a degree of political correctness far outweighing that of religiosity. Nevertheless it is a term which encompasses many concepts which by their very diversity may produce confusion in those who

may be asked to implement aspects of it into health-care policy. The issue of whether staff or patients regarded spirituality as an opportunity or burden was raised by Walter (2002), when he identified a need for “differentiating” between patients rather than assuming that everyone wanted or needed, “a universal search for meaning” (p.133). Walter raised concerns about “spirituality” overtaking “religiosity” as the preferred terminology in western, mainly English speaking societies which seem to “distrust institutional authority” (p.135). In recent times, these societies have adopted the ideology of individualism which according to Walter, create opinions such as,

“I will believe whatever seems right to me, not what the church or any other authority tells me”. (p.135).

He questions therefore, whether every patient can be accompanied on a spiritual journey by every staff member since an ideology of individualism negates a common end purpose to existence. If every patient is treated as an individual (one of the precepts of palliative care) then it may have to be accepted that some patients may never need spiritual accompaniment and that some staff may never be able to provide it when it is needed. In view of these more recent findings, it would seem appropriate to advocate the use of validated questionnaires on patient’s arrival at a palliative care unit. Patients could be screened for depression / anxiety and for attitudes towards religion and spirituality. Similar tests could also apply to staff. By so doing, documented evidence of similarity of attitude would exist which would provide a basis for pairing staff members with patients when both groups wished to participate in a shared journey of experience.

Published data in 1994 suggested that depression was present in up to 25% of terminally ill patients compared with a prevalence in the general population of around 5% (Chochinov, Wilson and Enns). The Hospital Anxiety and Depression Scale (HADS) has been widely used as a screening instrument for anxiety and depression and found to be an effective screening instrument for depression and anxiety in palliative care (Le Fevre, Devereux and Smith 1999). In 2000, Holtom and Barraclough explored the impact of using the HADS in the setting of a palliative care unit (Reading, England), on depression recognition and treatment. Retrospective case-note reviews of 100 consecutive patients admitted to this unit had suggested that depression was frequently unrecognised, with only 15% of patients receiving antidepressants. Holtom and Barraclough proposed that the HADS appeared to be acceptable to the patients and that as well as yielding a numerical score, it often acted as a catalyst to facilitate the discussion of psychological topics. They recommended that the administrator of the HADS should have the time and the skills to deal with the psychological and emotional issues likely to be generated by its use. They

proposed that regular HADS screening on first referral to palliative care would probably enable earlier detection and treatment of depressed and anxious patients. Drugs such as Tricyclic antidepressants and Flupenthixol were also recommended. Results such as these are interesting and significant to the present research topic as they identify the presence of depression and anxiety in patients with non-curable illness together with the frequent lack of adequate counselling or psychological assessment.

The increasing use of the term “spirituality”, prevalent within the more recent research studies mentioned above, gained momentum during the 1970’s and 80’s by researchers such as Reed (1986b). Citing spirituality as one characteristic particularly salient during the dying phase Reed postulated that it must be taken into consideration in any study investigating the terminally ill. Other studies of the time also concluded that spirituality variables were related to low death fear, low discomfort, decreased loneliness, emotional adjustments and positive death perspectives among terminal cancer and other seriously ill patients (Gibbs and Achterberg-Lawis 1978; Miller 1985; and O’Brien 1982a). Using spirituality as a coping strategy not only helped individuals to cope with the day to day management of their stressful situation, but also generated a sense of personal well-being (Reed, 1987; Moberg, 1982; and Gibbs and Achterberg-Lawis, 1978).

Results of studies such as these, provided support for regarding spirituality as potentially significant in the dying process. Findings within the Reed (1987) study for example, recorded that patients with life-threatening illnesses indicated a significantly greater degree of spirituality than did a matched group of healthy adults who did not perceive the end of their life span to be near. Significantly higher levels of spiritual well-being were also found in a chronically ill group than were found in a healthy group in a study by Miller (1985). These results are significant in demonstrating a need for hospital and hospice chaplains and for a need to investigate whether health care workers would be willing to discuss matters of spirituality with their patients. Criticism however, would have to be levied at the small relationships recorded between spirituality and the terminally ill and whether they were justifiably defined as significant. In addition interpretation of results was limited in the Miller (1985) study as there was lack of control between age and gender. The age variable was particularly relevant within these studies as younger terminally ill patients had lower well-being scores than older patients. This however is consistent with Neugarten’s (1979) “timing of events theory” in that as dying is more usual among older members of the population, it follows that the latter would accept it better than younger members. Criticism could also be directed at the definition of the word “spirituality”



since it is not as clearly defined as religious belief. Also, the fact that spiritual well-being scores were recorded as “higher” in terminally ill people than in non-terminally ill patients, may not necessarily be interpreted by everyone as indicative of a need for spiritual counselling, or of a belief in spirituality itself.

Later research studies conducted by Koenig and colleagues (1992,1994,1998) included the variables of loneliness and depression within their test measurements. Results indicated that religious faith (as significant from spirituality) provided solace to the dying person, fortified in the belief that death was not the end, thus lessening greatly the conditions of depression and loneliness, so prevalent among the terminally ill. When combined with the physical torments of pain (visceral, bone, muscle, nerve), nausea, immobility, pressure sores etc., it became increasingly obvious that mentally adopting the most appropriate coping strategy could be a decision of the utmost importance to the dying individual. Indeed it is one of the few decisions which the patient is capable of choosing on their own, without consultation to medical practitioners although it is often an unconscious one. Resulting from these studies, it is interesting to speculate whether drug free contemplation (i.e. religious belief / spirituality) is preferable and kinder to the overall well-fare of the physical body than altering the state of an individual’s mind by drug inducement. The latter could also interfere with any clear decision making about coping strategies. According to Hughes and Keown (1995), Western bioethics have become increasingly troubled by,

“ .....questions about the autonomy, continuity and authenticity of the self. Do anti-depressants create an inauthentic self, or is the self more authentic when it is cheerful? Is one respecting a patient’s autonomy by respecting the treatment preferences they expressed when healthy, or those they express in the throes of illness? Is it ever possible for a patient to give truly free and informed consent to treatment? (p.2).

As Kubler-Ross (1982) theorised,

“If we could internalize our own fears and share our own unfinished business, we would not have to resort to prescribing Valium, which really does not sedate the survivor but sedates, unfortunately, our own conscience” (p.181).

The issue of a shift in terminology from religiosity to spirituality in recent times is perhaps a result of recorded suspicions concerning the subject. Many psychologists have been critical of the dependency aspects and reality issues of religion (notably Ellis 1971, and Dittes 1969), although one of the best known critics, Freud (1927) was not totally damning in his evaluation of an individual’s belief system - from a psychological perspective. According to Pargament (1997),

"Freud (1927/1961), maintained that people turn to religion, albeit unconsciously, out of a sense of helplessness"; that religious beliefs and practices, "provide some respite from tension and anxiety.....The outpouring of emotion at a religious gathering, the repetition of behavior in the religious ritual, and the explanation of the workings of the universe within religious dogma all serve to cushion the individual from life's pain and uncertainty" (p.49).

In this sense, Pargament (1997) is proposing that Freud accorded a limited value to religion. But as is well known, Freud felt religion was ultimately a childish solution to the problems of living; preferring that people face their state of helplessness head on, within the reality of the present world. But with regard to terminal illness, many patients find difficulty in coming to terms with the finality of death let alone coping with the process of dying. Some may use their faith as a buffer against the fear of this unknown journey, whereas others may have difficulty in accepting suffering or illness as part of God's plan for them, particularly those who adhered to religious dogma during their lifetime.

Dittes (1969) portrayed empirical research as associating religion with personality deficiencies such as a weak or constricted ego. He pointed out that psychological research reflected the,

"overwhelming consensus that religion (at least as measured in the research, usually institutional affiliations or adherence to conservative traditional doctrines) is associated with awareness of personal inadequacies, either general or in response to particular crisis or threat situations; with objective evidence of inadequacy, such as low intelligence; with a strong responsiveness to the suggestions of other people or other external influences; and with an array of what may be called desperate and generally unadaptive defensive maneuvers" (p.636).

Dittes (1969) further proposed that the general consensus of the time concluded that there may be particular differences among those individuals possessing weak egos in that there often occurs a curtailment of the usual patterns of perception. This in turn affects judgement and behaviour control. Furthermore, as religious ritual has been ascribed by some as being similar to hypnosis (Lang and Lang 1960) an atmosphere is produced whereby certain individuals become particularly responsive to the norms and suggestions of the immediate social group. As a consequence, some are caught up in unusual religious experiences such as hallucination and glossolalia. An obvious criticism of this assumption is that few religious adherents ever experience these occurrences and indeed Dittes acknowledged that most religious commitments were the result of processes of socialisation and free choice. Nevertheless they were, he proposed,

"...held under circumstances providing high likelihood of encountering contradictory data and beliefs, and hence, high dissonance. Many processes of ritual, group formation, and cognitive elaboration may be interpreted as prime instances of dissonance reduction" (p.603).

The tremendous expansion of scientific knowledge since the Renaissance to the present era has given rise to much criticism of religious beliefs and doctrines. As Hick (1983) pointed out, the more science has advanced, the more theological thinking has retreated, almost to the point where,

“Religion is seen as a losing cause, destined to be ousted from more and more areas of human knowledge until at last it arrives at a status akin to that of astrology”(p.37).

Nevertheless, scientific advance has not succeeded in disproving the existence of God and indeed as Hick (1983) argued, even although science proceeds as if no God exists, the latter is no validation of that presumption. Indeed Hick propounds his own theory that belief in God and Biblical / religious teachings cannot be restricted to the literal interpretations of pre-scientific writings and cultural beliefs. Referring to theological concepts of autonomy, Hick argued that humankind has free will to decide whether a relationship with God is a rational or irrational act given the fundamental concepts contained within Scripture and Biblical writings. He proposed that God created the universe,

“...(insofar as its creation relates to humanity), as a neutral space.....God maintains a certain distance from us, a certain margin for creaturely independence, which although always relative and conditioned, is nevertheless adequate for our existence as responsible personal beings”(p.38).

Similarly, Gale (1998) expounded a very novel argument for the existence of God (and evil) in his paper read at an international conference for the Philosophy of Religion in Munich (1998). Proposing that God may not be the “super-deluxe” model of traditional Western theism, Gale mounts an interesting theory of a God who may be worthy of adoration, love, worship and obedience, while nonetheless, not necessarily possessing,

“the divine perfections of omnipotence, omniscience and omnibenevolence” (p84).

Many physicians and psychiatrists have also been critical and even contemptuous of religious belief citing it as causing more harm than good; often promoting guilt, blame and even the belief that illness is a punishment from God for past sins. In her book, “Illness as Metaphor”, Sontag (1977) described illness as “the night side of life”(p.4). The interpretation of illness as God’s punishment for sins has had a very long history within the Judeo-Christian tradition. Stemming from accounts, particularly within the Old Testament, of God’s wrath upon sinfulness, Sontag points out that throughout history, disease has frequently been taken as a metaphor; that it has often been represented as supernatural punishment or demonic possession. Attitudes within

society towards the devastating Bubonic plague in the fourteenth century throughout Europe could be compared to reactions in the present century, with regard to the AIDS virus. Many religious fundamentalists adhere to the belief that God intervenes and administers punishment to earthly sinners even although this train of thought is in opposition to the texts of the New Testament. There is unfortunately a historical tradition within the Christian churches of a strong association between health and righteousness. The human body has been described as a temple, which remains intact as long as the individual lives in a manner appropriate to their religious beliefs. For religious adherents, having a life-threatening illness may produce such feelings of intense guilt or anxiety that they enter into a state of denial towards their medical condition, which renders them incapable of conducting appropriate acts of closure or reconciliation with family and friends.

In recent research, illness has been viewed as an “obstacle” which may be helped through “intercessory prayer”. Studies have been published citing examples of greater recovery from surgery among patients who reported receiving strength and comfort from their religious convictions (Oxman, Freeman, and Manheimer, 1995). In other studies religious belief is cited as promoting physical health. Based on their review of relevant literature, Hill, Butler and Eric (1995) suggested five factors that promoted better health, i.e., lifestyle choices, social support, hope, comfort and the positive effects of prayer. To the religious individual, old superstitions arising from previously mentioned traditions of linking illness with divine punishment could dramatically increase stress levels, thus increasing the likelihood of depression and the necessity of receiving counselling or psychotherapy. Depression is a common symptom in individuals with serious or terminal illness (Cohen and Mount, 1995) although its strength of severity may be mitigated by factors, such as the individual’s religiosity or personality traits.

In 2000, Maltby and Day published a study designed to examine the relationship between religious orientation and depressive symptoms among cognitive, personality and social correlates of depression. Results showed that depressive symptoms were significantly associated with higher scores on the measures of extrinsic-social and extrinsic personal religious orientation, neuroticism, attribution style and wish and avoidance coping. Lower scores were recorded on the measures of intrinsic religious orientation, optimism, self-esteem and problem-focussed and support seeking coping. This study indicated that in times of severe stress, the intrinsically orientated religious individual used their religious beliefs as a “problem-focused” coping strategy, which in turn alleviated depression levels. However, in the same year (2000), Maltby et al also

presented another study which examined the relationship between religious orientation and schizotypal traits. The results suggested that among men, an intrinsic orientation towards religion accounted for unique variance in borderline personality. Among woman, an intrinsic social orientation towards religion accounted for unique variance in borderline personality and Paranoid and Suspiciousness aspects of the schizotypy personality. The authors stated that these findings demonstrated partial support for the suggestion that religiosity is related to schizotypal personality traits. However they stressed that this relationship was gender specific and applicable only to particular aspects of religiosity and schizotypal personality traits and was of a limited strength.

For each patient with non-curable illness, life is coming to an end and he / she must find a way of dealing with the consequences of that fact. This involves not only coping with the physical symptoms that accompany serious ill health but also the psychological stress of dealing with a subject which for the most part individuals are unaware during healthier times of life. Both Freud (1927) and Heidegger (1927) discussed the theme of denial of death within everyday existence. Most individuals confine it to the outer reaches of their mind as if it were an unbearable secret, which is too intolerable to contemplate. Freud extended this view as a consequence of humankind's inability to accept death as the end of all existence. In other words, humans are basically narcissistic, refusing to accept the fact that their vitality and intellectual prowess could cease to exist at the time of physical death. Consequently a fantasy of immortality exists within the human species although according to Lifton, 1973 this is not in itself pathological but in fact contributes to a healthy lifestyle, producing creative abilities and helping to dispel anxieties and fears associated with conscious thoughts of death and possible annihilation. For some, death is a longed for state, releasing them from the burdens of an unhappy way of life. For the non-religious person death signifies the end of their existence and their personal contribution to a secular society. For the religious adherent, it represents entrance into eternal happiness and a perfect state of spiritual existence. For the spiritual person, death represents an intriguing event, which may or may not result in the realisation of something "greater than themselves" (Tillich, 1952).

Interestingly, Grzymala-Moszczyńska and Beit-Hallahmi (1996) propose that in reviewing the small amount of clinical studies carried out to date on the subject of death,

"The most important difference between normal and pathological groups is that psychologically disturbed subjects emphasize one or other particular meaning of death by separating it from the plurality of possible meanings.....What is striking in the clinical and psychodynamic research literature on the psychological

meaning of death is the great thematic variety of death representations, not only in children but also in adult subjects and not only in psychologically disturbed subjects but also in the so-called normal groups. One has to conclude that, in normal adult life, death is psychologically present probably in more than one way in the same individual. An adult assumes the rational idea (knowledge) of death as the irrevocable end of physical existence. This idea when made conscious is loaded most of all with anxiety or fear. And it can be called normal for one to try to cope with this anxiety by means of the mechanism of repression or denial. Clinical studies have proven however that the death representation is not one-dimensionally negative and that it is not always loaded with anxiety. Finally it is curious that none of the reviewed clinical studies report the subjects making a spontaneous appeal to religion as part of their coping strategy towards death" (p.63).

These may be legitimate findings from the specific studies involved, however the researchers themselves stated that the total amount of investigated studies were small and in addition, results such as these are contrary to other findings dealing with similar subjects.

With regard to conscious levels of religious attitude towards death and dying, Grzymala-Moszczyńska and Beit-Hallahmi (1996) proposed that when a religious faith promotes blind obedience to solutions concerning "complicated questions of existence" (p.50), it may also promote unrealistic thinking and an immature personality which can lead to mental health problems. It is interesting to record that throughout history noted religious mystics have had the same criticism levied against them. For example Jeanne d'Arc was regarded as a paranoid schizophrenic, St. Teresa as a hysteric and St. Paul as an epileptic. Freud (1907) also stated that religious rituals could lead to what has today become known as "obsessive compulsive disorder"-

"It could be ventured to understand obsessive compulsive neurosis as the pathological counterpart to religious development, to define neurosis as an individual religiosity; to define religion as a universal compulsion neurosis" (p.21).

Many viewpoints have been expressed throughout history as to whether religious belief and ritual are beneficial or otherwise to self-esteem, autonomy, personal well-being and mental health. It is now generally recognised and agreed that for some individuals, religious practices and beliefs can be beneficial whereas for others, the same practices and beliefs would be harmful. Empirical research has shown that with regard to mental health, religion can be a haven, a hazard, a therapy or an expression or suppression of mental pathology (Spilka, Hood and Gorsuch 1985). According to the latter, religion can,

1. Cure the pathological by working as a therapeuticum;
2. Repress the pathological by suppressing potential deviant behaviour by religious socialisation;
3. Hide the pathological when religion becomes a haven;
4. Express the pathological in religious form.
5. Cause the pathological when it is the cause of mental anxiety", (cited in Grzymala-Moszczyńska & Beit-Hallahmi, 1996 p.37).

Paloutzian and Kirkpatrick (1995) expressed similar views when they purported that,

“Religious beliefs and institutions can foster prejudice or inhibit it; enhance family cohesiveness or destroy it; encourage sympathy and support for disease victims or vilify them; promote productive coping or suppress it; and/or provide a life perspective of hope and optimism, or of fear and resentment” (p.9).

Results such as these raise the critical question of cause and effect. Does a mentally healthy person develop and cultivate what Allport and Ross (1967) described as an intrinsic religiosity or does intrinsic religion cause mental health problems? In common with many experiences in life, outcomes of personal choice, and the subsequent consequences to an individual, are shaped by their cultural background, personality traits and inherited tendencies. Ultimately however research and empirical study into religion and spirituality can but record observed tendencies and results as they affect an individual in a specific situation. Investigative study can in no way scientifically prove or disprove the truth concerning, for example, the existence of God and the notion of eternal spiritual existence after death. Mitchell (1973) encapsulates this reasoning when he states that,

“Religion is not capable of rational assessment in any straightforward sense. The individual has ultimately to make an existential choice, unsupported by reason, for or against religious belief. It is indeed possible to make a rational case for and against a system of religious belief, but it is a case which relies on a set of interrelated arguments, which do not conform to the ordinary pattern of deductive or inductive reasoning”. (p.34).

In 1988, Pargament et al attempted to measure three types of religious coping, which they proposed gave the individual responsibility and control. He defined the three coping strategies as,

1. “The self-directing approach, wherein people rely on themselves in coping rather than God”.
2. “The deferring approach, in which the responsibility for coping is passively deferred to God”.
3. “The collaborative approach, in which the individual and God are both active partners in coping” (p.180).

Pargament et al proposed that,

“The relationship with God may be particularly supportive to the individual faced with the limits of personal control through the knowledge that the deity will be there to make events durable. Further studies are needed to specify the qualities of the individual’s relationship with God of greatest significance to the coping process” (p.103).

Theorists have (for at least two decades) suggested that religion may offer unique contributions when coping with negative events. Spilka, Shaver and Kirkpatrick (1985) proposed that belief in a loving, fair and just God seemed to be predictive of a more positive outcome to negative events, than belief in a punishing God. This belief portrayed a view of existence that was better

integrated into the psychological functioning of the human mind. To present God and the workings of the universe as orderly and fair, offered a possible explanation to seemingly unanswerable questions and as such offered the religious individual within negative situations, a source of meaning to both existence and death. In contrast, belief in an unfair, vengeful God tended to create within the religious person, a sense of loss of control in their lives consequently leading to a personal sense of loss of self-esteem.

In summarising their 1995 publication, Pargament and Park proposed that a helpful way of thinking about religion could be as,

“...a way of coping with life's most difficult problems than as a defensive reaction to trouble.....it may be easier to sidestep stereotypes and easier to recognize the many ends people seek through their faith in times of crisis, the many ways people use religion to achieve these ends, and the possibilities for both success and failure in this process”. (p.28).

Within today's society it is obvious that the non-believer cannot comprehend the faith and beliefs associated with the religious devotee and vice versa. The void between the two camps may be lessened somewhat by consideration of (although not necessarily belief in) a suggestion by Grzymala-Moszczyńska and Beit-Hallahmi (1996),

“It is easy to see that religious believers hold bizarre beliefs, but mostly use them only in a religious context. They allow themselves this escape from reality only under very specific circumstances. The miraculous events which run counter to everything we know about nature and humanity are usually believed to have happened long ago and far away. They have no real implications for the management of immediate reality. They may be a source of enjoyment and moral inspiration, and thus can enhance functioning, not interfere with it” (p.75).

A specific criticism of this viewpoint would be centred on the suggestion that religious belief has no bearing upon reality. The intrinsically religious person, on the contrary, lives all aspects of daily life according to their religious beliefs and traditions. Therefore, having lived a life in which God is included, it follows that during traumatic occasions, such as ill health or terminal illness, trusting in life-long religious beliefs very often shape the manner in which coping strategies are adopted.

When terminally ill patients feel they have lost all control of their situation, research has recorded that the majority will often agree to participate in studies investigating intercessory prayer. As far back as 1872, Galton conducted studies into this subject, prompting Roland (1970) to comment that in his opinion, Galton's research represented one of the first applications of statistics to



science and one of the first objective studies of prayer. Although further investigations have been sparse, it is nonetheless an important consideration within any study dealing with the coping strategies of the terminally ill as it may be one of the few strategies with a religious connotation which the non-religious patient may accept. Interestingly Byrd (1988) investigated the therapeutic effects of intercessory prayer in a coronary care unit in San Francisco. Altogether 393 patients were entered into a prospective double-blind randomised protocol of which only 57 refused to sign the informed consent. Thus using computer generation, patients were randomly assigned to receive or not to receive intercessory prayers. The intercessors themselves were also randomly assigned, although all were members of a Christian religion. Each intercessor was asked to pray daily for a rapid recovery and for prevention of complications and death. The patients not only did not know to which group they had been assigned; they had also agreed not to be contacted with the results. The latter in fact showed that the control group required ventilator assistance, antibiotics and diuretics more frequently than patients in the intercessory prayer group thus suggesting that intercessory prayer had a beneficial effect. Several criticisms could of course be mounted against this experiment, foremost among which would be the fact that unknown to the researchers or patients, several patients in the control group could have had prayers said for them by unknowing relatives or even members of a church congregation. Another could be that results were purely co-incidental or that the assumption that God responds to prayer by altering physical reality is just too far-fetched to be believed by the majority of readers. A previous study by Joyce and Weldon (1965) studied 19 matched pairs of rheumatic patients on a clinical double-blind trial on the effects of intercessory prayer. During the first half of the 18 months study, the prayed for group did do better, however in the second half of the study, the control group did better. The overall results therefore recorded no significant differences between the two groups. Four years later, Collipp (1969) reported the result of another experiment into the study of intercessory prayer. On this occasion results from a triple-blind study of 18 leukemic children indicated better overall benefits within the prayed for group. However statistics could not reach significant levels as the subject size was too small. Nevertheless it is obvious that if more research was done into the interesting subject of intercessory prayer, and if results showed the latter to be significantly beneficial in the majority of these studies, then analysis of the effects may be deemed scientifically valid.

The proposal that intercessory prayer has a beneficial effect on both ill and terminally ill patients derives from the concept of transcendence, which according to the literature reviewed so far, is associated with the end of life. This propensity has also been cited in the works of Chinen (1984),

Labouvie-Vief (1980), Moberg (1982) and Neugarten (1979). Spirituality is one empirical indicator of the human capacity for transcendence but as Conrad (1985) pointed out, spiritual transcendence does not imply a detachment from other dimensions of one's life, but that the person is open to the possibility of other dimensions beyond spatial and temporal boundaries. Therefore concepts such as God and intercessory prayer are meaningful to the patient within the context of terminal illness. In 1987, Reed conducted a study in south-eastern United States with 300 adults, divided equally into 3 groups. Group 1 consisted of terminally ill hospitalised cancer patients; group 2 were composed of hospitalised non-terminally ill patients and group 3 was made up of healthy non-hospitalised people. Her hypothesis that terminally ill hospitalised adults would indicate greater spiritual perspectives than either non-terminally ill hospitalised adults or healthy non-hospitalised individuals was supported. An important aspect underlying the framework of this study is the assumption that dying, like other developmental phases in life, is accompanied by characteristic changes. Foremost among these, is the individual's attitude towards spirituality and religious belief. If this is indeed the case, then it would follow that the role of the chaplain within a hospice or terminal ward of a general hospital would be of equal value to that of the nursing staff. Inferences regarding spiritual change as influenced by crises and life-threatening experiences have been cited in the work of Hall (1986) and McLaughlin and Malony (1984). Reed's work has empathised the need for continued research into spirituality in palliative care, which is proving to be increasingly worthy of integration into the care system of the terminally ill. The critic may of course propose that measurements of spirituality are ineffable and are indeed (as previously discussed) a sign of an unhealthy mental state. Moreover, it could be argued that just because patients with terminal illness register higher scores of spiritual perspectives than those of healthy adults, it does not follow that they need or would benefit from pastoral care.

The most prominent criticism directed specifically against intercessory prayer would be its relevance when dealing with the terminally ill. There are those who would argue that it is futile unless as a plea for a miracle. However many terminally ill religious patients regard prayer for "a good death" worthwhile, and all patients would undoubtedly be grateful for a pain free period where they can be cognisant of their family during the closing phase of their lives. To the non-religious individual, and to some religious / spiritual believers, attainment of a miracle would be worthwhile, even if it was achieved by a means normally alien to their principles. It should be noted however, that some religious adherents believe that anything can be achieved, including changing reality, if it is prayed for intensely by themselves or by others on their behalf. Indeed, in

1993, Eissenberg, Kessler et al, proposed that some patients regarded prayer as a type of “alternative” therapy treatment.

For most seriously ill individuals, acceptance of their terminal state becomes vital for physical, mental and spiritual well-being. No longer dependent on the surgeon for healing, the individual must relinquish their physical needs into the hands of the health-care worker. But their mental or spiritual needs must be reconciled to their own ideology. Reed’s (1987) study indicated that most terminally ill people display greater propensity towards spirituality than non-terminally ill individuals. This would in turn suggest that during the last stages of life, non-religious as well as religious patients, contemplate aspects of their present existence and future death within the ideology of a spiritual context. Pargament (1997) suggested that,

“Generally we cope with the tools that are most available to us. As many studies show, religion is a more accessible tool for those who make religious beliefs, feelings, practices and relationships a part of their orienting system. These are the people who are most likely to translate their religious commitment into action in particular situations. Why? Perhaps in part, because the more religion is embedded in the guiding framework for living, the more quickly and easily it can be accessed in coping” (p.145).

Surveys conducted throughout general hospitals in America found that approximately 50% of patients reported having spiritual needs and that they had not been satisfactorily met (Martin, Burrows and Pomilio, 1983). Although most hospitals within the U.S.A. have pastoral or chapel services on offer, it was found that only a small percentage of hospitalised patients (12% to 33%) were referred to them by hospital staff (Gartner et al 1990). One explanation for non-referral may be that in general, attitudes of health-care professionals towards religion may be different to those recorded in surveys and polls (refer to page1). They may not recognise spiritual needs as medically important to their patients and would consequently not take the appropriate action. Indeed many may be influenced by writers such as Chesen (1972) who held the general view that religion could be hazardous to health, or Ellis (1971) who emphasised the psychological dangers of religious guilt (which may be of particular relevance during terminal illness). Later research by Ellis (1980) proposed that,

“The devoutly religious person tends to be inflexibly closed, intolerant, and unchanging. Religiousness, therefore, is in many respects equivalent to irrational thinking and emotional disturbance.” (p. 637).

On the other hand, on reviewing empirical research literature Hood, Spilka, Hunsberger and Gorsuch (1985) found that religion correlated equally well with evidence of both positive and negative adjustment for persons of all ages. Indeed there was no evidence that religious people

became psychotic more or less frequently than those considered non-religious. However within palliative care, the patient's psychological state may be as important as their physical well-fare and it could be argued that health-care staff should be drawn from those within the medical profession who possess counselling skills and express a desire to work with the terminally ill.

In 1991, Koenig et al, conducted yet another study in order to determine differences in religious beliefs between patients, patient's relatives and health-care workers (doctors and nurses), who provided direct medical care to patients hospitalised in acute care settings. A sample of 130 physicians, 38 nurses, 77 inpatients, and 60 inpatient families from Duke University Medical Center were surveyed concerning their attitudes towards and involvement with the hospital's chaplain service, their personal religious beliefs, activities and backgrounds and their use of religion as a coping mechanism. Results of this interesting study illustrated that religious opinions, activities, background and coping mechanisms of patients and their families differed notably from those of the health-care workers, particularly physicians. (Koenig et al proposed that this was the first study to address these issues among health-care providers, patients and families within the same setting at the same time). The differences in opinions indicated that health care teams were unable to recognise or respond to the spiritual needs of their patients. This may in fact be the reason why few medical professionals refer patients to pastoral counselling within the hospital setting (as was indicated by the Gartner et al 1990 study). The small amount of referrals will also have an effect on the pastoral services operating within the hospital resulting in them being run less effectively. Another criticism of the study may be that the low response rates from physicians (12%) may limit the validity and generalisability of the results. It is also possible that those who did respond to the questionnaire had strongly held feelings towards religion and pastoral services. Literature within the study suggests that these opinions were favourable, and that those individuals who were opposed would most probably disregard the questionnaire. Another problem that occurs frequently within palliative care is that those patients who are the most seriously ill are not physically able to answer questionnaires. This occurred in the Koenig et al (1991) study and thus it could be concluded that the study results were biased towards a healthier population within the hospital. It could also be argued that the physician's responses were consistent with the views of doctors in America as a whole, as most of the physicians who care for patients at Duke hospital come from all over the world. However Koenig et al pointed out that their views may be more representative of medical professionals perspective of religion in general.

In a more recent study (2002), Chibnall et al sought to identify demographic, disease, health care and psychosocial-spiritual factors associated with death distress in a controlled clinical trial (n = 70) of out-patients with life-threatening diseases in an American medical unit. Their findings suggested that the experience of death distress (death-related depression and anxiety) was principally associated with the psychosocial-spiritual dimension of the patient's life especially regarding patient-perceived physician communication. The other areas investigated, such as physical symptoms, psychological symptoms, quality of health-care provision and social support also played a major role in alleviating or promoting death distress among patients in health-care settings. The researchers proposed that the psychosocial-spiritual domain may lessen the negative affects of death distress in patients with non-curable illness –

"The present data indicate that spirituality may buffer the fear and dread of death, and for this reason may warrant the acknowledgement and support of the physician" (p.336).

Perhaps the biggest criticism of this interesting study was the correlational nature of the sample group data, which prevented the generalisation of findings. Only 19% of those contacted agreed to answer the communications / questionnaires which could imply that only the most physically capable of respondents or most motivated, chose to participate in the study. Another important consideration in all such studies is that in order to supply an opinion about end-of-life decisions patients must be fully cognitive of their disease and future prognosis. The latter is often too overwhelming to comprehend or come to terms with, thereby resulting in many patients adopting a state of denial about the true nature of their condition. Questions about "preferences regarding end-of-life care" and "resuscitation if critically ill" could be very frightening and confusing to out-patients who would rather not be pressurised into giving opinion on such matters – particularly in questionnaire format. In the Chibnal et al (2020) study, 91% of the respondents were Christians, which must be taken into account when considering the study's main findings particularly in view of the fact that only 70 out of a total of 350 contacted patients consented to participate in the study.

Interestingly, Frankl (1963) was one of the first psychiatrists to acknowledge spirituality as essential to psychological health. He also proposed that spirituality contained a religious element and that both these aspects combined to provide meaning to the lives of human beings. Growing out of his experiences as a prisoner in a Jewish concentration camp during World War 2, Frankl theorised that,

"To live is to suffer, to survive is to find meaning in the suffering. If there is a purpose in life at all, there must be a purpose in suffering and dying. But no man can tell another what this purpose is. Each must find out for himself, and must accept the responsibility that his answer prescribes. If he succeeds he will continue to grow in spite of all the indignities" (p.xi).

The theoretical position that individuals strive for meaning and that this meaning is linked to physical and psychological health was the foundation of Frankl's (1963) study. This has potentially important implications for health workers in palliative medicine. If Frankl's theory is correct, then the more spiritually well an individual is, the greater capacity that individual will have for order and for deriving meaning out of the most stressful occasions in life. This in turn will directly affect their choice of coping strategies during terminal illness. Frankl believed that the spiritual and religious qualities that a person possessed determined emotional hardiness. Furthermore these qualities allowed physically frail individuals to tolerate intolerable situations. The ability to believe that life is meaningful, is essential to what Frankl described as hardiness and it allows individuals to make choices and to a certain extent accept the inherent challenges of his or her suffering or pain –

"Life ultimately means taking the responsibility to find the right answer to its problems and to fulfil the tasks which it constantly sets for each individual" (p.122).

The work of Frankl (1963 and 1987) has not had a great deal of influence on mainstream medical care. Nor has it influenced health staff, particularly physicians (refer to Appendices 4). During the last 30 years or so, there has however, been more interest into whether spirituality (pertaining to ultimate meaning and purpose in life) has clinical relevance (Foglio and Brody 1988). The latter study concluded that patients are especially concerned with spirituality in the contexts of suffering, debilitation and dying. It also gave support to Frankl's (1963) theory that "spirituality" can be defined in terms such as belief in a power greater than one's self, purpose in life, trust in providence, prayer, ability to find meaning in suffering and gratitude for life which is perceived as a gift.

Recently developed and clinically tested "spiritual well-being" scales provide measurements for both the existential aspects of meaning in life as well as the religious aspects of meaning (Hatch, Burg, Naberhaus and Hellmich 1998). Research into patient's spirituality found that the key to emotional coping with serious illness was frequently found within the matrix of a patient's spirituality. Studies indicated that this matrix had clinical significance because it provided an interpretative framework for many patients in handling the stress of illness (Pargament 1997 and McEwen 1998).

At present, deciding how best to respond to a patient's spiritual concerns can present medical professionals with several difficulties. Because patients often draw on religious or spirituality beliefs in the context of their serious illness (Koenig 1999), physicians who have no such beliefs themselves must still consider how to respect, and when appropriate, support patient's beliefs which may assist them in coping (Post 1993). This indicates the importance of assessing spiritual and religious needs with the goal of optimising therapeutic efficiency in the context of standard medical care. Delbanco (1991) emphasised the importance of the patient / doctor relationship declaring that if the patient deems it necessary to involve religious belief into this relationship, then the physician must respect this as being an expression of patient autonomy. Indeed the Association of American Medical Colleges Medical School Objectives Projects (1998) states that,

"physicians must seek to understand the meaning of the patient's stories in the contexts of the patient's beliefs, and family and cultural values. They must avoid being judgmental when the patient's beliefs and values conflict with their own" (p.1).

In 1988, Larson et al conducted a study, which highlighted the opinion that referrals to chaplains could be just as critical to good health care for many patients as referrals to other specialists and that the lack of appropriate clinical spiritual referrals could constitute a form of negligence. The following year, O'Connor (1989) stated,

"Conscious of their own struggles with the mysteries of life and death and with the mystery of God, chaplains are both a symbol of strength and at the same time a witness of finality and helplessness. While it may be true that they have come to grips with their own faith, and with faith answers to the problems of life, they cannot presume faith to guarantee the answers to another's problems.....Chaplains everywhere (and other carers too) continually meet those with a resilience and an inner strength where none would have been anticipated. The spiritual dimension is one area that does not permit generalization" (p.182).

In 1999, Mitchell and Sneddon carried out research in 10 palliative care units in hospices and hospitals within central Scotland. The study sought to investigate,

1. How chaplains understood spiritual care.
2. How chaplains practice spiritual care.
3. Do chaplains distinguish spiritual / religious?
4. Has palliative care influenced chaplaincy?
5. What factors are important to the delivery of good spiritual care?

Overall results showed that there did not appear to be a clear definition of spiritual care precisely because chaplains recorded the view that it was something which was individual to each person. Therefore it needed to be more inclusive rather than precise. There was a clear understanding of the place of religious care within spiritual care but a common frustration expressed by

respondents was that health-care professionals in general did not make the same distinction and thought that “spiritual” and “religious” meant the same thing. It was also readily acknowledged that when understood in the widest sense, spiritual care could be provided by all health-care providers and was not the sole remit of the chaplain. The study also showed that the palliative care influence was strong. 70% of chaplains had palliative care experience with four hospital appointments having a joint hospice element. Most significant was the fact that in palliative care, the patient and their families were seen as part of the team whereas the same was not true of general hospital care staff where the inclusion of family or carers was not so prevalent. Mitchell and Sneddon (1999) concluded by stating that,

“Chaplains have a very clear understanding of their role to provide spiritual and religious care. They are not the sole providers of spiritual care. When understood in its widest sense, all health-care providers can provide spiritual care and often do so without thinking about it. With religious care it was all about the right person for the patient. Although other members of staff could listen and say the same things, sometimes others needed to hear the words from the “right person” and that was the chaplain, God’s representative” (p.5).

This is an interesting study as it provided information about how chaplains viewed themselves as part of a health-care team. A criticism of the study could arise however, from incomplete data. By their own admission chaplains tended to write an account of only some of their daily appointments.

For the religious person, the chaplain can act as a reinforcement symbol of their religious beliefs, particularly the belief in life after death. The latter is central and fundamental to the Christian faith and may indeed constitute a coping mechanism in so far as the believer in life after death has an explanation for their earthly life nearing its end. As was previously stated on page 25 however, not all religiously orientated people welcome their death. Many within the more fundamentalist sectors of the Christian faith may believe in a punishing God and may be anxious of God’s judgement. It was Freud (1927) who popularised the link between fear of death and the wish fulfilling beliefs in God and in life after death.

When confronted with a diagnosis of a terminal condition, individuals react differently to that prognosis. Consequently how a person copes in the last phase of life depends greatly on their mental attitudes and beliefs. Some may be so traumatised by the information that their only means of coping is by the mechanism of repression or denial. Others try to pretend that the situation is not happening to them but to another person who happens to be occupying their body. In other words a type of depersonalisation occurs, similar to the situation described by Bettelheim



(1968) in his observations of those who survived the Nazi concentration camps during World War 2. Thus denial or suppression of reality could in certain circumstances be regarded as appropriate coping strategies (for certain people) and ones wherein religion and spirituality do not feature. However a criticism of these views are that they were focused directly on the powerful urge to survive deplorable almost inhuman situations. Although death surrounded their daily existence, survival remained paramount to the extent that it was in a certain sense,

“Necessary to give up all frames of reference, not only religious ones, but also all other accustomed modes of thinking and of affective life” (Levi, 1987, p.31).

With reference to this present research however, there is no chance of survival, as all patients receiving palliative care in a hospice environment are aware (or almost always aware) of the fact that they are seriously ill and possibly close to death. It is probably not appropriate therefore to compare coping mechanisms within inhuman situations with that of a palliative care environment. Nevertheless the fact that both Bettelheim (1968) and Levi (1987) describe coping mechanisms devoid of religious connotations during times of severe anxiety, is something which cannot be overlooked in any study investigating how the terminally ill contend with the fear and anxiety of death. It is worth pointing out that relevant literature on this subject reveals a number of different responses to coming to terms with death. Some individuals do cite religious belief as a coping aid to approaching death, whereas others seem to accept death as an inevitable part of life. Some individuals are unable to mentally cope with their situation and deteriorate rapidly whereas others become determined to achieve ambitions and interests previously denied to them through lack of time or motivation. (The latter could only be attained by patients in a relatively pain free terminal state).

In recent times, residents within a palliative care hospices, are increasingly being offered a choice of past-times which, (in the outside environment), are often included in a range of therapies referred to as “alternative health”. For example, terminally ill patients may often gain temporary psychological and physical relief from massage, reflexology, yoga, aromatherapy, flower essences, music or acupuncture. Some Health Boards encourage short visits from animal organisations while others encourage student artists to demonstrate the relaxation benefits of paint exploration (St.Christopher’s Hospice London). Palliative care aims to achieve the best possible quality of life for patients whose disease is not responsive to curative treatment (WHO 1996). However depression, loss of hope and meaning to life can become so prevalent to the

circumstances surrounding the terminally ill patient, that it has been described as “a social death” (Sweeting and Gilhooly 1991/92).

St. Christopher’s hospice has also adopted art therapy as a means of bringing relief from stress and anxiety to their patients and of fostering a therapeutic relationship between therapist and patient (Kaye 1997). A new acupuncture service was introduced at the Hospice of the Good Shepherd in Chester, England in 1999. It was initially used for patients who were already attending for symptom control but as the service developed, an acupuncture clinic was established as part of an outpatient complementary therapy service. Patients with persistent symptoms were offered acupuncture despite the necessary application of daily drug treatment. Weekly treatments were given for four to six weeks. The aim of the study was to review all patients treated with acupuncture during the year 1997. Out of four hundred and sixty-five hospice referrals occurring that year, 168 chose to accept treatment by acupuncture. Results showed that 62% had a good response to treatment and 55% reported it to be a worthwhile alternative to pain control (Leng, 1999). Acupuncture is becoming recognised as an integral part of modern medicine and within palliative care, has been shown to be beneficial in the relief of breathlessness, nausea and pain (Thompson and Filshie 1998). In a study by Stux and Pomeranz (1995) in New York, 156 patients with pain due to advanced malignancy reported findings of worthwhile improvement lasting longer than seven days from 56% and limited improvement of a few days from 22%. In an overall review of acupuncture for chronic pain, a response rate of 55-85% was reported with a 30-33% response to placebo. However a criticism of this study could be that the number of patients treated for non-pain symptoms was too small to draw any meaningful conclusions with regard to choice as a coping strategy. Nonetheless these studies and projects encompasses the phenomenological approaches advocated by Maslow (1968) and Rogers (1961) whereby participating in a creative activity enhances the individual’s sense of self-esteem, autonomy and integration; thus producing a sense of purpose and meaning in whatever set of circumstances individuals finds themselves. Although perhaps not achieving Maslow’s ultimate goal of “self-actualisation”, projects such as these may give back to the seriously ill patient their former capacity of self-control (albeit in a limited fashion). They can also, according to Herth (1995) promote,

“The spiritual or transcendent process of hope involving a sense of faith or certainty about something that has not yet been proven and the transformation of the present reality into one of greater aliveness” (p.20 ).

Muyskens (1979) defined hope as a form of trust for the future. It is often deeply ensconced in a religious cultural matrix and as such can encompass eternal, as well as earthly life. Because it can be of particular importance to patients with terminal diagnosis, the fostering of hope should be encouraged by both physicians and chaplains. Holland et al (1999) found that the spirituality / religious beliefs of patients provided a helpful active cognitive framework from which to face life-threatening malignant melanoma. According to Post (1995), hospice care, grew out of a tradition of spiritual care and in times of serious illness, hope may be mediated through ritual, meditation, music, prayer or traditional sacred readings. Importantly, Smart (1969) argued that religious influence should never be disregarded when investigating any subject as it is influential within society as a whole, and will inevitably have become entrenched within cultural attitudes, beliefs and awareness. As was stated at the beginning of this research study, the spiritual dimension within nursing (particularly palliative medicine), is now gaining more publicity because of the positive influence it can have on maintaining unity and peace of mind within the individual. According to Thompson (1984), this is something which is out-with the scope of science and medicine.

Researchers such as Kastenbaum and Weisman 1972, Weisman and Kastenbaum 1968, have attempted to reconstruct the final phases in the life of a patient, using a procedure known as psychological autopsy. This involved interdisciplinary conferences in which information about recently deceased patients was presented and discussed with the aim of studying the psychosocial context in which the death occurred. After reviewing 80 cases in one sample and 35 in another, they concluded that patients entering the terminal period could be separated into two groups on the basis of their responses to impending death. One group seemed to be aware of and to accept impending death. Most of these patients withdrew from daily activity and remained inactive until the end. The other group was also aware of imminent death, but vigorously engaged in daily activity, initiating new activities and interpersonal relationships. For these individuals, death came as an interruption to daily living. (This latter point could be presented as a criticism of the 1970, Kubler-Ross study).

More than a decade later, a study by Antonoff and Spilka (1984-85), examined the patterning of facial emotional expressions of patients who were either in the early middle or late stages of their illness. Observers rated the facial expressions of patients during interviews in order to assess their levels of fear, anger, sadness and happiness. Contrary to the Kubler-Ross stages, sadness

increased from the early to the late phase of illness, and no systematic patterns were found for anger and happiness.

It has been previously mentioned that the terminally ill patient may choose to cope with their illness by means of a whole host of coping strategies, which are not affiliated to spirituality or religious belief such as acupuncture, hypnotherapy, aromatherapy, reflexology, art appreciation, psychotherapy, counselling and social networking. However as this present research is concerned with religious belief and spirituality as possible coping mechanisms, the reader may find it of interest to consult the *Journal of Palliative Medicine* (2003) where several examples of research are cited in which patients with an advanced sense of psycho-spiritual well-being seem able to cope more effectively with the process of terminal illness and find meaning in the experience. Other studies recorded a high percentage of patients in which there was a link between religious faith and lower dependency on health professionals while others reiterate the importance of including spirituality and religious issues in quality of life assessments.

All of these studies are testament to the research literature, which describes coping in terms of an individualistic pursuit. Within Western cultures, which lay value on individual freedom and choice, religion is often regarded as a more personal matter than a social pursuit. Indeed William James (1890) described the primary religious force as personal emotional experience. This theory undoubtedly features prominently in terminal illness as the individual is faced with the fear and anxiety of death together with the conscious realisation that only they can make the decision to cope, or not to cope, with their own personal crisis. But emotions, cognitions, behaviours and relationships are not independent of each other either, and probably play a large part in the patient's decision about whether to include spirituality or religious belief as an aid to coping with the dying process. Interestingly, in a recent 1996 study, Hood, Spilka, Hunsberger and Gorsuch, describe how patients who did not regard themselves as religious, sometimes choose to participate in therapies with distinctly religious overtones, for example meditation, healing or yoga groups. The question could be posed as to whether they are indeed seeking meaning to the purpose of existence and death, which feature as central themes within phenomenological psychology (Maslow 1962 and Rogers 1961). Alternatively, critics of this assumption may propose that they are merely passing the time available to them with group therapies, which happen to be on offer within the palliative-care unit.

One area, briefly mentioned on page 16, was the coping strategy of social networking. This multidimensional concept is another example of a technique, which can be both, consciously or unconsciously used by the dying patient as a means of alleviating the personal stress associated with the inevitability of death. As a terminally ill patient within a hospital or hospice environment, contact and relationships with a small array of associated people is both inevitable and necessary. The manner in which the patient responds to each of these relationships will depend on their own personal make-up and the policies within the medical unit. Before the introduction of specific palliative care centres, the general premise was that patients should be told only what was in their best interest to know (Blumenfield and Blumenfield 1982). Accordingly, patients who seemed to be in a state of denial were to be respected by family, friends and health-care workers as it was clear to all concerned that the patient could not confront the prospect of their own death. In 1953, Fitts and Ravdin questioned 444 Philadelphia physicians concerning their attitude towards informing terminally ill patients about their condition. At that particular time only 37% informed patients about their diagnosis. In a classic study of 219 physicians by Oken in 1961 at a hospital in Chicago, only 12% stated that they did inform patients of their terminal illness and in 1965, Feifel reported that between 10% and 31% of physicians favoured letting patients know that they were dying. During the last 30 years, attitudes and opinions within the medical profession have changed and by 1974, Mount, Jones and Patterson found that 78% of physicians usually told patients their diagnosis. It is now mandatory policy in America to inform all patients admitted to a hospice centre of their terminal state although this is not always adhered to and is still a problem as was cited in the British studies (refer to p.p.24 - 25). This change in policy has to a certain degree been brought about by cultural and social changes within society in general, which recognises honesty as the best policy in dealing with all areas of medicine. Some physicians would criticise it because it does not take into consideration an individual's disposition or personality traits. It also poses the question as to whether health care staff can constantly cope with patients who have been told that they are dying and that whether they personally consider it to be the correct policy. A study by Blumenfield, Levy and Kaufman (1979a) asked medical students in Brooklyn whether,

1. If they themselves had a fatal illness, would they want to know or not.
2. What was their attitude towards informing their current or future patients?

Results showed that 89% of medical students, 93% of interns and 90% of the residents said that they would want to be told if they had a terminal illness. With regard to the second question,

results showed that 81% of the medical students, 80% of the interns and 90% of the residents believed that patients had the right to know about their fatal condition. Of this group only, 3%, 7% and 2% respectively felt that patients should be protected from the truth. An obvious criticism of this study is that attitudes and opinions of healthy individuals can often change once they themselves become sick or terminally ill. Also medical students may possibly change their opinion on the policy of informing patients about their terminal state after qualifying and having practised for several years.

Although the main goal of medicine is to promote healthy lifestyles and to perform operations designed to extend, if not cure ill health, the role of the medical practitioner within the hospice environment is obviously different. Devoid of the role of healer, the physician's tasks become varied and challenging. Abilities such as competence, dedication and above all patience are essential to the traits of health professionals whose work with the sick encompasses both long and short-term management. Their attitude and manner in dealing with the terminally ill patient will in turn determine the quality of social interaction between each. It may also impact upon the relationships between patients and family. As far back as 1976, Cassell urged the medical profession to consider the psychological needs each patient brings into every encounter with a doctor. He proposed that all patients either recover quicker or suffer less, (depending on whether the illness is terminal or not), when the physician seeks to be a "healer" in the holistic sense. Cassell's traced the failure to meet the needs of the time to,

"Those factors in the history of medicine that, in artificially separating the person from the disease, have directed our awareness away from the nexus of the problem", and also to, "The failure of both physicians and society to realize that medicine is inherently a moral profession" (p.119).

At the beginning of the 21<sup>st</sup> century, the question that needs to be considered is whether Cassell's evaluation of doctor patient relationships still applies. One of the biggest fears recorded among patients with life-threatening illnesses is that of abandonment by both relatives and health-care staff (Blumenfeld and Blumenfeld, 1982). Within the palliative care unit, patients are often confronted by people who had previously meant little to them and with whom they may have had little in common. In the final stage of their life, these former strangers now become of the utmost importance to them, as also do family and friends. Surrounded by a myriad of health-care professionals as well as family visits, these patients have to find their own techniques in order to cope with the strains as well as the pleasures of social relationships, in addition to coping with their own terminal medical position. The challenge facing patients therefore, is how to interest,

please and cajole the numerous individuals within the social network of palliative care in order to prevent feelings of abandonment in both the physical and psychological terms. Whichever means is consequently consciously or unconsciously chosen by the individual patient in their efforts to please, self-image features highly in that choice. It must also be stressed at this point that not all patients with non-curable illness have easy access to a hospice care centre.

Between 1995 and 1997, Rose conducted a series of continuous studies concerning the relationships between the terminally ill and their carers. This was an interesting study as it concentrated on family and friends as carers as opposed to medically qualified professionals (although the latter were not excluded from the investigation). The most common carer / patient relationship was that of spouse, with 9 women looking after husbands and 6 men caring for wives. One of the most prominent recurring themes throughout the study was that of carers perceptions about time. During terminal illness, immense disruptions occur to the lives of both the carer and the patient. Disruptions take the form of time consuming activities such as, practical tasks, emotional tasks and other general demands. In 1993, a study by Thibodeau identified demands on time as a key factor in determining how caregivers felt about looking after elderly parents; the greater the demand, the more negative the experience was perceived to be. To a certain extent this was reiterated in the Rose investigations as the burden of care seemed often to fall on the one informal carer. The latter overburdened and exhausted by the experience found that the very structure of their lives had been challenged by what had occurred. The more any type of work associated with caring disrupted normal existence, the more fatigued the carers became. As well as the problems associated with looking after a relative within the home, Rose (1997) found that there were also external demands made on the carers by health professionals and relatives. Although “meaning well” these outsiders often presented additional problems and burdens to the spouse caring for their dying relatives. For example, the carer often felt obliged to offer food and drink to their relatives when they came to visit and health care professionals often failed to keep appointments, thus increasing the carer’s fatigue and uncertainty about their ability to manage the patient’s disease. Interestingly with regard to the present research under study, the subject of visits by clergy was also investigated within the Rose study. Almost without exception, the patients recorded feelings of closeness and friendliness with the minister or priest as they had invariably been formerly acquainted with them. As well as professional support for the carer while looking after their terminally ill relative at home, Rose found that it was essential that the patient should be referred to a palliative-care unit for short periods so that the carer could experience some free time in order to regenerate themselves. Managing time effectively was the

central theme of the Rose (1997) study, and it was one which had also been highlighted in a 1990 study by George, Jackson and George. They proposed a very detailed and regular timetable of daily events incorporating medicine giving, physical care routines and rest periods (for both carers and patients). They concluded that planning time effectively was the key element to achieving equilibrium in the emotionally and physically exhausting task of caring for a dying relative. Moreover Rose stressed that,

“Managing time does not consist merely of assisting carers to plan when to perform certain tasks, but also includes appreciating the nuances of their emotional state and the hidden demands on them. It includes, too, realizing that carers’ experience is profoundly affected by the appropriateness and sensitivity of the support given to them by professionals” (p.349).

Both the Rose (1997) and the George et al (1990) studies are interesting additions to this literature review as both are centred upon the home caregiver as opposed to the professional health-care worker in hospitals or hospice centres. Both studies uncovered an underlying fear among spouses that placing their loved ones in the hands of professional care workers signified a failure on the part of the lay carer and signalled to the dying patient that they were unduly overburdening their partner and family. Interestingly, research by John and Spilka (1991) pointed out that it is during these circumstances that the role of the clergy, or resident chaplain within a hospice setting, for example, can help patient and relatives to come to terms with the stressful situations -

“Physical problems are compounded with a host of psychological difficulties, not the least of which are feelings of isolation, separation, dependency and helplessness. In such circumstances, religion and prayer have a high likelihood of becoming prime supports for the individual” (p.21).

They stressed that control over one’s life is thereby placed in the hands of others; feelings of powerlessness can ensue and self-esteem may be adversely affected.

This review has sought to demonstrate that the primary goal of hospice care is to help terminally ill patients continue their lives with as little disruption as possible. Working as a team, health-care professionals spend some time talking and listening to the views of patients and their families although priority is given to the alleviation of physical pain and discomfort. In 1981, the National Hospice Organisation outlined standards and principles of hospice care (Rando 1984). It was designed to compare results of studies in America between matched groups of hospice and non-hospice terminally ill patients and their families. The study involved terminal cancer patients from 40 hospices and 14 conventional oncological care settings. Periodic interviews with the patients and their primary care person were conducted in an effort to determine whether their experiences were significantly different due to care setting (i.e. hospital-based hospices, home-



based hospices and conventional care settings). The main findings and conclusions of the study by Greer and Mor (1986) are presented below.

1. "Patients receiving hospice care underwent less aggressive intervention therapy and diagnostic testing.
2. The patients' quality of life (i.e. performance status, global quality of life, pain and symptoms, satisfaction with care and social involvement), was not significantly different due to care setting, except that in the hospital-based hospice setting, pain and symptom control may have been better and patient satisfaction with care tended to be higher.
3. There were no significant differences in the following family outcomes due to care settings: secondary morbidity, hospitalization rates, medication for nervousness, or alcohol consumption.
4. Families of patients in home-care hospices were more satisfied with site of death (which was more likely to be the home) than were families of patients in conventional care settings, but they also experienced higher levels of stress, social disruption, and bereavement –related psychological distress.
5. Home-based hospice costs were less than those of hospital-based care, which were roughly equivalent to the costs of conventional care" (p.6).

Hinton's (1979) study also recorded other positive effects attributed to hospice care. For example, hospice participants reported lower levels of depression when compared to individuals receiving conventional care. In addition, a study by Parkes (1979a) indicated that the family of a terminal patient is more prepared for death and better able to deal with bereavement when the terminal patient has been involved in hospice care. Typical comments by such family members reflect that they feel more in control of the situation and are glad to be actively involved in the care of their loved ones. One important outcome of research into the terminally ill and the hospice movement in general is to highlight to the medical community the importance of care as opposed to cure in patient diagnosis. Bass (1985) maintained that maturation of the "hospice ideology" has helped to establish "care" as a genuinely important goal, which is gradually being addressed by conventional health care practitioners within general hospitals.

The main area of empirical research in this present study concerns whether faith or spirituality may aid the patient with non-curable illness to achieve a higher quality of life and as such, merit recognition as an appropriate and important coping strategy.

As far back as 1952, Tillich expressed the view that it was difficult to find scientifically acceptable populations with which to investigate areas such as spirituality and religious belief. This was mainly due to the fact that culturally, society had moved so far away from the assumption that there is a human capacity to experience God (whom he referred to as the Ground of Being). His main premise was that personally experienced spirituality was health promoting in

the sense that it reduced anxiety. Specifically, Tillich proposed that “ontological insecurity” was a primary cause of anxiety. As this concept is important to the present study’s investigation and will be included within the empirical study, it merits further explanation.

Ontological insecurity is the perception that life lacks fundamental meaning and that no God (or Ground of Being) exists. This tends to be in accord with society’s views today, which Tillich criticised as being responsible for producing high levels of anxiety and distress in individuals when faced with stressful life circumstances. The solution, he suggested was to re-establish relationships with the “Ground of Being” (which had been previously part of the human psyche for thousands of years). The resulting “ontological harmony”, would provide a perspective which would reduce anxiety even in the most stressful of life’s circumstances. Tillich’s emphasis on the importance of personally experienced spirituality was similar to Allport and Ross’s (1967) focus on the value of intrinsically orientated religiosity. Interestingly between the years of 1975 and 1979, Tillich worked with Rogers (1961) on the staff of the Person-Centered Approach Project. He found that person-centred workshops enabled participants to experience their inner selves and in doing so, a significant proportion of them began to experience their inner selves as “greater than themselves” and rooted in the “Ground of Being”. This type of experimentation is difficult to validate as it relies solely on emotional response from participants who may be classed as having personality disorders. Even when results are replicated among the general population, associations between its origins and counselling therapy would inevitably remain. Nevertheless from the 1970’s onward, investigations into spiritual and religious experiences progressed. Random samples by Greeley (1974) in conjunction with the National Opinion Research Center in the United States and by Hay and Morisey (1978) in Britain and the United States, suggested that somewhere between 30% and 40% of Americans and Britons have had experiences that convinced them of the existence of God. It must be pointed out however, that Greeley’s estimations have been reduced somewhat by analyses conducted by Thomas and Cooper (1978) and that criticism will always be levelled at any investigation into religious belief and experience as neither can be scientifically validated.

Hay and Morisey’s study also suggested that experiences resulting in belief in God contribute to psychological well-being. This has been further corroborated in research by Hood (1975), and Hood et al. in (1979) which suggests that mystical experiences are part of a human being’s normal perceptual capacities and contribute to psychological health. Additional corroboration that such experiences are part of a human being’s normal perceptual capacities came from

psychophysiological “states of consciousness” research using EEG suggesting that mystical experiences are a function of a deepened ability to achieve internally focussed states of consciousness (Kass 1990). Observations such as these, were described by Kass as “experiences of the spiritual core”. Kass proposed that participants were experiencing perceptions which were part of a natural spectrum of human abilities rather than simply a function of social or theological belief. Most significantly (to the present research), these experiences seemed to contribute to the perception that life is meaningful and coherent even during negative life circumstances. Working at the Section on Behavioral Medicine at Boston’s Deaconess Hospital, Kass developed an Index of Core Spiritual Experiences (INSPIRIT) (Kass et al, 1991a). This Index contained seven questions designed to help identify experiences of the spiritual core. Using outpatients in a 10 week behavioural medicine programme, Kass et al. found that patients who entered these programs having previously had core spiritual experiences, showed higher increases in life purpose and satisfaction as well as greater decreases in the frequency of stress related medical symptoms. These results suggested a measurable relationship between core spiritual experiences and a psychological strength during crisis and also the ability to gain control over stress related medical symptoms. Kass (1991) proposed that spiritual practices which help the individual to develop an internally focused perceptual orientation, increase the likelihood that core spiritual experiences will take place. Using EEG data, Kass showed that as internally focused states of consciousness lower the frequency of electrical impulses within the brain, qualitative changes in personal experience take place. Results from the outpatient study (Kass et al 1991a), showed that a pattern could be discerned in which an internally focused perceptual orientation reduced arousal, increased feelings of peacefulness, increased internal imagery and intuitive modes of learning and increased the likelihood of experiences of the spiritual core.

In the same year, Kass, Burton, Ferranti and Davis (1991b) (conducting an ongoing study with divinity students), tested to see if the occurrence of core spiritual experiences were correlated with psychotic or obsessive-compulsive symptoms, (as psychoanalytic theory has suggested); or with intolerance of ambiguity (as sociological theory has suggested). No such correlation was found within this matched group of samples.

Results of these interesting studies suggest that core spiritual experiences may be a natural capacity of the human organism, but that today’s cultural beliefs fail to recognise the value of this internally focused perceptual orientation. Thus many individuals may be denied an important asset in dealing with extremely stressful life situations. These studies are of particular interest to the present researcher as a primary objective of this investigation is to evaluate whether religious

belief / spirituality is beneficial to the terminally ill patient as a means of not only coping with their illness, but of maintaining a higher quality of life. Studies such as these add impetus and authority to this research, giving it a legitimate basis for investigation, and presenting the researcher with an opportunity of contributing additional data to the processes of coping with stressful situations.

Finally, although published material on the subjects of death and dying has increased during the last decade, Schulz and Schlarb (1991) attest to the fact that these subjects are not yet accepted into the mainstream of the scientific community -

“...even though research on stress and coping has become a central focus among researchers in a variety of disciplines such as psychology, psychiatry, and sociology, the topic of dying is rarely treated in this context. Perhaps researchers implicitly make the assumption that if an individual is going to die anyway, then issues such as coping are irrelevant....We have little direct information about the length of illness prior to death, the magnitude of patient's disabilities, the physical pain and psychological distress experienced by the patient, coping strategies used, the amount of care received or needed, or even basic information regarding the number of patients who are aware of their terminality before dying” (P.370 / 371).

Schultz and Schlarb (1991) suggested that studies investigation death and dying provide valuable opportunities to develop the existing theories about coping with stress. Researchers, they proposed, should focus on certain specific aspects surrounding the process of dying, such as pain or depression rather than trying to define “a good or dignified death on a global sense” (p.386).

In conclusion, the literature review recorded in this chapter has been chosen to reflect an objective view of research into terminal illness and the coping strategies of patients with life-threatening illnesses. The review has also sought to present objective opinions of spirituality, religion and faith in respect to palliative care, coping, psychological and spiritual well-being. Inevitably such a diverse array of investigative detail has raised issues which need to be further explored, explained and defined as they are of crucial importance to the understanding of the present research study's aims and objectives. Consequently, Chapter 2 will attempt this clarification, concentrating on the main subject areas of coping, coping strategies, coping criteria, bereavement, spirituality and religiosity.

## Chapter 2

### Issues Arising from Literature Review Research

Within research, coping has been described as an individualistic pursuit, encompassing,

1. "An array of covert and overt behavior patterns by which the organism can prevent, alleviate or respond to stress-inducing circumstances" (McGrath, 1970, p.33).
2. "Any and all responses made by an individual who encounters a potentially harmful outcome. In addition to overt behaviors we would include cognitions, emotional reactions and physiological responses (Silver and Wortman, 1980, p. 281).
3. "Constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman, 1984b p.141).
4. "Coping involves purpose, choice, and flexible shift, adheres to intersubjective reality and logic, and allows and enhances proportionate affective expression" (Haan, 1977, p.34).

Several researchers have attempted to identify the characteristics of people who seem to be able to cope better than most during normal and abnormal times in their lives. Tyler (1978) for example developed a tri-dimensional model. What he described as "effective people", have a favourable set of attitudes towards themselves and the world. They regard themselves as worthwhile whether life's circumstances are good or bad and are particularly characterised by an efficient problem solving orientation. Although the latter cannot be specifically applied to terminal illness, some patients are nonetheless able to attain a certain degree of self-esteem and satisfaction by coping with the management of their illness to the best of their ability, (thereby lowering their stress and anxiety levels). Literature on person variables, such as the five-factor model of personality (Costa et al, 1996; McCrae & Oliver, 1992) may contribute to the understanding of "effective people". Therein may lie a key as to why some individuals are able to cope, possibly using one of the 4 definitions above, and why they sustain positive psychological states during stressful circumstances, while others fail.

Theorists have also acknowledged the existence of internal and external forces in life but disagree as to whether people are simply products of these forces, (Bandura, 1979, Bronfenbrenner, 1979, Rappaport, 1977 and von Bertalanffy 1968).

Pargament (1997) stated that,  
 "If it is true that we are shaped by the situations we encounter, it is also true that we avoid, select, construct, define, and redefine these situations as well.....The evidence of people curious about and actively engaged

in mastering their circumstances; of individual differences in response to stress; of resilience in the face of terrible conditions, and of people living effectively in a topsy-turvy world has led to the conclusion that people are engaged in transactions with the environment around them" (p.81).

According to literature, coping is something individuals engage in to attain significance in stressful circumstances. These individuals bring with them an orienting system and a way of dealing with the world, which helps them through difficult times. Fishbein and Ajzen (1975) proposed eight assumptions about the coping process in their study about the power of intentions. These are,

1. People seek significance.
2. Events are constructed in terms of their significance to people.
3. People bring an orienting system to the coping process.
4. People translate the orienting.
5. People seek significance in coping through the mechanisms of conservation and transformation.
6. People cope in ways that are compelling to them.
7. Coping is embedded in culture.
8. The keys to good coping lie in the outcomes and the process.

According to Lazarus and Launier (1978) "coping" refers to a process encompassing behavioural as well as cognitive acts. Dominant within the latter are "defence mechanisms" such as "avoidance" and "denial". Lazarus and Launier were the first theorists to introduce the term "palliative" to describe emotion-focused responses. Both internal and external coping processes are generated by situations or experiences which for the most part exceed a person's normal capacities to such an extent that they are only able to be dealt with by the mobilisation of purposeful effort. The general aim of the coping process is to achieve a balanced state between the immediate demands of the crisis situation and the capacities of the individual in order to attain the least stressful scenario. People differ in their degrees of ability to handle stressful life events and similarly in their employment of coping strategies as a means of doing so. As stated on p.66, coping has been described as constantly changing cognitive and behavioural efforts to manage specific external and /or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman, 1984b). The latter distinguished between emotion-focused coping and problem-focused coping. They defined problem-focused coping as that which is directed at managing or altering the problem causing the distress, and emotion-focused coping as that which is directed at regulating emotional response to the problem. It may be the case that different strategies are effective at different stages during an illness.

In a more recent publication, Lazarus (1993) reiterated a list of coping mechanisms most often applied in times of crisis. These were, confrontative behaviour, self-controlling, seeking social support, accepting responsibility, planful problem-solving, positive reappraisal, escape-avoidance, distancing and denial. A search of relevant web-sites and library references on the topic of coping with non-curable illness has revealed remarkably little information or research into the subject. The small amount of published research relating to this subject has generated information which most often concerns the coping strategies of the patient's spouse, relatives or care-givers (Rose 1997, p.60 and George 1990 p.61). A recent study by Folkman again illustrates this point. In 1997, Folkman published a longitudinal study of the care-giving partners of men with AIDS. What made this study different from most other coping and bereavement studies is that it illustrated the co-occurrence of both positive and negative psychological states during a period of intense stress. This is an extremely important contribution to the subject of coping, especially from the perspective of the care-givers. Even during the year before the partner's death (with the exception of the last interview before death), caregiver's states of mind were significantly less depressed than those reported by the community sample. Four types of coping processes (according to Folkman, 1997) were associated with positive psychological states. These were,

1. Positive reappraisal
2. Goal-directed problem-focused coping
3. Spiritual beliefs and practices
4. Infusion of ordinary events with positive meaning.

Folkman assessed that,

"The findings, which are based on both quantitative analyses of questionnaire data and qualitative analyses of narratives from the interviews, show the diverse ways that meaning can be created in the midst of stressful circumstances" (p.1212).

The four coping processes described by Folkman (1997) once again illustrate the importance of personal beliefs and values so often cited in other studies. But where this study is original is in the highlighting of fairly prolonged instances of positive psychological states not normally associated with caregivers during a time of severe stress. Folkman accordingly proposed that Lazarus and Folkman's 1984b coping model should be modified to take account of occasional positive psychological states. This longitudinal study must be taken into account and undoubtedly replicated with other terminally ill subjects in order to determine whether the 314 men who took part in the study (87 % of whom participated during the 2 years of research) possessed personality

traits or characteristics markedly different from those of the more usual caregiver. The latter is more usually the spouse, partner or child of the seriously ill patient, whereas in the Folkman study, all caregivers were the homosexual partners of the patient many of whom may themselves have been HIV infected (Folkman et al., 1994a). A relevant question resulting from this research would be whether Folkman's four coping processes could also be considered as coping strategy aids for patients as well as caregivers.

Recent research has established that the development and progression of cancer has been associated with a type C personality, characterised by suppression of emotional reactions especially anger, and by a conformity / compliance attitude (Greer and Watson, 1985). Significant association has been found for example, between a cancer-prone personality comparable to the type C construct (Eysenck, 1988) and death from cancer in a large follow up study (Grossarth-Maticcek et al., 1988). Type A personality, characterised by hostility, anger and aggression (Friedman and Booth-Kewley, 1987) has also been cited as having associations with individuals prone to coronary heart disease and stroke (Eysenck, 1990; Chesney and Rosenman, 1985). This type of research although controversial, has nevertheless highlighted the possibility of associations and psychological interactions between the central nervous system and the immune system. If there is a direct association between personality and the onset of cancer, or similar life-threatening disease, it would follow that coping with the consequences of the illness may also be associated with particular personality traits and characteristics. Following initial diagnosis of life-threatening illness, depressive symptoms may be expected to occur within the majority of patients. However as the disease trajectory progresses, the patient is confronted by an additional series of unexpected happenings consisting of physical, psychosocial and psychological changes. Although familiar to health care professionals, these changes are unfamiliar and frightening to seriously ill patients who, perhaps already burdened with depression, may not have the strength either physically or psychologically to cope with the reality of their situation.

Coping strategies have been related to quality of life measures (Heim, 1991), and are specific techniques used in adjusting to illness or other major stressors (Lipowski, 1970). The efficacy of a given coping strategy depends greatly on the phase of a stress event in which the given coping strategy is applied. For example, in the palliative coping acts, the efficacy of these strategies would be proven, at least initially, by the reduction of the emotional arousal level. Within terminal illness, these aspects would include fear, anxiety, depression, disorientation etc. However, it is questionable whether a terminally ill patient will ever recover sufficiently from the



initial shock of diagnosis in order to adopt a suitable problem-orientated approach towards death. (This may account for the palliative acts being the most commonly recorded examples of coping strategies within research). Nevertheless, it is generally recognised that successful coping depends on the individual's personality, background, experiences and beliefs (Averill, O'Brien and DeWitt, 1977) and also on the point of the phase sequence at which the emotional arousal was challenged. In situations where sufficient time is available to confront the crisis, a heightened arousal level at an early stage of preparation phase may very well be adaptive with regard to an optimal handling of the stressor. On the other hand, Khrono and Schaffner (1983), proposed that little or no preparation time to confront the stressor, may result in it being more adaptive for the individual concerned to direct coping strategies against the arousal and then to turn to the problem. Common to many instances where coping choices are consciously involved, patients often find conflict between emotion-related and problem-related responses. This makes the whole process of coping problematic and exhausting to individuals who may already be disorientated and anxious of treatment outcomes. In 1986, Leventhal et al reported that unsuccessful coping served only to increase distress by reducing the patient's sense of control and they recommended that future research should examine whether there are specific coping efforts (e.g. meditation or exercise) which are associated with lower reported distress.

If personality plays a part in determining choice of coping strategy, then it would follow that the "helpless-hopeless" orientated personality (Cassileth et al, 1985; Lampic et al, 1994) may adopt the most common method of coping with severe stress – i.e. denial (Holden, 1978; Carver, Scheir and Weintraub, 1989). Other types of emotion-focused strategies include, "avoidance", (Friedman et al., 1990), and "resignation-fatalism", (Heim, 1991). Generally these types of emotion-focused coping strategies do not appear to be adaptive. Problem-focused strategies (Lazarus and Folkman, 1984) on the other hand, appear to have more success, particularly in psychosocial functioning. These include "active strategies", (Friedman et al., 1988), "confronting", (Burgess et al., 1988). Traditional psychotherapy has been generally orientated towards helping the terminally ill patient manage the emotional trauma of the diagnosis and find meaning in their personal circumstances (Le Shan, 1989). Personal meaning most often determines which coping options are available to patients. As the disease trajectory progresses, it could be stated that the goal of psychotherapy is to provide psychological support while encouraging the patient to cope realistically with the illness and impending death (Bahson, 1975; Hackett, 1976). In 1978, Spiegel and Yalom's research with the terminally ill reported that group psychotherapy was the most successful method in assisting patients to adjust to their illness. Their recommended techniques were,

1. Modelling effective coping strategies of other patients.
2. Detoxifying dying.
3. Working through family problems.
4. Encouraging communication with health care professionals.
5. Living a full life in the face of dying.

The first technique could be criticised in so far as although theoretically admirable, within group situations it is often the case that individuals do not always recount the exact truth of their given situation. Consequently it may not be appropriate for some patients to model what they perceive as effective strategies in others. The second and third techniques are desirable but are applicable only to those patients who have not adopted “emotion-focused” strategies such as “denial” or “avoidance”. The fourth technique is extremely important to patient’s acceptance of their illness, however most research has shown that health care workers are generally too busy with the physical aspects of a disease to adequately deal with patient’s emotional concerns and anxieties. In addition, patients frequently fear realistic diagnosis of their physical illness (refer to p.23 - Meredith et al, 1996 study) thereby perpetuating the general pattern of infrequent, superficial conversation with health practitioners. Lastly the fifth method is feasible only to those patients in the early stages of a non-curable illness, when pain and exhaustion is either slight or readily treatable. However, Spiegel and Yalom’s (1978) research is commendable for two reasons. Firstly, it made a sincere attempt at establishing a means of enabling patients come to terms with the realities of their disease. Secondly it specifically concentrated on patients with non-curable illness. This type of research is rare as it is difficult to gain permission from Health Boards to interview terminally ill patients (Caddell, 2003b). In addition, working with seriously ill patients can be harrowing and technically difficult as researchers have to contend with frequent interruptions of their work due to medical intervention (pain control etc), patient exhaustion, physical illness (nausea and vomiting) and death. In 1983, Spiegel and Glafkides reiterated the findings of Spiegel and Yalom by stating that group psychotherapy was indeed helpful in helping terminally ill patients cope with the course of their disease. Their study found that group exposure to physically deteriorating cancer patients stimulated discussion of meaningful issues without producing or promoting negative affect. It could be argued that by merely experiencing contact with other patients and particularly health practitioners, a feeling of psychological well-being is generated which improves quality of life and coping ability.

The majority of research in the fields of cancer / oncology, approach the subject of coping from the perspective of a specific technique / strategy designed to aid patient recovery rather than

helping them manage (cope with) the last phase of their illness before death. For example, in 1986, Telch and Telch introduced “group coping skills instruction” modules whereby group members were instructed in behavioural strategies intended to facilitate coping. These included,

- A. Homework assignments
- B. Goal setting
- C. Self-monitoring
- D. Behavioural rehearsal and role playing
- E. Feedback and coaching.

In the same year, Cain et al presented a “structured thematic counselling mode”. Their group themes included,

- A. What is cancer?
- B. What are the causes of cancer?
- C. The impact of treatment on body image and sexuality.
- D. Relaxation.
- E. Diet and exercise.
- F. Relating to caregivers.
- G. Talking with friends and family.
- H. Goal setting.

In both examples, group member results indicated a superiority of coping skills in relation to affect, satisfaction with lifestyle, cognitive distress, communication and coping with medical procedures than those patients who had not participated in group therapy. Although some of these techniques would undoubtedly benefit patients with life-threatening illness, coping with a non curable, progressively worsening disease presents patients with series of physical, emotional and psychological problems. While goal setting, talking with friends and family, relaxation and relating to caregivers are significantly vital during terminal decline, other factors such as body image, sexuality, role playing and homework assignments inevitably cease to have prominence in the lives of those with non-curable illness. Frequently, retrospective examination of personal lifestyle occupies the mind of the patient often producing increased distress and emotional upset (Sweeting and Gilhooly 1991/92 – refer to p.55). A study by Philips and Osborne (1989) applied a phenomenological method of group therapy known as “forgiveness therapy”. This holistic approach to “mind-body forgiveness” encouraged sharing experiences among group members leading to eventual catharsis and peace. Criticism of this approach would undoubtedly centre on

the notion that all patients experience personal guilt for their illness and also whether any resulting benefits could be readily replicated. Nevertheless, recent research by Krivohlavý (2003b) stressed forgiveness as an important factor for optimal human functioning. Being a key element of the well-functioning human personality, Krivohlavý proposed that it enabled an insight into the relation between dispositional forgiveness and mental health.

One coping technique recommended in conjunction with “relaxation methods” is that of “imagery and visualisation” based on the work of Simonton et al (1978). Participating alone, patients are encouraged to imagine and visualise their own defence mechanisms, within their immune system, attack and conquer invading tumours. Research has recorded some success in this area in as far as there has been some regression of cancer tumours (Mears, 1982/83).

The human potential to cope in excessively stressful situations is generally greater than usually assumed (Bettelheim, 1986) although research has shown that it is rare when one coping mode is applied throughout the stressful situation (French et al, 1974). The latter used the term, “person-situation fit” which is particularly relevant to terminal illness. For example throughout the disease trajectory, individuals may choose the strategy most appropriate to the disease stage plus their own mental state and physical ability. During the initial stage, patients may concentrate on “visualisation” and “goal setting” techniques, whereas as the disease moves into the middle phase, they may direct their efforts towards group therapy, gaining information about the disease or partaking in counselling sessions. But during the latter stages of terminal illness, emotional exhaustion, physical weakness together with the side-effects of medication, may render the patient immobile and reticent of unfamiliar company. It is during this stage that “forgiveness-therapy”, relaxation techniques, faith or spirituality may be of particular benefit in providing the patient with a tangible means of coping with the process of dying. The latter undoubtedly presents the patient with intense emotional feelings and fears. In 1982, Parker & Brown pointed out that in Western society, death and suffering had become taboo subjects for 4 reasons,

1. Loss of traditional religious beliefs.
2. Medicalisation and specialisation in the care of the sick that separates the sick from common daily experiences.
3. A consumer-orientated, materialistic focus in society that values the replacement of the old with the brand new, thus de-emphasising and avoiding loss.
4. An association of a good death with “cleanliness” and a cultural obsession with youth as “clean and shining” bodies, which lead to an avoidance of death as a disintegration and decaying of the body.

Parker and Brown's four statements of cultural attitude (1982) still hold firm today. These combined with an ever increasing secular society almost pressurise the terminal patient into achieving what Bradshaw (1996) described as a "good death" (i.e. one which ends with the least amount of embarrassment and loss of dignity to the patient, their family and health-care providers).

It follows therefore, that some patients with life-threatening illness today may struggle to cope with death because of its taboo connotations and due to the previously mentioned topic of "ontological insecurity" (Tillich, 1952 p.62). Patients may very well follow Kubler-Ross's (1970) "stages of grief" but become so immersed in the "practical process" of dying that it is to this they devote much of their coping skills. If death holds no mysticism, spirituality or consequential meaning, then "a good death" in the sense of coping with hygiene, dressing oneself, defecation etc, may become paramount to the coping concerns of terminal patients. For other patients however, spirituality signifies the optimum coping skill. This was illustrated in a small research study conducted by Axelsson and Sjoden (1998) in Sweden. Results showed that among the 37 terminally ill patients taking part, "meaningfulness" in life and death constituted the item with the strongest correlation to "global quality of life". (Meaningfulness also correlated strongly with the existential domain). Although representative of only a small sample of population, this particular study was conducted over a three year period but was affected by common problems within empirical palliative research i.e. patient exhaustion; inability to complete the study and sudden death.

Threats to life provoke the most basic of emotional responses and behavioural reactions within the individual. Initial responses of shock, fear, anxiety, and grief, are generally followed by anger, depression and sadness. Unlike accident victims, those with life-threatening illnesses have a period of time in which to react and come to terms with the situation but as previously stated, an individual's personality, background, experiences and cultural beliefs can significantly influence their ability to cope (Averill, O'Brien and DeWitt, 1977). The primeval instincts of "fight or flight" are analogous to coping with non-curable illness in that the patient may respond with a "problem-focused" strategy (fight) or a "emotional-focused" one (flight). The latter involving, "denial" and "avoidance" denies the patient closure with both their family and themselves. The former while psychologically preferable presents the patient with arduous challenges. "Problem-focused" patients cope with coming to terms with the demise of their own life, settling affairs with family while managing the physical symptoms of terminal illness. Tyler's (1978) "effective

people” model is most appropriate to the “problem-focused” individual who can maintain self-esteem and derive satisfaction while coping with the physical and mental strains of non-curable illness. Inevitably some “effective-people” cope alone while others take advantage of group therapy or individual counselling sessions.

Chapter 1 highlighted various examples of research studies in which “coping processes” have been explored, and the mechanism by which individuals employ these processes during times of stress. What has become apparent however, is that in many of the studies reviewed, a wide variety of coping strategies have been presented with a view to alleviating personal stress and producing positive outcomes for participants. The question arises therefore, as to whether judgement of successful outcomes are arbitrary or whether criteria have been established against which results may be assessed. For example, is patient longevity the pinnacle of coping efficacy or are “quality of life” measurements the determining factor in successful as opposed to unsuccessful coping attributes? Does lack of complaint and control of emotion indicate positive coping attainments whereas demonstrations of rage and outbursts of anger signify negative coping abilities? Emotional and psychological distress, together with the measurement of longevity, featured in the Greer, Morris and Pettingale (1979) study (p.25) where it was found that among women with breast cancer, those who expressed denial, or a fighting spirit outlived those women who had expressed feelings of hopelessness or acceptance. In 1978, Holden (p.26) also used the same criterion of longevity when results recorded that the more despairing, less social patients tended to die before those individuals who expressed anger towards both their disease and their doctors. (Other studies using longevity as a criterion are also recorded on p.26).

Measures applied to achieve the alleviation of psychological anxiety were used in research by Schultz (1978) – p.26, by Koenig, Pargamaent and Neilson (1998), p.32 and by Folkman (1997) – p.69), and as such may indicate the type of information considered relevant of inclusion into coping efficacy evaluations. But the problems associated with judging and clarifying efficacy still apply. For example, is good coping simply a matter of choosing the correct strategy at the correct time or is it a question of applying a chosen strategy effectively? These issues were highlighted in the Lazarus (1993) study – (p.68), the Folkman (1997) study – (p.69), the Spiegel and Yalom (1978) study - (p.71) and the Cain et al study (1978) - (p.72). Personality and self-esteem may be other areas of importance to coping efficacy although these attributes can be applied to individuals in opposing ways. Firstly there are those referred to by Tyler (1978) as “effective people” (see p.76) who adopt Lazarus and Folkman’s (1980) “problem-focused” approach while

others adopt the more common forms of coping techniques- “denial” or “avoidance” (i.e. “defence mechanisms”, Lazarus and Launier, 1978). Yet, significantly, it must be asked whether the “problem-focused” approach has in fact been established as the more effective technique for all patients. Although the latter approach has been correlated with higher measures of self-esteem (Spilka, Shaver and Kirkpatrick, 1985), it is open to question whether “defence mechanisms” are poor or unsuccessful strategies in coping efficacy. In fact, they may prove to be highly effective coping mechanisms – for some patients.

Considerations of whether patients can be taught to choose the correct or most appropriate strategy (see Pequegnat below) was highlighted in the Spiegel and Yalom (1978), Spiegel and Glafkides (1983) and Telch and Telch (1983) studies – (refer to p.72). These may again point to areas worthy of inclusion into coping efficacy guidelines but the question must be asked whether procedures promoted in these studies advocate higher coping attainments for patients who choose to take part in them or are they simply providing a type of group therapy?

Interestingly, the “intercessory prayer” study (Byrd 1988, p.46) listed a number of specific medical interventions relating to outcomes in the control and experimental groups. For example, more frequent use of ventilator assistance, antibiotics and diuretics etc was required by the control group. However whether these specific outcomes could signify negative criteria in all “coping” assessments is again open to debate.

In 1998, Pequegnat presented a paper to the Institute of Mental Health in Rockville (USA) on the subject of coping with HIV and AIDS. His concluding section called for more research into the examination of successful coping styles and coping repertoires. He questioned whether good coping skills could be taught - with a view to improving quality of life and the subsequent possibility of bolstering the immune system. He recommended research into,

1. Identifying predictors of failure to cope, or maladaptive coping.
2. Develop interventions to teach the identification of problems and effective coping.
3. Investigate the role of hope and its components in effective coping.
4. Identify biopsychosocial factors that predict which patients survive over long-term treatments. (Do these survivors have personality traits indicating “a survivor personality”?)
5. Identify quality of life measures specific to the needs and lives of HIV and AIDS patients receiving long-term medical treatments.

These are important recommendations which will be identified and appraised within the present research. Nevertheless if they were to be used by health care providers, they would inevitably become subject to criticism as each assessment would be subject to individualistic preference. Within coping research, there is general agreement that coping activity is judged to be effective or ineffective thus promoting the notion of good or bad choice on behalf of the individual / patient. Wrubel, Benner and Lazarus (1981) and Lazarus and Folkman (1984b) tried to break away from this viewpoint by distinguishing between coping activity and coping effectiveness. This allowed for a separation between the activities of the person and the effect they had on eventual outcome. Within most research, an assumption tends to exist whereby the judgement of someone outside the situation i.e., health care provider or researcher, is thought more superior to that of the individual within the situation. This is a negative approach as it denies the personal meanings, which make a particular action correct for an individual even although it may not necessarily be good for them. In the majority of stressful circumstances, the choice of coping strategy is of a temporary nature, leading to eventual successful outcome and cessation of stress. This factor probably contributes to the surprising uniformity in categories within coping modals (eg. Heim, 1988 and Haan, 1977) on the subjects of favourable as opposed to unfavourable coping. Examples of these are “tackling problems” as opposed to “resignation/fatalism”, “attention and care” as opposed to “isolation and social withdrawal”, “optimism “ as opposed to “rumination”, “acceptance and stoicism” as opposed to “denial”. The subject of investigation within the present research concerns how individuals cope with life-threatening illness and as the nature of the topic negates favourable outcomes (in the sense of a cure) there is always the possibility that coping preferences may not comply with those quoted above. For example, repression, denial and suppression of feelings may feature more significantly among the terminally ill population, which once again raises the question of whether judgement of successful or unsuccessful coping should be standardised or subject to criteria evaluation.

The majority of studies within the Literature Review considered the consequences of negative events on individuals who adhered to spiritual or religious beliefs. Spilka, Shaver and Kirkpatrick (1985) for example, asserted that to a degree, religious beliefs can serve a number of psychological functions. In so far as they are integrated into the religious person’s view of the world they can, during times of intense stress, offer a sense of meaning to seemingly unanswered questions. Spilka, Shaver and Kirkpatrick 1985 (p.44) and Pargament and Park, 1995 (p.45) raised the concept of “a vengeful versus a benevolent God” and how an individual’s interpretation



of these issues can effect their sense of meaning, self-esteem, and control in their lives. For example, in an interview study of patients with advanced cancer, reports of religious beliefs were associated with lower levels of reported pain and greater happiness – Yates et al, 1981. Conversely, the Literature Review made mention of decidedly more negative conclusions regarding the same concept (Sontag, 1977, p.40). The subject of spirituality and religiosity opens up challenging areas for researchers interested in investigating the relationship between religious and non-religious coping especially in the face of negative outcomes over which there is no control. The work of Koenig (1999) and Pargament (1990) (both leading proponents in the field of coping and religiosity) focused on whether people in stressful situations, including terminally illness, turn to spirituality or religion as a means of coping.

In 1990, Pargament et al proposed that,

“The key to good coping lies in the whole process – how well the system works together” (p.798).

Pargament is also one of the few authors who has sought to project the specific influence of religious belief into the wider arena of “the coping process” by offering some criteria for evaluating effectiveness. Pargament justifies the study of religious belief since it is integral to many global societies, and as such, well suited to cross-cultural studies. Its study, he proposed, also helps connect it to other areas of scientific investigation such as sociology, psychology and anthropology and in so doing, may help remove some of its abstract connotations. Pargament proposed that “religious coping” should be considered as an area of coping within the overall coping process – to those individuals for whom it has meaning. In addition, he stressed that some religious individuals may choose not to involve their religious beliefs in the coping process in the same way as some non-religious (and religious) people often adopt “denial” or “avoidance” strategies.

Although focusing on religion, Pargament (1990) offered the following criteria as a means of evaluating the effectiveness of the coping process.

1. “Comprehensiveness” – Pargament explored whether it (religion) can include a variety of situations? For example, he alluded to instances when individuals tend to rely on their belief system during times when life is going well. However in times of crisis, the same individual often experiences difficulty in accessing their belief system (as a coping mechanism) due to overriding feelings of guilt brought about by fears of punishments vented by a vengeful God. In these circumstances, and to these individuals, religious coping is ineffective since it is not comprehensive. This is undoubtedly true of many individuals adhering to a more fundamentalist type of religious belief. However the majority of religious adherents seem to

dismiss the notion of a vengeful God as a concept more in keeping with a bygone age, preferring to opt for a more liberal view of God as “all loving” and “all forgiving”. In these instances, it would seem logical to conclude that this type of religiously orientated individual would use their belief system as an aid or comfort in times of severe stress.

2. “Flexibility”- This issue Pargament related to comprehensiveness in the sense that the individual’s capacity to cope with new ways of looking at their beliefs becomes challenged. He pointed out that former coping aids (such as religion) may in fact limit rather than extend the individual’s capacity to discover new mechanisms to deal with stressful occurrences. Consequently, he argued that flexibility was an important asset, and one which must be included in any estimation of coping criteria. For patients with life-threatening illness, it could be argued that flexibility and choice may not be helpful or even applicable. Generally fatigued and confused, seriously ill individuals may cling rigidly to long held beliefs (such as religion) as the most beneficial coping aid since little cognitive effort is expended. The notion of exhausted individuals actively seeking alternative areas of coping is not tenable. Thus in this instance flexibility would be inappropriate as a coping mechanism although in situations where health status is not an issue, it may prove a rich source of alternative thinking.
3. “Integration” – This concept, Pargament separates into 2 areas – personal and social. He proposed that some individuals choose to believe in a God who can intervene in the day to day lives of human beings. Consequently, in stressful occasions, they may use this belief to beseech God for a favourable outcome – while others (adhering to the same belief) may choose to ask God for the strength to help them through the negative situation. Others place the inevitable outcome “in the hands of God”, while some individuals strive to “work with God” to resolve their problems. Pargament questioned whether these types of coping processes “fit with the nature of the larger social system” (p.810). An element of fragmentation may exist in these examples due to a lack of fit between an individual’s beliefs and society’s norm. Pargament is prompted to inquire whether these types of coping strategies are “suited to the demands of the situation?” (p.810). This is similar to the French et al 1974 study (p.73) which referred to the same situation as “person-situation fit”.
4. “Benevolence and Fruitfulness” – Pargament equates coping efficacy with concepts of a benign world in which individuals have the ability to deal with their problems free from fears of wrathful Gods or similar ideologies. Effective coping is also fruitful in the sense that it should lead to a good outcome, not only for the individual but for society in general. Arguably this is too idealistic a projection for those confronted with stressful situations within today’s western culture. Altruistic thoughts of what is best for society will most often not be consciously taken into consideration by anxious / confused individuals engulfed within stressful circumstances. Nevertheless from a historical perspective, these criteria may be important to psychologists / psychotherapists in evaluating effective as opposed to ineffective coping strategies during specific events in history. Coping methods deemed the most effective could then be suggested to those individuals who choose to partake in counselling sessions.

Pargament (1990) stressed that the above 5 criteria were not so rigid as to be applied only to religion or spirituality. Their form and content could be applicable to other areas of coping, - (eg - “psychoneuroimmunology”, Glaser and Glaser, 1995, p.20) or “psychobiology” (Frankenhaeuser,

1979) – refer to p.20 – or “exercise and meditation”, Leventhal et al 1986, (p.70) and vary from person to person, within different cultures. He concluded that they did however provide,

“...some standards for evaluating effectiveness both within and across social settings, so we are not left with the problems of a completely relativistic point of view” (p.191).

In concluding this section concerning the concepts of coping, coping strategies and coping criteria, it is worth stating that some patients seem to cope with terminal illness in the same way relatives cope with bereavement. As previously stated, research into the subject of how patient’s cope with life-threatening illnesses is scant, however a search of the literature on the effects of bereavement reveals interesting analogies between patient coping and relative’s bereavement patterns. Just as some patients adopt strategies of “denial” or “avoidance” during terminal illness, some bereaved relatives try to avoid painful reminders of their loss by clinging to unrealistic fantasies such as the dead person is still alive. Interestingly both groups struggle to exclude the reality of the situation by embracing medical interventions (pain relieving drugs, sedatives and tranquillisers). By so doing the unrealistic dimension of these tactics can become further compounded by medical practitioner’s belief that they have helped to alleviate a crisis when according to Parkes et al (1996) all they have done is to postpone it for relatives and create new problems for patients. This type of coping once again mirrors the “emotion-focused” style proposed by Lazarus and Folkman (1984c).

The “problem-focused” (Lazarus and Folkman) bereaved relative suffers from the same degree of stress, shock, anxiety, depression and grief as that experienced by the “emotion-focused” relative but differs perhaps in personality factors such as self-esteem and confidence. These qualities produce individuals whose principal intent is to direct their behavioural and cognitive strategies towards a programme of coming to terms with the realities of non-curable illness. Grieving for the loss of one’s relative is similar to the grief patient’s experience in the realisation that personal control must be relinquished in favour of medical intervention. According to bereavement studies (Parkes, Relf and Couldrick, 1996) bereaved relatives experience two important “phases” in which counselling services should be offered –

1. Impact
2. Adjustment.

Interestingly, the initial “impact” of shock and numbness following the death of a relative is similar to the shock and numbness experienced by the patient following diagnosis of a life-

threatening illness. If Kubler-Ross's (1970) "stages of grief" for patients model is correct, initial shock is often followed by a period of disbelief and anger before the second "phase" of acceptance and "adjustment" is reached. However the important factor in this analogy is that the terminally ill patient is offered equal amounts of counselling opportunities during the periods of impact and adjustment, as the bereaved relative. "Problem-focused" patients with life-threatening illness know they have a short time only to settle relationships and any outstanding differences with family and friends. Parkes, Relf and Couldrick, (1996) research highlighted the fact that those who have anticipated a loss and who begin the process of "emotional inoculation" or "anticipatory grieving" cope better with the process of dying (patients) and bereavement (relatives) than those who have undergone no such preparation. Parkes et al (1996) also stressed that grieving required individuals to,

1. Accept the reality of the loss.
2. Work through the pain of grief. (p.142).

Again both requirements are applicable to the coping strategies of the patient as well as the bereaved. Parkes, Relf and Couldrick, (1996) proposed that the "pain of grief" could be worked through counselling sessions to enable relatives accept the "reality of loss". The authors used LePoidevin's (1989 - unpublished) widely used "dimensions of loss" sessions. Parkes, et al stated that they constituted,

"... a practical tool which enables us to examine systematically each of the main ways in which bereavement influences the human mind, body and social network, and to remind ourselves what problems and resources can be brought to bear" (p.147).

The dimensions are (pp. 147 –148),

1. Identity – "Identity includes the ways in which bereavement affects our inner world, the way we think about ourselves and our capabilities".
2. Physical - "The physical dimension includes stress related symptoms as well as minor illnesses reflecting loss of resilience. It is not uncommon for bereaved people to imagine that they are suffering from symptoms similar to those suffered by the person that has died. Whatever the cause of these symptoms, the more people worry about them the worse they tend to get. It is always wise to ask clients about their health if this has not been discussed in the course of a meeting".
3. Emotional – "Emotional components may be expressed or hidden. Men are particularly likely to conceal their feelings. This may have an important influence on their well being and may cause great concern if their feelings break through, or give rise to psychosomatic problems if they are repressed. Although it is unwise to force people to express feelings that are being repressed, a simple question – How do you

feel about that? – will often give people the permission they need to acknowledge the existence of feelings”

4. Family / Community - “Family and community are important influences and may themselves be affected by the bereavement. Counsellors should find out how the family are responding to the loss and whether such responses are helpful or unhelpful, what support is the client receiving from or giving to others, and what new roles the client is taking on”.
5. Lifestyle – “Lifestyle is often affected by the loss. The counsellor needs to know how the clients financial status, housing and occupational prospects have all been affected”.
6. Practical – “The practical dimension includes the bereaved person’s ability to cope with the demands of everyday living, looking after children or other dependants, getting to work and so on”.
7. Spiritual – “ The spiritual dimension is essentially concerned with finding meaning in life. It is important for the counsellor to understand how bereavement has affected the bereaved person’s beliefs about the world, faith and spiritual core”.

Although these dimensions are applicable and beneficial to bereaved relatives, it is noteworthy that the same dimensions could also be applied to patients. The first dimension, “identity” is of equal importance to the patient for as previous research has established, the coping strategies chosen by patients are directly attributed to self-esteem and self-confidence (Tyler, 1978). The second dimension, “physical” is also of particular importance to patients with life-threatening illnesses because research has shown that patient’s deteriorating physical condition is often not as a direct result of their illness but due to anxiety. According to Parkes, Relf and Couldrick (1996), healthy people experience a multitude of aches every day but are not unduly concerned. People with non-curable illness, on the other hand, differ in that they,

“...focus their attention upon the ache and worry it into a pain. Such worry causes the pain to get worse, as does any sensation that is magnified by fear” (p.86).

It follows therefore, that patients who learn to control fear may attain a distinct coping advantage over those who are unable to do so. The latter point should also encourage patients (particularly men) to confront and acknowledge the existence of their emotions (third dimension). The fourth dimension (family/community) is once again of equal importance to the terminally ill patient as it is to the bereaved relative. Patients often experience communication difficulties with their relatives and vice versa since both must come to terms with eventual grief and loss. Coping with

the process of dying can be difficult for both patients and relatives. According to Wilson et al (2000),

“Pain, nausea, weakness, incontinence, mental confusion, helplessness, loss of privacy and independence – all of these may be part of terminal illness. And both for the person dying and their loved ones, there is emotional turmoil; anger tears, fear and uncertainty” (p.34).

This particular “pain of grief” is applicable to every patient who is part of a loving family. Consequently where counselling is offered to patients concerning communication difficulties with their families during the span of a terminal illness (and not just during relative’s bereavement), this should greatly assist their coping management skills.

Discussion of patient’s changing lifestyles and circumstances (Dimensions 5 & 6 Lifestyle & Practical) within group or solo counselling sessions may help individuals come to terms with the severity of their illness and the practical reality of their altered lifestyle. Counselling may also allow them (perhaps for the first time) to publicly express emotional concerns regarding themselves and their families. Once again, these factors highlight the interesting analogy between the plight of grieving patients and that of grieving relatives.

The last dimension (Spiritual) is of particular interest because it is a central focus of the present research. Trying to find meaning, and attempting to make sense of the circumstances of living with death and dying are spiritual issues that are as important to the majority of patients, as they are to bereaved relatives. The former also suffer from a loss – that of their former identity and continuing way of existence. Researchers such as O’Connor et al (1997) argue that the concept of “making sense” is central to all aspects of spirituality and may indeed be its most fundamental characteristic. These attitudes, they propose, are crucial to the patient’s well-being and quality of life during the span of a life-threatening illness.

The subjects of religiosity and spirituality are difficult concepts to both determine and distinguish. O’Boyle (1996) stressed that spirituality and religious belief were not synonymous and that this should be recognised by health care providers. Spirituality for example, is very important to some patients as results of studies investigating this subject illustrated (Gibbs, and Achterberg-Lawlis 1978, Miller, 1985 and O’Brien, 1982a – see p.37). With a view to attaining clarification on these subjects, since they are of importance to the present study and its empirical research, the remainder of Chapter 2 will be devoted to rendering some explanations of these issues. Definitions of religion and spirituality will be offered together with an account of their origins

and why it is that terminally ill patients today may use either or both as coping strategies during their illness.

## Religion

At the outset it is important to point out that the terms “religion” and “religious belief” will for the most part relate to and be directed towards the Christian faith. This is because the majority of studies and research relating to religiosity and coping strategies during ill health and life-threatening illness have been written from the perspectives of the Christian tradition.

Religion and religious belief has been an integral part of the thoughts, rituals and activities of the human race from the beginning of recorded history (and very probably long before), evolving and expanding within the psyche of the species, from the most primitive of ancient cultures, to the present era. Most definitions of religion include the fundamental belief that men and woman strive to attain the highest possible good in their way of existence on Earth, following doctrines and teachings which have been passed down to them, in order to achieve spiritual, eternal happiness following their earthly death. Beliefs such as these have transmitted from one generation to the next, initially orally and then in written form, establishing the common consensus among historians and philosophers that religious belief evolved around social contexts. Durkheim (1915) nevertheless argued against this premise when he posed the question –

“ If religion is the product of social causes, how can we explain the individual cult and the universalistic character of certain religions? If it is born “in foro externo”, how has it been able to pass into the inner conscience of the individual, and penetrate there ever more and more profoundly? If it is the work of definite and individualized societies, how has it been able to detach itself from them, even to the point of being conceived as something common to all humanity?” (p.424)

Durkheim conceded that religion was a force which “animated the clan”, but stressed that this force became “particularized by incarnating itself in particular consciousnesses” (p.424). The concept of individual and collective consciousness was prominent in the writings of Jung (1928). From his extensive research into religiosity, he formed his proposition of “archetypes”. These he described as universal elements pertaining to the faculties of imagination and creativity which have been inherited since ancestral times and tend to be reborn from the unconscious to the conscious. Jung proposed an archetypal image of God, although not as a spiritual being as such, but as an illustration of the dynamic relationship between the elements of good and evil. O’Doherty (1978), described Jung’s (1928) idea of religion as,

“..... a purely psychological phenomenon composed of emotional and imaginative elements, from which all rational, spiritual, supernatural and objective content was expunged.....He thought that such things were

in any case unknowable. He prescind from the existence of God and regarded the propositions of all religions as equally true, having what he called "psychological truth", that is, they were true for those who believed them" (p.15).

Most researchers writing about the origin of religion in ancient times however, search for answers within cultural practices, including traditional ceremonial rights as well as magic and supernatural belief systems. Tylor (1873) for example, defined religion as a "belief in spiritual beings" while Geertz (1966) proposed an altogether more eloquent hypothesis, proposing religion to be,

"A system of symbols which acts to establish powerful, pervasive and long-lasting moods and motivations in men by formulating conceptions of a general order of existence, and clothing these conceptions with such an aura of factuality that the moods and motivations seem uniquely realistic" (p.36).

Thouless (1924) argued that in order to be described as religious, individuals must possess a system of feelings, a mode of behaviour and intellectual opinions which culminate in the belief that, "religion is a felt practical relationship with what is believed in as a superhuman being or beings" (p.4).

Another researcher, Burkert (1996), proposed a biological theory in his assessment of the origin of religion in ancient times. In a recent publication, he theorised that the human capacity for communication through language, gives culture a range of capacities that biology did not give other species. Thus within a social context, Burkert expounds the notion that in order to create a stable and orderly world of human exchange, hierarchy was necessary within that culture and those who ranked highest, began to communicate with the "divine" in order to transmit information between humans and Gods. In this way social order was enhanced and with Gods as guarantors of human transactions. Most importantly, the ethical demands of the deities guaranteed the social order. At this point, allegiance, oaths and rituals began to play a central theme in ancient religions. Those taking the oaths were held accountable not only by the high-ranking witnesses of the tribe, but also by the Gods. Burkert attested that,

"All the gods and powers venerated by established tradition who guarantee hierarchical order, who are made partners in gift exchange, who are experienced in terror and held responsible for the well-being or illness of the individual, the family, tribe or country, are used in the context of oath-taking, and prove to be useful indeed. The guarantee of absolute truth is with god. (p.172).

Burkert's theory is that religion originated in the human species as genetic developments which made communication possible. Through language and then ritual, beliefs and myths began to become ingrained into the human psyche, passing from one generation to the next in a way similar to Jung's (1928) archetypal images and memories. Religion therefore was able to persist and survive throughout human history because it is become viewed as an adaptive strategy for survival in the face of external threats. Practising ancient religions in the forms of rituals and



oaths of allegiance to the superhuman powers would guarantee survival and continuation of the system. Burkert attests that religion is generic or natural -

"Natural religion, that is, basic and common forms of addressing the supernatural, did not develop in a void but through adaptation to a specific "landscape", conditioned by the age-old evolution of human life" (p.21).

In 1975, Scobie also speculated that that ancient religions evolved as an evolutionary process, -

"It is not surprising that a wealth of information about religious ideas and beliefs arises from anthropological studies of primitive cultures. It would appear that most, if not all, primitive societies have their own religious myths, legends and rituals.....In general, religion is seen as an evolutionary development. Man first worshiped the spirits that dwelt in the rocks and trees, i.e. animism. From this he progressed to totemism, where an animal or object became the emblem or symbol of the tribe; and then to pantheism, the recognition of a spirit or being indwelling the whole of nature. Then there arose polytheism, the idea that there are many gods, each one with a specific function or location. Monotheism, the concept of one God, represents the height of religious development" (p.17).

O'Doherty (1978) extended the origin of religion theory by stating that,

"The facts that the idea of God is borne in human images or that prayer is akin to ritual, appear to have constrained the analysts to say that therefore religion is a subrational process. On the contrary, however, since religion is God's revelation to man we should expect to find it in just those elements that cater to our needs. If God reveals himself to man he will do so on terms of man's nature and through the normal channels of acquiring knowledge. The fact that a religious function satisfies a non-rational process or need does not negate its religious value. But we must be clear that the religious value does not derive from the infrarational" (p.19).

Durkheim (1915) stated that there was no time when religion came into being and therefore it was fruitless to pursue the quest, but most historians try to study and explain religion through historical events which have occurred within social contexts. These events often caused a change in attitudes and morals, changing substantial aspects of religious adherence. Central to the Judaic and Christian traditions were the revelation of Yahweh to Abraham and the birth of Jesus Christ in Bethlehem respectively. Both heralded a new philosophy, which is still reverberating and influencing intellectual thought today. Swinburne (1977) proposed that succeeding generations have always discussed God's existence and that their view of God has been formed by,

"the clear and unambiguous picture of God in the Old and New Testaments, and Jews and Christians have formed their ideas of God by continual study of the Scriptures" (p.7).

The dominant ideology of the Bible themes became legitimised and maintained throughout succeeding generations. Harris (1984) made a powerful case for the survival of both traditions but particularly the Christian religion by way of the fact that its particular ideology has been continuously available and widely disseminated in a multitude of forms, including stained-glass windows for those unable to read. Harris proposed that,

"The hegemony of biblical codes and ideas permeates just about every aspect of our Western way of life, from codes of behavior and law, to morality, as well as to the way our passage of time is structured around religious holidays" (p.8).

In 1973, Mitchell stated that it was only due to God's choosing to reveal Himself to man, that mankind knows anything about God at all. This is a profound statement and one which requires faith on behalf of believers in order to assimilate the enormity of the concept involved. In 1924 Thouless stated that faith and belief are often determined more by the will and the wish to believe than by the intellect, or any sense of truth. In other words, they are very often affectively determined and sometimes irrationally construed. Nevertheless throughout history, scholars, theologians and religious mystics have provided substantial accounts of reasoning as to the existence of God as creator of the world. Great thinkers such as Aquinas (1265) and Descartes (1641) strove to understand the nature of God by presenting and analysing evidence and arguments. Messer (1993) pointed out the fact that up until the Enlightenment, Western philosophy was largely concerned with classical theism found seminally in Aquinas.

Aquinas, (1224-1274) priest, theologian, and philosopher is considered to be one of the greatest Christian philosophers of all time. His "Five Ways" was a presentation of philosophical thought and deductive reasoning contained within the "Summa Theologiae"(1265-74), leading to the rational conclusion that, God exists. Aquinas observed that the universe worked in such a way to be concluded that it was designed by an intelligent designer by whom all natural things are directed. This designer, Aquinas concluded was God. Although written in simple language, the "Proofs" contain logic of such scholarly profoundness as to merit their discussion throughout the centuries by critics and advocates alike. For example, based on Aquinas' Five Ways, Descartes (1641) expanded the "ontological" argument that existence is perfection; non-existence an imperfection. The idea of God is the idea of a perfect being. Therefore a perfect being has existence as one of his attributes. In other words, God exists. In 1924, Thouless while exploring the psychology of religion, raised the traditional argument of belief in God from experience. Referring to the "Five Ways", he surmised,

"What is called the "cosmological" argument infers God from the necessity to account for the beginning of the chain of causal sequence. Every event in the world has its cause in some previous event which was itself similarly caused. Once such a series of events are started, it may go on for ever, but there is no reason in itself why it should ever have started. A first cause must be assumed which is God" (p.79).

Thouless (1924) also described the "teleological argument", as creations of nature which seem to indicate particular characteristics of a common creator. He stated,

"Living things show in their structures evidences of order beyond what can be conferred by the operation of physical laws. Things seem to have a purpose to fulfil beyond that of their own existence, in their effects on other things. Thirdly, it is sometimes urged that a single order, a unity, is observed in the whole of things. In each of these cases, it is argued that such marks of design point to a designer" (p.80).

Swinburne (1977) construed the traditional "Proofs" as attempts to show that it is probable that God exists, especially if used in conjunction with Bayes Theorem.

In a recent BBC Radio 3 interview (December 2000), Joan Bakewell talked to Professor Paul Davies about today's scientific advances and whether they could shed light on the origins of the universe. As a mathematician and physicist, Davies professed that most scientific discoveries seem to follow certain rules and patterns –

"I believe there is a real existing order in nature that we discover through doing science and so since this is an intellectual input, you can't avoid the fact that there's got to be an intellectual input, that there's something clever, something really ingenious, rational and intelligent to us out there in nature and the word of God seems to encapsulate that very well ..... But the God we're talking about is not a cosmic magician, not some miracle working super-being".

Davies although not declaring a belief in a traditional understanding of God nonetheless alluded to the same notion of cosmic designer as did Aquinas. Religion, he proposed, does seem to, "fulfil a social and psychological function" for those who believe, but if God exists, Davies was adamant that He did not "interfere in earthly happenings".

Davies (2000), when persistently asked by Bakewell whether science was able to prove the existence or non-existence of a creator, responded by stating that at this present moment in time "the methods of fundamental physics are simply inappropriate" to determining an a decisive answer. Nevertheless, he propounded –

"What strikes me is that there is something purpose-like, design-like, goal-like in all this... I think it's legitimate to say that in some sense the universe is about something..... it's not just arbitrary and absurd..... I think the originating event (the big bang) can be brought within the scope of science. I think we can have a thoroughly scientific account of the universe at all times, including the origin of things. But you have to ask, - where do these laws come from? Why those laws and not some other set. is there anything special or peculiar about the actual laws?

Davies's views challenge previously adhered to scientific theories of a universe without a God. Interestingly, as an eminent mathematician and physicist he is questioning his own former convictions using a similar deductive logic to that contained within the writings of the "Five Ways".

One of the strongest arguments supporting belief in God's existence, comes from the moral and ethical code of human conduct and consequently named the "moral argument" (Newman, 1801-

1890 for example, proposed that the consciences of human beings illustrated the ultimate proof of there being a God and Creator). In most cultures, humanity recognises the concepts of good and evil and the belief in God as infinitely good. Whether considering themselves to be religious or otherwise, the majority of humans on this earth conduct their lives in such a way as to promote good deeds over evil ones. Within western cultures, books, plays, films, television etc., portray scenarios in which good prevails (and is expected to conquer) evil. This fact is so common that it is often taken for granted and often overlooked. Many individuals have never thought to contemplate the consequences of a world in which evil thought, deeds and actions were not only the norm, but promoted as being desirable.

However it cannot be denied that evil exists within the world and its very existence has been cited as an example of why God's existence is questionable. Phillips (1966) for example regarded theodicies as morally and grammatically "misconceived projects" to justify God in the face of evil. If God is "the supreme spirit" (in Christian terminology), and mankind is formed in His image, then evil must be an overwhelming moral objection to God's existence. Phillips concluded therefore that God could not be an existent, because if he were, he would be morally culpable for evil. Augustine, reflecting upon this enigma in the 6th century wrote,

"Since God is the highest good, He would not allow any evil to exist in His works, unless His omnipotence and goodness were such as to bring good out of evil" (Enchiridion xi).

This he proposed was part of the infinite goodness of God, that He should allow evil to exist, and out of it produce good.

For Wittgenstein (1961), belief in God ought to be regarded as a type of yardstick for contemplating one's life and existence on earth, and not as something to be inferred from some other measure such as philosophical reasoning. Belief in God is a way of looking at the world and not the result of simply looking at the world and then trying to explain it. - (Messer, in his 1993 publication gives an excellent account of the diversity of opinions between Swinburne from a rationalist tradition of the philosophy of religion and Phillips from the Wittgensteinian school of religious philosophy. Although too detailed to be included in this section, with its aim of presenting various definitions of religion and religious beliefs, it would nonetheless furnish the interested reader with considerable information in contemporary religious debate).

Traditional philosophy of religion holds that religion is written in such a way as to project facts about the existence of humankind. Hick (1983) for example wrote,

“This deeply ingrained tendency of traditional theism to use the language of fact.....traditional Christian and Jewish faith has always presumed the factual character of its basic assertions” (p. 94),

Swinburne (1977) also alluded to,

“The vast majority of those who have used religious language have certainly treated the affirmation that God created the world as the confident propounding of a hypothesis explaining its existence” (p.92).

The meaning of religious language is different from ordinary language because belief in God necessitates the acceptance of a transcendental being for whom no earthly equivalent is possible.

Swinburne (1977) proposed that the cognitive nature of religious language implied that believers hold God to be an eternal, independent reality to which true religious statements correspond. This view, Swinburne proposed, can be borne out by

“ an extensive sociological and literary survey of what the utterers of theological sentences suppose to be implied by what they say” (p.93).

Swinburne (1981), presented this personal definition of religion -

“I propose to understand by a religion a system which offers what I shall term salvation.....I shall understand that a religion offers it if and only if it offers much of the following: a deep understanding of the nature of the world and man's place in it; guidance on the most worthwhile way to live, and an opportunity so to live; forgiveness from God and reconciliation to him for having done what we believe morally wrong; and a continuation and deepening of this well-being in a happy after-life” (p.128).

The ideology of living life in accordance with God’s commandments, in order to attain spiritual existence in Heaven, is fundamental to the Christian and Jewish faiths. As Ford (1999) pointed out, the character and initiative of God is central to the idea of salvation and for Christians, the character of God became revealed in the incarnation of Jesus Christ. To critics of religion this alliance of the human and the divine provides fuel for derision. Ford (1999) however proposed that,

“Thought about salvation also needs to take account of the whole natural world and the cosmos, the knowledge of it in the sciences, and aesthetic appreciation of it..... The God who saves is discerned in evolution and in human history, including the secondary creation produced by human beings in cultures, cities, technologies, and other transformations of nature”(p.104).

As Ford (1999) explained, the knowledge of “God” first became revealed in the stories of figures in history such as Abraham, Isaac, Jacob and Moses. Such stories revealed God’s compassionate involvement in the sufferings of humans and were recorded in written language, which evokes comparison to epic cinema screen productions. When God revealed to Moses the mysterious

name - “I am” - that statement was able to convey to humans, the power of a being so superior in intellect to themselves that it defied comprehensive ability. The same perception of awesome power was later to be repeated in the life of Jesus Christ but most particularly in his death and resurrection. Ford declared that,

“.....The resurrection was a God-sized event.....The resurrection was the great surprise. The first Christians ascribed the raising of Jesus from the dead as comparable to creation. The content of this event was the person of Jesus who in this way could be seen as identified with God by God. Jesus was seen as God’s self-expression (or Word), intrinsic to who God is, so that their worship began to include him” (p.36).

Many opponents of Christianity often overlook the fact that adherents to religious belief base much of their convictions on the sacred and ancient writings of the Bible and the newer and radical writings contained within the Gospels of the New Testament. Ideology from these Gospels has contributed much to the ethical codes and practices of Western civilised societies, particularly in spheres connected to healing and care of the sick. Often as Danforth (1989) pointed out, ideologies are constructed not so much with the view of understanding the world but with living in it successfully –

“....religious ritual often concerns itself with the problems of human suffering by placing it in contexts in which it can be expressed, understood, and either eased or endured” (p.54).

While recognising the impossibility of providing absolute proof for the authenticity of Christian ideology, Plantinga (2000) nonetheless put forward a theory which he proposed to be rational and worthy of consideration as an epistemic model. The latter consisted of 3 main themes –

1. The Bible
2. The Holy Spirit.
3. Faith.

According to Plantinga, humans were,

“....created in the image of God.....with affections and with knowledge of God and his greatness and glory” (p.126).

But due to an undocumented catastrophic and disastrous event, humankind gained knowledge of “sin” which resulted in an initial separation from their Creator. According to the modal, God eventually instigated a reconciliation process involving redemption and salvation for those who chose to believe. He did this in the form of a “three tiered cognitive process” (p.126) namely, the Bible; the suffering and death of Jesus Christ and lastly the Holy Spirit and Faith.

Plantigna (2000) summarised the essential features of the modal thus,

“The internal instigation of the Holy Spirit working in accord with God's teaching in Scripture is a cognitive process or belief-producing mechanism that produces in us the beliefs constituting faith.” (p.141).

These beliefs, Plantigna (2000) believed, were justified, rational and warranted to those humans who chose to believe in their authenticity. In addition, the holders of such beliefs did not merit the criticism of being cognitively dysfunctional because if indeed true, the beliefs have been generated by a special working of the Holy Spirit. Although there has been philosophical objections to the truth of Christian belief, Plantigna claimed that in its actual content, his modal could withstand any objection levied against it.

The writings of great philosophers and theologians such as Augustine and Aquinas spread Christianity throughout the Western world influencing not just religious teaching, but underpinning much of the social, cultural, political and morality aspects of governmental policy in these regions. (Included within morality issues were matters of health and sickness). Belief in the miraculous occurrences associated with the life of Christ and adherence to the Christian religion remained fairly constant from the 3<sup>rd</sup> century AD until the end of the first millennium.

Bradshaw (1994) theorised that the prominence of Christian ideology during the Middle Ages provided a religion for the “sick”, stemming from the viewpoint that God (manifested in Christ) shared in the sufferings of humanity. However the 18<sup>th</sup> century saw a move away from the unquestioning acceptance of traditional Christian values towards secularism and a new belief in man's own capacity for progress. Baly (1980) suggested that Florence Nightingale's recognition in the 19<sup>th</sup> century that a rising population and changes in medical knowledge meant that religious orders could no longer cope with the provision of nursing, accounted not only for her own success but also the further advance of secularism. Thus by the 20<sup>th</sup> century, all aspects of nursing and care for the sick and the dying had become divorced from religious tradition and spirituality. According to Douglas and Tipton (1983), the effects of modernity on religion are fourfold. Firstly, the prestige and authority of science has reduced the explanatory appeal of religion. Secondly, the lives of most people no longer follow prescribed religious customs. Thirdly, bureaucracy has regulated people's lives in overt and subtle ways and fourthly, life in general is so profoundly separated from nature that it no longer sustains religious inspiration (p.32). Jarvis (1993) attests that the neglect of religious values within society, including the medical professions also led to a neglect of the spiritual aspects of holistic nursing. Nevertheless, as has been previously stated within this Chapter, the success of the hospice movement generated a revival in

the ideology of body, mind and spirit and indeed the approach to palliative care within recent literature has frequently advocated the reintroduction of spiritual well-being within nursing care. (Greenstreet 1999), and (Narayanasamy 1993). Of course as Jarvis reflected there is a void within contemporary society brought about by a lack of meaningfulness within such a materially orientated culture. Thus the implications of the latter are that, as members of society, nurses may well need support in filling their own spiritual / religious void before being able to support patients who are spiritually distressed.

While there has been much criticism of religion in the modern world, Berger (1983) stressed that there was currently a crisis of secularity's "myth of progress" (p.20). Illness, sufferings and injustices cannot be consoled by secular ideals (such as the triumph of natural science, the success of economic, revolutionary or other political struggles). These, Berger proposed are at odds with historical human tendencies for certainty and faith. It is also interesting to reflect that despite the disengagement of religious institutions from political, social and economic spheres of life, there appears to be little shrinkage in the character and extent of religious beliefs. Inhabitants of the United Kingdom and the United States are consistently recorded in Gallup polls as being believers in God and a spiritual afterlife (Chapter 1, p.1). Berger cites the interesting example of department stores that sell religious statuary in countries such as Japan, often report finding coin and flower offerings within the fonts of the displays. A recent example of the seemingly irrepressible nature of religious fervour came in television footage of distraught relatives of the sailors sunk in the *Kurst* submarine (2001). Despite years of religious suppression within communist Russia and her satellite countries, these relatives were televised displaying religious icons such as rosary beads, sacred pictures and medallions. Since the collapse of the Communist regime, and the opening up of former barriers to newspaper and television coverage, what had formerly been thought of as a secular, non-religious country are now shown to be quite the opposite. The long period of Communist rule during the 20<sup>th</sup> century did not totally destroy religious practice. Indeed in his Sunday morning "Letter from America" radio broadcast, journalist Alastair Cooke (January 2002) made mention of hearing the bells of St. Nicholas church (5<sup>th</sup> Avenue) strike for the first time since taking up residence in New York during the 1920's. The bell ringing in the Russian Orthodox church was to celebrate the arrival of President Putin at its Sunday morning worship service. Such a disclosure supports Bergin's (1991) theory of "historical human tendencies for certainty and faith".



It must be mentioned however, that critics of religious belief would agree with the Wittgensteinian school of thought which held that any definition of God was fruitless as he is out-with the scope of human language and thus, inexpressible. Indeed any attempt to describe God in human language may be inadvertently misconceived by the reader. As God does not depend for his existence upon anything else, Wittgenstein (1961) proposed that he could not be an existent. To treat God as an existent is to imply that he might not have existed and would consequently put into doubt the assertion that God is eternal and out-with time. Wittgenstein stated,

“There are indeed things that cannot be put into words. They make themselves manifest. They are what is mystical” (p.151).

For Wittgenstein, God is not an explanation for various scientific hypotheses, such as “the big bang” or evolution etc., nor should He be in competition with any explanatory theory. Constructing God as an explanatory hypothesis dismisses two fundamental elements of all Christian belief – namely, commitment to the belief in God’s eternal presence and to the notion that humans were created in His image and likeness.

True believers, according to Phillips (1966) do not give up their beliefs in the way in which beliefs in hypotheses are given up. For Phillips, belief in God necessitates a fundamental commitment to this belief and not just a leaning towards the probability of God’s existence. This is an important point when considered within the context of terminal illness. Individuals, who have lived their lives within a framework of belief in God and an eternal spiritual existence, may be able to cope with their last phase of life in a less anxious and depressed manner than those individuals struggling to make sense of a secular existence. The philosophical question as to whether the believer or the non-believer is authentic in their conviction is immaterial to this present research since its primary intention is to investigate whether belief in religion (or spirituality) is psychologically beneficial (or not) to the coping strategies of the terminally ill.

To conclude this section on religion and religious belief, it is interesting to note that when a person is diagnosed with a life-threatening disease, existential questions are easily evoked and accentuated. Thus religious beliefs may become beneficial to that person as a support during times of serious or terminal illness due possibly to some of the factors discussed in this section i.e. cultural, traditional / historical reasons, or even as a result of archetypal images and memories. Antonovsky, (1987) developed a model of health emphasising a sense of coherence in which questions of meaning in life were central to good quality of life (despite difficult or critical

situations). A sense of coherence, according to Antonovsky, is the extent to which an individual is able to cope with a severe crisis, and still maintain a sense of meaning within the situation –

“In the very nature of human existence, stressors are omnipresent. Yet many people, though far from most, even with a high stressor load, survive and even do well. Barring stressors that directly destroy the organism, people’s health outcomes are unpredictable. This is the mystery the salutogenic orientation seeks to unravel” (p.xii).

Therefore although other factors can generate a sense of meaning and good quality of life (for example relationships) this research is principally seeking to investigate whether seriously ill patients cope better by using their religious (or spiritual) beliefs as a means of coping with life-threatening illnesses.

### Spirituality

The concept of spirituality (as significant among the terminally ill) derives from the broader term of transcendence as a human phenomenon associated with the end of life (Amenta 1986). Transcendence is defined as a level of awareness that exceeds ordinary, physical boundaries and limitations. Kellehear (2000) outlined a descriptive framework of spirituality which is based on the idea that,

“...human beings have a desire to transcend hardship and suffering. In other words, people need to seek and find a meaning beyond their current suffering that allows them to make sense of that situation. This transcendence may be achieved by searching for meaning in situations, moral or biographical contexts, and / or in one’s inherited or chosen religious beliefs and ideas” (p. 150).

This ideology is similar to the previously mentioned theory of meaning propounded by Frankl (1963) when he stated that –

“It did not really matter what we expected from life, but rather what life expected from us. We needed to stop asking about the meaning of life, and instead think of ourselves as those who were being questioned by life - daily, hourly. Our answer must consist, not in talk and meditation, but in right action and in right conduct. Life ultimately means taking the responsibility to find the right answer to its problems and to fulfil the tasks which it constantly sets for each individual” (P.122).

Kellehear stressed that an individual’s spirituality was also dependent on their particular social, educational and cultural background. These factors emphasised the multidimensional nature of spiritual needs which Kellehear illustrated in his “modal of needs” diagram. His descriptive framework asserts that spirituality encompasses three areas, which become particularly important to an individual during the last phase of life. Usually triggered by serious or terminal illness, Kellehear named these areas as “situational”, “moral and biographical”, and “religious”. Briefly,

“situational” need (or transcendence) arises out of the immediacy of the situation of illness. Questions such as whether there is a higher purpose to pain and suffering come to the fore-ground as do emotions centring on making sense of why the illness happened in the first place. The immediacy of coping with diagnosis, treatments and side-effects together with the emotive aspect of hope are all present in the “situational” element of spiritual coping. In addition, Kellehear stressed that during these times “connectedness” with the hospital or hospice medical and social care team, often trigger a need to reflect upon the consequences and changes brought about by illness. Lynch (1999) stated that the impact of serious illness often resulted in solitude and loneliness for the patient and that human contact may make a difference to the individual’s state of being. He theorised that “being there” assumed a willingness to accompany the patient in the experience of illness as a spiritual journey. Foggart (1997) moreover suggested that the experience of hospice takes the patient into a “sacred space” inhabited uniquely by the patient during a time of transition.

The “moral” and “biological” needs arise, according to Kellehear (2000) as a result of these changes and contain a semi-religious overtone. Although not overtly religious, they are nonetheless philosophically related to religion as they contain what Kellehear described as “parallel concerns in traditional religious discourses”(p. 151). They include a yearning for peace, reconciliation and forgiveness with friends and family in order to “put things right” in the event of sudden death. Such feelings arise out of an individual’s moral and biological background, which may never have had any affiliations with religious ritual. Where Kellehear’s theory must be questioned however is when he asserts that the moral and biographical needs also include prayer and a yearning for belief in some type of afterlife where reunion with deceased loved ones will occur. These yearnings however are not necessarily connected to the traditional teachings of God or Heaven but are meant as a type of moral self-analysis, which act as a psychological closure during the last phase of life. In common with theorists who consider traditional religious beliefs to be a hindrance to spirituality definitions (such as Dyson et al, 1997), Kellehear does not satisfactorily explain how an individual can participate in a non-religious act of praying. From earliest times, praying has been associated with a religious ritual directed solely at God (or deities), for the purposes of thanksgiving, worship or entreaty. This part of Kellehear’s theory is also not clear in explaining why individuals who do not believe in a spiritual after-life in a religious sense, can nonetheless hope for a life after death “in whatever shape or form”. Criticism may also be levied on the decision of Kellehear not to include issues of reunion with others and prayer, within the “religious” section of his otherwise commendable model.

This third section, “the religious need” arises most often in patients whose background has included habitual religious ritual and practice and includes activities such as religious writings and scriptural readings, visits by clergy and discussions about God and salvation. The religious dimension of spiritual need is not inclusive to individuals with a former history of religious belief and practice in their upbringing. Kellehear attests that in previously non-religious individuals, there often arises a curiosity about religious issues and beliefs as a way of securing a last minute reprieve of eternal damnation in the event of there being a supernatural supreme being. More usually however, the spiritual dimension is prevalent in individuals who have adhered to religious belief for most of their lives and take comfort in the belief of divine forgiveness (as opposed to human forgiveness) for any earthly transgressions. They also attain levels of peace and psychological healing from the participation in familiar religious practices, rites, sacraments and support systems. Kellehear stated that the three different dimensions of spirituality contained within his model are not in competition with each other and that many people may have needs contained in all three or simply one. He proposed that,

“ For one person those needs may be largely situational, with only one or two religious needs or one or two moral needs. For another person the bulk of their needs will be in the direction of religious transcendence and this person may only express one or two needs that relate to his or her specifically illness-related predicament” (p.153).

The human propensity towards transcendence as the individual moves closer to death is also depicted in nursing and life-span development models such as Chinen 1984, Labouvie-Vief 1980 and Neugarten 1979. Transcendent perspectives accrued over one’s life-span especially in the dying phase may help the individual maintain a sense of well-being when faced with biological and perceptual loss associated with dying. In chapter 1, mention was made of the research conducted by Kass et al (INSPIRIT, 1991a) in which researchers found evidence supporting the proposal that individuals who had experienced “core spiritual experiences” during their lifetime seemed to possess greater psychological strength during negative life events. These former experiences also gave them the ability to accrue a sense of meaning and purpose into the most devastating of life’s circumstances, such as terminal illness (refer to p.59). Criticism can of course be levied at any research into spirituality due to the ethereal nature of its measurements and predictions and to the confusion in differentiation between spirituality and religious belief (as was illustrated in the Kellehear 2000 model). Also, whether one patient’s higher quality of life and lower anxiety or depression levels are due to spirituality or religious influences, must be carefully evaluated against other variables, such as temperament, personality, character, genetic make-up, childhood education, cultural influences, peer pressure etc.

Chinen (1984) proposed that spirituality is an empirical indicator of the human capacity for transcendence. It is defined in terms of personal views and behaviours that express a sense of relatedness to something greater than the self. Chinen emphasised however that spiritual transcendence does not imply a detachment from other dimensions of one's life but represents an openness to the perceived environment that extends beyond spatial and temporal boundaries. Labouvie-Vief (1980) pointed out that as a broader term than religion or religiosity, spirituality may or may not incorporate religious ritual and behaviour and may not necessarily involve participation in religious organisations. The latter assertion, it can be argued, typifies the most common fallacy applied towards the religious adherent. It is extremely common among critics of religiosity, to equate religious belief with extrinsic aspects of religion- i.e. belonging to a specific denomination, church attendance and ritual practice. Whereas, the devout religious believer is specifically intrinsically orientated, expending most energy in the pursuit of a meaningful relationship with God and a quest to acquire the knowledge to achieve this aim. Thus criticism could legitimately be levied at the use of the term "spiritual" as indicative of something beyond religious spheres for in this specific context, spirituality and intrinsic religiosity are theoretically, one and the same.

One of the main difficulties with presenting an overall definition of spirituality is the fact that most researchers and scholars offer differing proposals precisely because of their own interpretation of the elusive concept. For example, according to Reed (1986b), indicators of spirituality include prayer, sense of meaning in life, reading and contemplation, sense of closeness to a higher being and interactions and experiences that reflect spiritual awareness. Within literature, spirituality has been described as being the same as religion; as being a deeper consequence of religion and as being completely opposed to religious ideology. In 1993, for example, Roof asserted that,

"To be religious conveys an institutional connotation; to be spiritual is more personal and empowering and has to do with the deepest motivations in life" (p.76).

These motivations can include what Roof refers to as a curiosity in the power of nature, thereby introducing yet another element into the concept of spirituality i.e., that of paganism. Certainly within western cultures, there has been a recent increase in "new-age religions", centring on "green issues" and concern for the global planet. Taylor (2001) refers to Gorbachev's (1997) view that all mankind is linked to the cosmos; to nature; to the sun and the forests and consequently to the view that for some, nature is "god". Taylor contends that this type of spirituality is "earth-based", focusing on ecological movements designed to maintain and

preserve planet Earth. Followers of this type of spirituality focus their thoughts and aspirations on planet earth and not on transcendent, ethereally orientated aspirations of a supernatural after-life.

Other scholars maintain that spirituality need not necessarily oppose traditional (Christian) religious thinking but should overlap into some secular concerns. King (1996) proposed that spirituality included “both sacred and secular”, and that it,

“.....enabled a fundamental rethinking of religious boundaries. Its very ambiguity and flexibility suggest a richness and texture which allows traditional religious maps to be redrawn and minorities to find a voice. This makes it a more flexible concept than religion and encourages the user to reflect and to challenge institutionalized thought..... The search for the spiritual takes place not only through the renewal or rediscovery of religious traditions, but also through psychotherapy, social concerns, involvement in movements for justice and peace or through careers in science or the arts” (p.177).

Indeed Walter (1997) raised the critical question of how humanistic ideas of spirituality differed from psychological care. He proposed that some conceptualisations of spirituality are difficult to distinguish from common anthropological ideas about meaning, morality or connection to community.

Engebretson (1996) proposed that an individual’s religiosity may fit well with their spirituality. But as previously stated, for the intrinsic religious believer, church attendance and ritual observations are not high on their list of priorities. Rather it is the fundamental belief in the existence of God and the search for a personal relationship with Him that distinguishes the intrinsic from the extrinsic believer. Advocates of both aspirations search for meaning and existence in life in the realms of the transcendent. According to Amenta (1986), one’s spiritual nature is the inner self or the “I” that communes with the transcendent, while Lipsey (1988) stated that spirituality involved looking beyond the physical, looking within and having an awareness that there is something sacred that can be shared and witnessed within the world. Confusion often centres on whether the term ascribed to the sacred (i.e. God, Ground of Being, Nature etc.) distinguishes and separates spirituality from religion. Thus in times of crisis (such as terminal illness), critics of religion often ascribe an individual’s propensity towards the transcendent as being a search for spiritual well-being, when in actual fact, it could be argued that the individual may very well be searching for religious well-being. The fact that religious denominational affiliation and religious adherence is at an all time low within the United Kingdom, may be the reason for the recent adoption of the term “spiritual well-being” as opposed to “religious well-being”. The former term fits succinctly into the present day cultural terminology. However, as was indicated on page 1 of Chapter 1, many people in both the United States and the United Kingdom believe in the concept of a Creator or God even although they do not belong to a

particular religious denomination. Thus this recent application of the term “spiritual well-being” may be an example of researchers applying an elusive conceptual term in order to comply with the current cultural trend of ambivalence towards all things religious. Kellehear (2000) commentating on similar issues stated,

“In an ironically ecumenical effort, other formulations have simply been overinclusive – an attempt to satisfy all corners” (p.150).

“Spirituality” is frequently cited as integral to the dying person’s achievement of the developmental task of transcendence and is important for health-care providers to recognise and foster (Highfield, and Larson 1992). Spiritual identifiers are used in research with the terminally ill patient and address certain issues concerning death and ill health, but once again the question of confusion in definition between spirituality and religiosity must be raised. For example, the following are included among a list of questions, which assess patients in their last months of life. A critic may find it difficult to discern between the spiritual and the religious aspirations contained within each question -

1. Is there a purpose to their life as they suffer?
2. Are they able to transcend their suffering and see something beyond it?
3. Are they at peace?
4. Are they hopeful or do they despair?
5. What nourishes that sense of value of themselves, prayer, religious commitment, personal faith and relationship with others?
6. Do their beliefs help them cope with their anxiety about death, with their pain and with achieving peace?

If caring for dying patients is to achieve a clear and precise definition of the concept of spirituality, Soeken & Soeken (1989) proposed that it must address the paradox which often exists among theorists and researchers in defining the “whole” person. Valliot (1970) postulated that the spiritual was, “opposed to the biological and mechanical dimensions of the individual” (p.30) whereas Piles (1991) argued that “the spiritual dimension was different from the psychological dimension” (p.49). Piles regarded the spiritual dimension as seeking to revere something outside human control, something which sustains a person, especially at a time of crises. Hence, it is a source of strength that can be “tapped into”, in times of need. The psychological dimension on the other hand, is concerned with the human mind and therefore, limited to those things associated with the individual’s human resources. In contrast, psychologists such as Erikson (1963), Maslow (1970) and Frankl (1987) and sociologists such as

Moberg (1979) recognised that a person is not just a conglomeration of separate entities, but is rather, an indivisible whole.

Theoretically, if the theories of Valloit and Piles were to be generally accepted then it would follow that spirituality would be regarded as something which was not unifying and integrated to the whole person, but as something which is possibly non-functional, isolated and abstract. To a degree it could be argued that spirituality is consequently indefinable, as the whole area is ultimately beyond the understanding of the human mind (Martsof and Mickley (1998) for example believe that spirituality is purely subjective). However, if the views of Erikson, Maslow, Frankl and Moberg were generally accepted, then spirituality would be regarded as something understandable and integral to the human species.

Dettmore (1984) described it as “a unifying force which permeates, interacts with and even stabilises all the other dimensions of an individual”(p.46). This latter assertion may have instigated publicity in recent years among health researchers regarding “the spiritual dimension”. In other words, it has recently been recognised that spirituality can have a positive effect on maintaining an individual’s equilibrium or peace of mind; something which both science and medicine has formerly been unable to achieve on their own.

These relationships of interconnectedness and interdependence were illustrated as far back as 1975 by Stallwood’s “conceptual modal of the nature of man”. Stallwood strove to demonstrate that spirituality was at the core of human existence; that it permeated and influenced all other dimensions of human nature both physical and psychological. Stallwood believed that an imbalance in any of these components would affect the entire equilibrium and dynamics of an individual. Stoll & Stoll (1989) emphasised that this model demonstrated the human person’s function as, a dynamic whole. They extended Stallwood’s model by suggesting that spirituality consisted of a vertical and horizontal dimension (or axis). The vertical dimension was associated with a person’s transcendent relationship with the “ultimate other” (the ascending axis). The horizontal dimension on the other hand, reflects a person’s beliefs, values and lifestyles (the transverse axis). Stoll & Stall proposed that there is a continual interrelationship and exchange of energy between both dimensions. A criticism of this model however, is that as a two-dimensional approach, it implies that transcendence is separate from the psycho-social and physical spheres of human existence. This is difficult to substantiate as both dimensions are intimately intertwined (Piles 1991). Stoll & Stoll nonetheless provided an eloquently, although decidedly religious definition of spirituality when pointing out that, while not a prerogative of religious believers,



spirituality is most probably a “dimension within every person”. They echoed the Hebrew sense of spirituality when stating,

“Spirituality is my being; my inner person. It is who I am – unique and alive. It is me expressed through my body, my thinking, my feeling, my judgements and my creativity. Through my spirituality, I give and receive love; I am driven forward, sometimes because of pain, sometimes in spite of pain. Spirituality allows me to reflect on myself. I am a person because of my spirituality – motivated and enabled to value, to worship and to communicate with the holy, the transcendent” (p.6).

Farran et al (1989) suggested that all beings have their own unique and personal definitions of spirituality based on life experiences, values and beliefs. For example, a patient may present with a psychosomatic disorder as a result of guilt (particularly during terminal illness), which appears to be psychological in origin but which in fact may have resulted from unresolved spiritual conflicts. Elkins et al (1988) working in the field of humanistic psychology used a theoretical and phenomenological approach in order to define and describe spirituality. They identified nine major components,

1. Transcendent dimension
2. Meaning and purpose in life.
3. Mission in life
4. Sacredness of life
5. Material values
6. Altruism
7. Idealism
8. Awareness of the tragic
9. Fruits of spirituality.

Farran et al (1989) suggested that this type of systematic and methodological approach should be replicated and applied within nursing by incorporating both the nurse and patient perspectives. They emphasised that if theoretical and conceptual unity was ever to be achieved then there was a need for universality and consistency in the terminology and language that was used to describe the spiritual phenomenon. They further proposed that empirical knowledge of spirituality and its impact upon patient care (particularly of the terminally ill) was limited and abstract and based on intuitive reasoning (embracing terms of religion) and personal, often sentimental opinions. Thus there was a need to provide a definition of spirituality which would be universal in its approach, taking into account the importance and relevance of the phenomena to clinical studies and

research which took into consideration the uniqueness of what Soeken & Soeken (1989) described as the “whole person”.

One definition which may embrace and fulfil this criteria was cited by Murray and Zentner (1989) who described spirituality as,

“A quality that goes beyond religious affiliation, that strives for inspirations, awe, reverence, meaning and purpose, even in those who do not believe in God. The spiritual dimension tries to be in harmony with the universe, and strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death” (p.163).

This definition however does not clarify the difference between religion and spirituality but merely alleges that spirituality “goes beyond religious affiliation”. In addition, use of the word “affiliation” once again implies a generalisation of religiosity towards extrinsic aspects of denomination, ritual worship and church attendance. A universal definition of spirituality would certainly make it applicable to all human beings, however it could be argued that by defining spirituality in broad terms, it would make the concept harder to understand and more specifically harder to measure within empirical research. Soeken & Soeken (1989) described measurement as one of the most challenging and critical aspects of the research process and that without it, spirituality would remain on an abstract, ethereal level. Also, without conceptual and empirical knowledge, the concept of spirituality would remain elusive and subject to individual assessment. Evidence now emerging from published literature suggests that spirituality is so intimately interwoven with and fundamental to human existence, that it cannot be separated or segregated from any of the other dimensions of human nature. Reed (1992) describes this unifying force as,

“ A relatedness between all dimensions, intrapersonally, as a connectedness within oneself, interpersonally, in the context of others and the natural world, and transpersonally, referring to a sense of relatedness to an ultimate other or an awareness of an eternal dimension” (p.26).

Reed postulated that spirituality was a very complex phenomenon but not so complex that it becomes meaningless and unworthy of investigation. She presented an “emerging paradigm for the investigation of spirituality” (within nursing) which had its origins in the “developmental contextualism worldview of life” based on the work of Lerner (1986). Developmental contextualism shares the belief that the person and the environment represent a process by which the conflicts and challenges inherent to life are transformed into energy for innovative change. This view suggests that all levels or aspects of an individual are interconnected with each other and the environment. Reed described this interconnectedness thus,

"Interactions within the person and with the environment generate conflicts that can provide the impetus for development through self-transcendence" (p.94).

The paradigm offers a framework for the investigation of the concept of spirituality by emphasising the wholeness of the individual in terms of connection with, instead of a separation from the environment. Reed continues,

"Central to the paradigm is the epistemological assumption that spirituality can be empirically investigated and ultimately applied in practice, using methods of science and praxis accepted by the nursing community"(p.95).

A literature review of the Medline, Cancerlit and Bioethics data revealed several spiritual identifiers and scales, which have been used in recent years in clinical studies and research into chronic or terminal illness. A selection (together with brief descriptions) are listed below. They have been chosen because of their appropriateness to the topic under investigation in this present study.

1. Spiritual Well-Being Scale (Paloutzoan and Ellison 1979). A 20-item self-administered scale with two dimensions: religious and existential. (Initially tested in a college population, this test has since been used with sick patients).
2. Death Transcendence Scale (VandeCreek & Nye 1993). A 25 self-administered scale based on the premise that "death is transcendent through identification with phenomena more enduring than oneself". This scale has been tested in a diverse adult sample including the hospital setting.
3. Meaning in Life Scale (Warner 1987). A 15-item administered by interview scale, tested in a facility for the chronically and terminally ill. The intent is for the patient to report his or her assessment of the worth of life remaining.
4. Herth Hope Index (VandeCreek 1994). A 12-item interview containing three dimensions, temporality and future, positive readiness and expectance, and interconnectedness. Tested in community and hospital patients and family members.
5. Index of Core Spiritual Experiences (INSPIRIT) (Kass 1991). An 18-item interview scale used for spiritual assessment in general population as well as hospital patients.
6. Spiritual Perspective Scale (Reed 1987). A 10-item structured interview or questionnaire format administered in healthy and terminally ill adults, shown to be reliable, accurate and relevant in those populations.
7. FACT-Sp (Fitchett 1998). A 12-item scale that can be used alone or with the FACT-G, a general measure developed for cancer patients. Items examine faith and a sense of purpose and meaning in life.
8. McGill Quality of Life (Cohen et al, 1995). A 17-item interview or self-administered questionnaire format tested with seriously and terminally ill patients in hospice setting. Developed for cancer patients, this measurement contains 4 sub-scales, physical, psychological, meaning and existential.

Each of these scales (above) claim to assess and measure spiritual well-being, and / or spiritual distress. Analyses of results consistently provide reliable indicators of an individual's level of peace and serenity or alternatively, insecurity and despair. But learning to assess in this way is not easy and requires practice and experience. Most medical practitioners and health-care workers are familiar with common physical signs indicating peace or contentment in their patients. For example a smile, a relaxed manner and an eagerness to communicate would be cited as indicative of a certain degree of acceptance of health status, and also of what O'Brien (1982b) proposed "spiritual well-being" would entail. The latter could be observed by,

"The presence of an interior state of peace and joy; freedom from abnormal anxiety, guilt, or a feeling of sinfulness; and a sense of security and direction in the pursuit of one's life goals and activities" (p.98).

Spiritual distress, on the other hand, is altogether harder to understand and assess, either by analysis of spiritual assessment scales or by everyday observation of patients by medical staff. The difficulty in recognising spiritual distress is caused by the fact that ill health often challenges the "wholeness" of spiritual integrity. Pain, discomfort, separation from family, lack of medical control, loneliness and fear of impending death add to any problems the patient may be already experiencing with what Speck (1992) referred to as the "why" questions (eg. "why me?"), suggesting a need to make sense of all that is happening; a search for existential meaning within a particular life event). O'Brien (1982b) stressed the importance of teaching professionals in the medical field (while still students) how to recognise the outward signs of spiritual distress. These she divided into seven components,

1. Spiritual pain: This is manifested by a deep sense of hurt, stemming from feelings of loss or separation from the individual's source of spiritual sustenance. For the religious this could be their God, and for the non-religious, it could be their life partner.
2. Spiritual alienation: This often occurs when materialistic concerns overwhelm the spirit.
3. Spiritual guilt: This is brought about as a result of number 2. It also occurs due to a sense of inadequacy or sinfulness before the individual's source of spiritual support.
4. Spiritual anxiety: This is associated with a fear of loss of this support.
5. Spiritual anger: Blaming this source of spiritual support for letting the individual become ill in the first place.
6. Spiritual loss: This is associated with a weakened or broken relationship with the individual's source of spiritual support.
7. Spiritual despair: This follows the loss of hope of ever regaining the love that stems from a spiritually supportive relationship.

With regard to these seven components, criticism could once again be levied at the basic ontological premise of each section, which could arguably be just as easily labelled religious as they could spiritual. O'Brien (1982b) proposed that loneliness of spirit was a common thread running through each of these seven components and stressed that all medical staff (particularly nurses) should be taught to recognise this type of loneliness (which was a prominent indicator of spiritual distress). As patient's spirituality was generally focused on its tangible expression through relationships, O'Brien believed that it was through communication skills that nurses and other medical practitioners would access their patient's spiritual needs. These inter-related skills of communication, interpretation and observation are paramount to the recognition of spirituality within patients, particularly in the field of terminal illness, and as such should be taught at student level to all entering the medical profession.

Emerging from this discussion on spirituality is the suggestion that it is so intimately interwoven with, and fundamental to human existence that it cannot be separated or segregated from any of the other dimensions of human nature. Some authors, such as Banks 1980, Colliton 1981 and Ellison 1983, proposed that the spiritual dimension resided in all people in a unique and mystical manner. It is a unifying force, the essence and the core of being. It enables humankind to transcend the natural realms and limitations of human existence, developing a consciousness of an eternal dimension. But all three authors are in agreement that it is not necessarily indicative of a belief in God or restricted to religious affiliation.

Highfield and Carson's (1983) definition of spirituality is specifically related to patients with chronic and terminal illness and consists of three dimensions i.e.

1. Love and Relatedness.
2. Meaning.
3. Hope.

As the object of the present research is concerned with the coping strategies of the terminally ill, and to whether spirituality and religious belief aids or hinders patient's coping levels, it is worthwhile expanding Highfield and Carson's three-dimensional definition. Love and relatedness involves a sense of connection with other people, especially family and friends. During times of serious and terminal illness, Highfield and Carson (1983) proposed that expressions of forgiveness and love for others introduce a spiritual dimension into this interconnectedness. Spiritual health was exemplified by expressions of love and forgiveness, whereas spiritual

distress would be evident in expressions of self-guilt and anger and expressions of anger towards others.

Love and relatedness has been found to have an impact on the pain levels of seriously ill patients (Dar et al, 1992). Of 40 married patients with metastatic cancer, 40% of patients reported that their pain was better in the presence of their spouse and that their spouse helped them cope with their illness. A limitation to this study was the fact that the average length of marriage of participating couples amounted to 32 years, thus perhaps introducing a bias towards more happily married couples. Nevertheless, relationships are important contributors to higher coping levels in the terminally ill (as was demonstrated in both the Kubler-Ross (1970) and Rose (1997) studies). However, the quality of that relationship is perhaps more important than the quantity of years together. However as the Pace and Stables (1997) research found, patient's with AIDS for example, frequently reported less social support and greater amounts of loneliness than seriously ill cancer patients (refer to p.16, Chapter 1). The resulting spiritual distress of the AIDS patient (as a direct result of relationship loneliness) could very well constitute lower coping levels and thus contribute to a less meaningful preparation for death. However a criticism of these studies centres on whether love and relatedness is indeed synonymous to the elusive concept of spirituality. Helminiak (1996) proposed that it was the "spirit" which makes human beings human. In this context, Helminiak is equating the spirit to the more theologically based concepts of the psyche or the soul. But whether love and relationships with fellow humans, as well as to God constitutes spirituality as opposed to religiosity, is again open to conjecture.

Highfield and Carson's second dimension of spirituality (Meaning) involves making sense of life, and the purpose of existence. As was discussed in Chapter 1, (p.50), Frankl (1963) was one of the first psychiatrists to link meaning in life and spirituality, and to relate personal tragedy with a type of spiritual triumph. Some patients who are terminally ill and who have accepted their diagnosis, expend a significant amount of energy on the meaning and purpose of their existence. According to Highfield and Carson (1983), signs of spiritual health related to this dimension involve expressions of contentment with the way individuals have lived their life especially if it has been in accord with their highest values. Spiritual distress on the other hand, was related to despair as individual patients found no meaning to their personal pain and illness. As pain is often difficult to eradicate completely in terminal illness, Burnard (1987) proposed that it was possible to reach a state of sheer physical and mental exhaustion and thus be incapable of searching for meaning. However Frankl (1963) proposed that choosing a redeeming attitude in the face of

suffering was one way to achieve meaning. By this Frankl meant that in many despairing circumstances in life, humans can experience tremendous indignity, humiliation and deprivation of former possessions or freedoms, but the one attribute which cannot be taken away from a human being is their personal choice in dealing with the situation. –

“Everything can be taken from a man but.... the last of the human freedoms – to choose one’s attitude in any given set of circumstances ... to choose one’s own way” (p.104).

The basic premise of Frankl’s theory can be found in studies associated with life-threatening illness. For example, among 100 terminally ill cancer patients in 1991, Barkwell’s study found that 35% viewed pain as a challenge, 23% as a punishment and 20% as an enemy. Those who viewed pain as a challenge speculated that it could be a manifestation of God’s malevolence or beneficence, thereby once again introducing a specifically religious connection and hence confusion in terminology between the concepts of spirituality and religiosity.

Greach (1987) proposed that patients who suffer pain often have the capacity to become involved in “pain work” as a direct way of coping with their illness. This coping strategy encompassed the transcendental component of opening oneself to the acceptance of pain and to the possibility of obtaining meaning and peace through total acceptance of the illness and its consequences. Of course, not all patients consciously seek a coping strategy in the face of illness and others do not possess the capacity to take part in “pain work”. However for those who do, it seems clear that a patient’s spirituality can greatly influence their attitude and reasoning towards pain which in turn influences their mental state with regard to coping levels. As far back as 1926 Schou was one of the few medical doctors prepared to recognise the relationship between psychology and the sick. He wrote,

“There is one point of great importance to all whose work lies among the sick, and that is, that every serious form of bodily suffering has a corresponding mental counterpart of some sort and in greater or lesser degree. It is a fact known from old, which all have learned from experience, that illness renders people sensitive, and occasions a mental change in them. But it is strange that this fact should have been so little noticed by spiritual advisers that they rarely take it into consideration when visiting the sick. They do not sufficiently reckon with the peculiar mental state of sick persons when speaking or writing for their benefit. They have, in a word, neglected the psychology of the sick-bed” (p.83).

And thus, Highfield and Carson’s second dimension of spirituality, “meaning”, although pertinent to the coping strategies of sick and terminally ill patients, can be criticised from the viewpoint of it applying only to those patients who are free of psychosomatic symptoms (the most common of which being anxiety and depression).

Highfield and Carson's third definition of spirituality, "Hope" is more obviously associated with the chronically, rather than the terminally ill as it encompasses the yearning for positive outcomes. Signs of spiritual health within this dimension include asking for truthful information and being prepared for realistic prognoses. Signs of spiritual distress are manifested in the patient becoming listless and withdrawn and uncommunicative. Highfield and Carson (1983) again linked pain in illness with this third dimension as the former can easily turn the dimension of hope into hopelessness and a sense of helplessness which negate any possibility of meaning within pain and suffering. Use of intense pain killing drugs may also dull the mind and create listless self-destructive behaviour (refer to Kubler-Ross criticism, p.29 Chapter 1). Highfield and Carson proposed that within terminal illness, two types of hope have been identified i.e., curative hope, which is the hope for a cure, and palliative hope, which is the hope for relief from pain and a peaceful death. Patients often expend energy hoping for new breakthroughs in medical science in order to alleviate or ease their pain. Highfield and Carson (1983) proposed that spirituality was a significant variable in the pain experience of sick and dying individuals and that it had important implications for nursing practice.

Helminiak (1996) considered spirituality to be a sub-division of psychology. As previously stated, he proposed that the mind has two inter-related components, the psyche and the spirit. The psyche, being characterised by emotion, memory, personality, thoughts and dreams. The spirit on the other hand, he proposed was characterised by self-awareness, insight, creativity and self-determination. Helminiak theorised that it was often difficult to discern the spiritual from the psychological because both were so closely interrelated. Overall the lack of a specifically consistent and universal definition of spirituality contributes to the neglect of spirituality concerns within the medical profession, even within the context of palliative care. Highfield and Carson (1983) suggested that lack of spiritual care education prevented medical practitioners obtaining the ability to deal with the spiritual needs of their patients.

There can be little doubt that the term "spirituality" is multi-dimensional and consequently recognition of these complex dimensions may have to be acknowledged by a number of different professionals. For example, religious dimensions of spirituality may best be dealt with most effectively by those so trained. In addition, if medical practitioners, social workers and psychologists are all to consider spirituality as a normal part of their work with the terminally ill, then someone solely trained in this area, perhaps a chaplain or spiritual director, may be a crucial part of the clinical team (Speck, 1993).



Fundamental to this review of definitions from literature and research is the acknowledgement that spirituality is a broad concept, encompassing religion but arguably not equating with it and involving a search for the meaning of critical lifetime events such as birth, illness and death. It is a concept which grows and develops in varying degrees throughout an individual's life-span but is most particularly universally associated with end of life. Wakefield (2001) summarises most aspects of spirituality thus, -

“Spirituality is what makes us tick – It is the sum of forces, influences, beliefs, disciplines, conscious or unconscious which possess us, determine our motives and behaviour and shape our personalities” (p.1).

In conclusion, Chapter 2 has attempted to provide the reader with an overview of the issues of coping, coping strategies, coping criteria, bereavement and definitions of religion and spirituality, in order to provide background information necessary to the understanding and aims of the present research project.

Hypotheses 1 – 7 (below) concern the main area of empirical research within this study i.e. “patient's coping strategies”, and will suggest an association between belief in religion / spirituality and lower levels of anxiety and depression, better management of pain, better acceptance of support and understanding of meaningful existence. In short, used as a coping strategy, religiosity or spirituality beliefs may aid patients during the trauma of terminal illness by providing a constant source of comfort in the form of rituals (such as prayer or meditation). Such acts may alleviate the pressures of physical discomfort and emotional distress thereby influencing their “quality of life” assessments in a positive direction. The scores mentioned in Hypotheses 1, 2, 3, 4 & 5 relate to the measuring tool used in the “Patient Research” study – McGill Quality of Life Questionnaire – Scottish Version (MQOL-SV). It is important to note that Hypotheses 6 & 7 were included for comparison purposes with other research studies. Statistical measurement was conducted by means of One-Way ANOVA for Hypothesis 6 and Chi-square for Hypothesis 7.

Hypotheses 8 – 11 concern a secondary area of interest within the empirical research i.e. – “attitude of staff members towards a range of spirituality policies together with their coping strategies and quality of life”. Hypotheses 8 & 9 will suggest an association between “High” “Spirituality Measurement Scores” (SMS) and more favourable attitudes towards the inclusion of religious and spirituality issues within hospice policy. Hypotheses 10 & 11 will propose that staff with “High” SMS will be less subject to occupational distress and that compared to staff with “Medium” or “Low” SMS, will attain higher overall “quality of life” scores. The scores

mentioned in hypotheses 8 – 11 relate to the measuring tool used in the “Staff Research” study – “Coping with Palliative Care Duties” (CPCD).

## **Hypotheses**

### **(Patient Questionnaire)**

1. Believers and Practising Church Members (BPCM) together with Believers but Non-Practising Church Members (B-NPCM) will achieve higher scores totals for the “Physical Sub-scale” than Non-Believers / Non practising participants (NBNP). (See Chapter 1, p.21 & 23: Chapter 2, p.70, 83 & p.110).
2. NBNP participants will attain higher scores totals for the “Psychological Sub-scale”(anxiety, sadness fear and depression symptoms) than BPCM and B-NPCM. (See Chapter 1, p.4, 5, 19, 20 & 51).
3. BPCM and B-NPCM will achieve higher scores totals for the “Meaningful Existence Sub-scale” (meaning in life /control) than NBNP participants. (See Chapter 1, p.29, 51, 56 & 63: Chapter 2, p.71, 74, 106 & 108).
4. BPCM and B-NPCM will achieve higher scores for the Outlook in Life Sub-scale (Support) than NBNP participants. (See Chapter 1, p.37, 42, 50 & 56).
5. Believers and Practising Church Members (BPCM) together with Believers but Non-Practising Church Members (B-NPCM) will achieve higher overall Quality of Life - (i.e.- Total Scores) than Non-Believers, Non-Practising (NBNP) participants. (See Chapter 1, p.4 15 & 21).
6. NBNP participants will attain similar score ratios to BPCM and B-NPCM participants with reference to acceptance of intercessory prayer. (See Chapter 1, p.5, 41, 46, 47 & 48).
7. Responses given by BPCM & B-NPCM to “General Questions” A, B and C will be more spiritually / religiously orientated than the responses given NBNP patients. (See Chapter 1, p.44, 45 & 48: Chapter 2, p.87, 88 & 90).

### **(Staff Questionnaire)**

8. Hospice staff with “High” “Spirituality Measurement Scores”(SMS), will achieve higher score totals for “Attitude to Spirituality Issues” (ASI) than staff with “Medium” or “Low” SMS”. (See Chapter 1, p.13, 37 & 52: Chapter 2, p.79, 96 & 102).
9. Hospice staff with “High” “SMS” will attain higher score totals for “Coping Category Inclusion” than staff with “Medium” or “Low” “SMS”. (See Chapter 1 p.16 & p.32: Chapter 2, p.78 & 93).

10. Hospice staff with “High” “SMS” will attain lower score totals for Coping with Occupational Depression (COD) than staff with “Medium” or “Low” “SMS”. (See Chapter 1, p.13, 18, 21 & 43).
11. Hospice staff with “High” “SMS” will attain a higher score totals for “Quality of Life” than staff with “Medium” or “Low” “SMS”. (See Chapter 1, p.13 & p.21: Chapter 2, p.78, 93 & 95).

## Chapter 3

### Methods

#### Design

This “between-subjects” quasi-experimental study (no repeated measures) was “questionnaire / interview” in structure. The research population, comprised 120 hospice patients with life-threatening illness together with 100 hospice staff from 2 hospices in the West of Scotland. The patients consisted of males and females between the ages of 23 and 98 years. Similarly, staff members included males and females but their ages ranged from 22 – 62 years. Both groups participating in the research study did so on a purely voluntary basis. All participants were measured using attitude assessment scales / questionnaires although administration of the latter differed between the 2 groups in that while the Staff Questionnaire was self-administering, the Patient Questionnaire was read to the patients by the researcher who recorded their self-rated scores onto a pre-prepared questionnaire sheet. The self-rated scores were assessed using a Likert-type scale. The Patient Questionnaire contained 16 independent variables (IV) - (refer to Appendix 1.1) and the Staff Questionnaire contained 22 (refer to Appendix 1.4). The dependent variable (DV) in both questionnaires concerned “coping”. This was assessed in the Staff Questionnaire by total scores within the variable “Spiritual Measurement Scores” (SMS) and in the Patient Questionnaire by the use of their “Religious / Practising Status” variable obtained from within the “Patient Files”. Since participants in both groups (Patients & Staff) already differed in respect to spiritual / religious orientation, they were subsequently measured on other variables in order to determine whether different categories of the former were associated with different levels of coping ability. Statistical Package for the Social Sciences (SPSS) version 11.5 for Windows was used for all statistical analysis.

The diagnosis of any life-threatening disease can often warrant the need for professional intervention because of patient psychological or psychosocial distress. The main measuring instrument in this research - the McGill Quality of Life Questionnaire (Cohen et al, 1995) contained scales which measured patient’s self-assessed “Physical”, “Psychological”, “Existential” and “Support” scores. All four components provide a good measure of Quality of Life (QOL) at all stages of the disease trajectory. Using an adapted version of the measuring tool, entitled the MQOL-SV (McGill Quality of Life – Scottish Version) the empirical research sought

to establish whether patients with high / low “Quality of Life” scores were associated with one of the 3 groups of interest within this research –

1. BPCM (Believers and practising church-members).
2. B-NPCM (Believers but not practising church members).
3. NBNP (Non-believers / non-practising)

Thus, “Patient Research” sought to establish whether spirituality / religious belief should be presented as worthy mediators which may in turn affect patient’s coping ability and quality of life as measured by MQOL-SV scores.

“Staff Research” sought to establish whether “High” Spirituality Measurement Scores (SMS) among palliative care staff were associated with higher scores for the introduction of spirituality issues within hospice policy. “Staff Research” also sought to determine association between staff with “High” SMS and higher scores for occupational coping and “Quality of Life” assessments.

Patient Research – (MQOL-SV Hypotheses 1, 2, 3, 4 & 5):

It is important to point out that although the 6 single-variable indicators of, Sex; Ethnicity, Age, Religious / Practising Status, Disease, and Stage of Illness, together with their frequencies and percentages, were measured following research within both hospices only data measuring “Religious / Practising Status” and “Hospice” were used within inferential statistics. These variables were considered to be the principal areas of focus concerning patient’s quality of life and coping strategies. The remaining variables, although of interest, were not included for the following reasons –

1. Sex: - Initial tests revealed no significant result differences for “patient” findings. Also male and female numbers were evenly balanced for 1 hospice only.
2. Ethnicity: - Within the “patient” cohort, descriptive data revealed 100% to be from white, mainly Christian backgrounds (see Chapter 4).
3. Age: Descriptive data revealed only 4% of patients from each hospice to be under the age of 50 years (see Chapter 4). These numbers did not constitute a high enough status to be considered useful to inferential statistical analysis.

4. Disease: Descriptive data revealed that 96.7% of all participating patients within both hospices were diagnosed with various types of cancer (e.g. lung, stomach, breast, colorectal etc). As only 3.3% of patients were diagnosed with a different disease (such as motor-neurone disorder), it was not considered useful to this present investigation to include "Disease Type" within inferential statistics.
5. Stage of Illness. Although "stage of illness" was initially considered to be of importance to overall "patient research" it was subsequently discovered that the 3 categories of "Rehabilitation", "Symptom Control" and "End of Life" (see Chapter 4) were difficult to differentiate. Patients within the grouping "rehabilitation" for example, often died before those within "symptom control" or "end of life". In addition, both Hospices (A & B) were classed as "specialised care hospices" – a term used to denote hospices which cared for patients with extremely acute palliative care needs. Consequently, all patients within both hospices could be classed as very seriously ill. Thus "stage of illness" was excluded from inferential statistical analysis as no meaningful rating could be established between the 3 sub-groups.

As Hypotheses 1, 2, 3 & 4 specifically related to score totals within the 4 "Sub-Scales" of the MQOL-SV & to Hypothesis 5, "Total Scores" (see below) it was judged legitimate to regard all score totals as interval in measurement. "Two Way Between Groups" ANOVA were employed (using a 3 x 2 factorial design) in order to assess the statistical significance of the relationship between the variances of,

1. Physical health (Physical Sub-scale – Hypothesis 1)
2. Mood states - (Psychological Sub-scale – Hypothesis 2)
3. Self-esteem - (Meaningful Existence Sub-scale – Hypothesis 3)
4. Positive outlook - (Support Sub-scale – Hypothesis 4)
5. Total Scores - (Hypothesis 5)

and those patients categorised as,

1. BPCM - (Believers and practising church-members).
2. B-NPCM (Believers but not practising church members).
3. NBNP (Non-believers / non-practising) - within both hospices (A & B).

The use of this particular single nominal independent variable helped establish whether religious orientation, as represented in the 3 categories (above) tended to be associated with patients who

scored higher or lower mean scores within the 5 dependent variables (“Sub-Scales” plus “Total Scores”).

The composition of the measuring tool (MQOL-SV) enabled research into the impact of spirituality / religiosity upon the 5 dependent variables. As previously stated, factorial ANOVA were conducted for each dependent variable rather than MANOVA which were considered to be complex and more difficult to interpret. Thus, in order to minimise the risk of an inflated “Type 1 error”, a more stringent alpha level was set by means of a “Bonferroni” adjustment. Authors such as Pallant (2001) advocate this procedure provided that the normal alpha value of 0.05 is divided by the number of tests within the measuring tool (p.217). As the MQOL-SV contained 5 tests, a probability value of 0.01 was set as constituting statistical significance.

The design of this research study had included Hypotheses 6 and 7 for two reasons. Firstly, in order to compare test results with those obtained in previously published studies and secondly, in the hope that they would generated support for the concepts and aims of the present research investigation. Consideration of the influences of an individual’s faith / religious beliefs or spirituality formed the subject matter of Hypothesis 7, while these beliefs (or superstitions) were further examined in Hypothesis 6

Hypothesis 6 concerned whether patients were willing or were not willing to have prayers said for them. The construction of this hypothesis therefore included only 2 meaningful categories. According to Weisberg et al (1989), levels of measurement do not matter in most circumstances for dichotomous variables. They can be treated as nominal, ordinal or interval without any loss of meaning although performing significance tests on them requires making assumptions about their distribution. However, while some analysts are willing to treat ordinal data as interval, caution is recommended when analysing results (Weisberg, Krosnick & Bowen, p.147). In consideration of these opinions, it was decided to perform 2 tests, one for ordinal and one for interval data. One-way Analysis of Variance (ANOVA) was utilised for the latter and Kendall’s tau for the former. Tau is the most frequently used ordinal measure of association and measures the extent to which a change in one variable is accompanied by a change in another variable. Since tau is a symmetric measure, it always has the same value regardless of which variable is the independent variable and which is the dependent. Both tests were performed and compared to “descriptive statistics” results. One-Way ANOVA was presented in Chapter 4 and tau was placed within Appendix 3.1

Hypothesis 7 investigated the answers given in response to MQOL-SV questions A, B & C, by those patients categorised as

1. BPCM - (Believers and practising church-members).
2. B-NPCM (Believers but not practising church members).
3. NBNP (Non-believers / non-practising),

As data from questions A, B & C was nominal / categorical in design, it was considered appropriate to use a non-parametric “crosstabulation procedure”- (3 x 3 contingency table) specifically chi-square, in order to determine the presence of an association between the qualitative variables. The scores of patients in both hospices (A & B) were combined in order to control “minimum level of expected cell frequency” exceeding unacceptable levels. Chi-Square results were presented within Appendix 3.2.

Staff Research – CPCD (Hypotheses 8 – 11):

The MQOL (Cohen et al, 1995) had not included questions for staff but in order to help account for possible result differences between Hospices A & B within the Patient Research programme, the author devised a “Staff Questionnaire” (Coping with Palliative Care Duties - CPCD). Details of this measuring tool are to be found in the Instruments section (p.126). Although the CPCD is not yet a validated or reliable measuring instrument, it nonetheless received approval and consent from the “collaborative team” within both hospices who were anxious to detect differences in hospice staff score totals. Following completion of empirical research, descriptive statistics were initially used to record the 4 single variable indicators of Age, Sex, Ethnicity and Occupation together with their frequencies and percentages (see Chapter 4). Frequencies and percentages were also recorded for the 20 scored variables included within the 6 sub-scales of,

1. Personal Spirituality Scores (PSS).
2. Attitude to Spirituality Issues (ASI)
3. Coping Category Inclusion (CCI)
4. Coping with Occupational Depression (CDO)
5. Quality of Life (QOL)
6. Religiosity and Ritual Scores (RRS).

Score totals for the sub-scales, PSS & RRS were combined to form a new independent variable entitled, “Spirituality Measurement Scores” (SMS) incorporating levels “High”, “Medium” and



“Low”. As the “SMS” ranged from 0 – 16, category groups were composed of the following staff scores -

1. High = 15 – 16 scored.
2. Medium = 11 – 14 scored
3. Low = 0 – 10 scored.

As Hypotheses 8, 9, 10 and 11 specifically related to score totals within the 4 remaining Sub-Scales” (see below) it was judged legitimate to regard these totals as interval in measurement. “Two Way Between Groups” ANOVA were employed (utilising a 3 x 2 factorial design), in order to assess the statistical significance of the relationship between the variances of,

Attitude to Spirituality Issues (ASI)– Hypotheses 8

Coping Category Inclusion (CCI) – Hypothesis 9

Coping with Occupational Depression (COD) – Hypothesis 10

Quality of Life (QOL) – Hypothesis 11

and the 2 participating hospices categorised as,

1. Hospice A.
2. Hospice B.

The use of the independent variable (SMS) helped establish which category (as represented by “High”, “Medium” or “Low”) attained the highest mean score totals for the sub-scales of ASI, CCI, COD & QOL.

With regard to the 4 original nominal variables of “Sex” “Age” “Ethnicity” and “Occupation”, only the latter was utilised within inferential statistics since it was considered to be of particular importance to the study. The remaining variables were not used due to the following reasons,

1. “Sex”: Data exploration revealed more than 70% of volunteer staff within each hospice to be female.
2. “Ethnicity” was also abandoned because 100% of staff volunteers were “white”.
3. “Age” was also not included since data recordings had been confined to 2 levels only (i.e. “below 40” and “over 40”) and it became apparent that within the categories of “Nurse” and

“Doctor”, less than 10% applied to the “over 40” cohort. Only within the “Other Job” category (which was of less interest to this study) did the numbers become more evenly balanced. In addition, “Age” had also not been included within “Patient Research”, thus making its inclusion within “Staff Research” less desirable.

“Occupation” incorporated 3 levels,

1. Nurse
2. Doctor
3. Other job

Statistical tests for “Staff Research” now composed two 3 x 2 factorial, Two-way Between Groups ANOVA, incorporating the independent variables of “SMS” & “Hospice” and “Occupation” & “Hospice”. The dependent variables incorporated the 4 CPCD sub-scales of ASI, CCI, COD & QOL.

For the same reasons as applied to “Patient Research”, it was again decided to operate a more stringent alpha level by means of a “Bonferroni” adjustment. As the CPCD measuring tool contained 4 tests, a probability value of 0.012 was set as constituting statistical significance.

### Participants.

#### Patients

All patients with progressive non-curative illnesses attending two hospices in the West of Scotland were invited to participate in this study - unless they fulfilled either of the following exclusion criteria –

1. Patients who were confused.
2. Patients who refused consent.

Patients assessed by consultants in palliative medicine as meeting the necessary criteria were issued with Information Sheets (refer to Appendix 1.2), which helped them to decide whether or not to participate in the research. The Information Sheets explained the rationale of the study together with a guide to what would be expected from each participating patient. Information given to patients adhered to strict criteria laid down by the Regional Medical Ethics Committee and all volunteers were assured that any personal information given in the study would be treated

in the strictest confidence. All participating patients gave permission for access to be given to their files concerning, date of birth, disease, disease status and religious affiliations. Once empirical research began, a total of 120 patients agreed to take part in the study (60 from each hospice- see p.130). During 3 months of empirical research within each hospice, 183 patients were admitted to Hospice A and 220 to Hospice B. Thus, MQOL-SV research was conducted with 33% patients in Hospice A and 35% of patients in Hospice B. The treatment of all patients involved in the research was in accordance with the ethical standards of the British Psychological Society and the Local Regional Research Ethics Committee Panel.

### Staff

All staff working in the two hospices involved in the study were invited to take part and issued with Information and Consent Sheets (refer to Appendix 1.5). "Staff" comprised medical and non-medical personnel. A variety of occupations were accessed, i.e. doctors, nurses, auxiliary nurses and administrative staff. Although predominantly female, both sexes were included, ranging in age from 20 + to 60 + years with a diverse attitude to spirituality and religious issues. Hospice A was staffed with 8 doctors, 65 nurses and 77 "others". Hospice B was staffed with 6 doctors, 70 nurses and 32 "others". The study attained 50 "Staff Questionnaire" returns from each hospice, giving a total of 100 participants (see p.131). The study included 100% of the doctors in Hospice A and 67% in Hospice B, 32% of nurses in Hospice A and 35% in Hospice B, 27 % of "other workers" in Hospice A and 34% in Hospice B. The treatment of staff involved in the research was in accordance with the ethical standards of the British Psychological Society.

### Setting

Both hospices were classed as "specialised care centres" for patients with life-threatening illnesses. The first hospice (Hospice A) was a 36-bed "in-patient" charity status centre with a small "Drop-In" day patient unit. Most admissions were patients in the terminal stages of cancer although within the Patient's Files, "Stage of Disease" could be recorded as "rehabilitation", "symptom control" or "end of life". The second hospice (Hospice B) had a 20-bed "in-patient" specialist palliative care unit together with a 12-bed elderly care ward. It also provided a daily "out-patient" clinic for both pain control and social activities. Although under the care of a religious order, the second hospice was "open to all without distinction of race, gender or creed" (Patient's Charter). Within the palliative-care wards of this hospice, all patient illness was classed as "life-threatening" with "Stage of Disease" recorded in the same manner as in Hospice A. Both

hospices offered social care, bereavement care, physiotherapy as well as complimentary services such as, aromatherapy, reflexology, reiki, hairdressing, manicure and chiropody.

Although a strict non-smoking policy applied within both hospices, a “smoking-room” was incorporated into their design for the use of patients only. Both hospices contained a number of individual rooms with en-suite facilities, as well as “bays” containing 4 beds with individual sink units and toilet areas. All bays were gender segregated and each bed was divided by curtains which provided privacy when it was desired by either patients or staff. Each hospice contained at least one family room with overnight accommodation, and a relaxation room where patients could enjoy dimmed lighting, soft music and a variety of water features, plants and stress reducing kaleidoscopic light patterns. Both hospices had also been designed to feature enclosed veranda and conservatory areas overlooking spacious and abundantly stocked gardens. Built on an elevated site, the first hospice enjoyed particularly spectacular views of the city and surrounding countryside.

The first hospice had a comfortably furnished “reflection / prayer” room in which a recently gifted stained-glassed window provided a particularly serene atmosphere. This room was available for patients, visitors and staff to use at any time. The second hospice, being associated with a religious order, had an in-built chapel in which religious services were a daily feature. These services were open to all but on 2 occasions each week, were specifically allocated to “inter-denominational” purposes. Both hospices offered daily spiritual care by way of a resident chaplain and spiritual director respectively and while both hospices offered group counselling and individual bereavement services, the second was unique in providing a children’s “Drop-In” unit one afternoon per week.

### Instruments / Measures

For the patient research programme, the measurement tool consisted of an adapted version of the McGill Quality of Life Questionnaire (MQOL, Cohen, Mount et al, 1995), subsequently entitled MQOL-SV (refer to Appendix 1.1). The original MQOL instrument (Appendix 1.3) was specifically designed to measure quality of life (QOL) in patients with advanced and progressive non-curable illness. Most instruments developed before this had concentrated on patient’s physical symptoms, social supports and on whether anxiety and depression were present. Cohen and Mount argued that as a disease progressed, observers invariably assessed deterioration in a patient’s QOL but stressed that in several studies comparing patient and observer assessments, the

patients consistently rated their QOL higher than did observers (Speck 1993). An account outlining the construction of the MQOL has been included in this study with the approval and permission of Dr.S.Cohen and may be viewed in Appendix 1.3.

Although the McGill Quality of Life Questionnaire is a most suitable instrument for the measurement of quality of life in patients with progressive non-curative illnesses, measuring quality of life is always problematic in the palliative care population since the majority of patients are often too ill to complete the questionnaires. The MQOL instrument was developed in Canada where the researchers were very much aware of the necessity of keeping questionnaires short when dealing with palliative care patients whose concentration is limited due to their low energy resources. On the other hand, in North America (where most medical and psychological research into palliative care populations is conducted), it is not uncommon for patients to be involved in research where there are between 3 and 7 self-administering instruments, each of which can contain between 5 - 40 questions per instrument.

In the West of Scotland however, where this present study was conducted, stringent restrictions apply to any research involving patients with progressive non-curative illness, especially those resident within or receiving treatment from a palliative care hospice. Each research study involving hospice patients must be approved by the Local Authority Medical Ethics Board. For this present study, the ethics committee comprised senior medical consultants whose principal objective was to determine whether the results of the proposed research study would ultimately benefit future patients. The Ethics panel was also concerned with the contents of the empirical study and whether it was likely to disturb the mental or physical welfare of the patient groups involved. In addition, to achieve a realistic chance of approval, most research proposals must be backed by the hospice in which the research study is to be conducted (Caddell, 2003b).

Initially, the researcher spent several months visiting 6 hospices within a radius of approximately 40 miles in order to present and discuss the study's empirical research together with its aims and objectives. In due course, the study gained backing from 2 West of Scotland hospices - on condition that certain staff from each hospice had an opportunity to contribute towards the design of the research for patients. Following a series of consultations, a small group of staff from both hospices, together with the researcher participated in a collaborative exercise designed to formulate a study which would combine maximum test results with the least amount of physical or psychological disturbance to patient's well-being. The "collaborative team" consisted of 1

consultant in palliative care, 1 chaplain, 1 spiritual director, 1 director of nursing and the researcher.

#### Patient Questionnaire (refer to Appendix 1.1)

The team decided that the format of the MQOL questionnaire should be abridged and adapted from that devised by Cohen et al (1995) in order to specifically concentrate the study on the main research themes of,

1. Coping and coping strategies.
2. Quality of life.
3. Spiritual well-being.

The collaborative study team also decided that the total number of questions should amount to no more than 16 (due to the disease status of patient's illnesses) and that criteria for patient medical inclusion should be specified as,

1. The patient feels well enough both physically and emotionally to be interviewed on the day appointed.
2. The patient has no cognitive impairment
3. The patients does not refused consent

The medical staff on the team insisted that the MQOL - SV, should not be self-administering but should be read out to each patient involved in the study by the researcher. (Once again the nature of the patient's severe illness status was reflected in this decision). It was considered appropriate that the researcher should also be given the task of recording patient's self-rated evaluations onto the questionnaire forms. Evaluation ratings were assessed on a Likert-type scale - incorporating score ranges of between 1-5 (where 5 always represented the highest quality of life). This contrasted with the original Cohen et al scoring of 1-7. Permission to change and adapt the MQOL to suit local patient circumstances was obtained from the authors, (Cohen & Mount). An example of the Likert-type scale, illustrated by question 2, is as follows –

#### MQOL-SV – Qu.2

“Have you been feeling depressed?” - 1 = (very depressed): 2 = (depressed): 3 = (neutral): 4 = (slightly depressed): 5 = (not depressed). – Self-rated scores to be recorded by the researcher, with the least desirable score represented as 1 and the most desirable as 5.

## MQOL – Qu.2

“I was; Not at all depressed 1 2 3 4 5 6 7 Extremely depressed”. – Patients instructed to draw a circle round their choice of scoring. A score of 1 being the least desirable and 7 being the most desirable. They also had to read and score the questions by themselves.

Within the original MQOL questionnaire, the first 3 physical questions were labelled A, B and C. and patients had to choose one symptom from a list of 10 physical symptoms to rate its significance. This was done by placing a chosen number alongside letters A, B and C. thereby indicating how they had been feeling over a period of 3 days. The study team proposed to change these 3 questions from physical into general existential questions. The change of questions, together with their sources, are recorded as follows,

- A. “During your lifetime, what has sustained you in times of crisis?” (Hospice B)
- B. “What has been on your mind recently?” (Hospice A).
- C. “What do you think gives meaning to life?” (Researcher).

There was general consensus that by altering the format of self-rated and self-administered statements into those described above would better suit the local culture and medical status of the patients involved. Medical staff in both hospices insisted on this course of action in order to prevent the study becoming too taxing for their patient’s mental and physical welfare. This design produced the subsequent advantage of eliminating unfinished questionnaires – a common feature within most palliative-care research.

From the original 14 MQOL questions, number 8 was eliminated as the team thought it very similar in context to number 6, and number 9 was shortened to “Do you feel that your life is in your hands and that you have control of it. (The latter is cited as number 8 in the changed version). This change was proposed as hospice staff felt the original question too long and too confusing for patients with non-curable illnesses. Number 13 in the original version was also eliminated in the interests of keeping the questionnaire as short as possible and number 14 was shortened to “How would you describe your quality of life in the past two days. The elimination of 2 MQOL questions was not considered a threat to the validity or reliability of the abridged MQOL-SV instrument. Lastly the present researcher suggested incorporating a question about prayer, as previous research results recorded this variable as significant among the coping strategies of patients with life-threatening illnesses, irrespective of whether they were spiritual or non-spiritual individuals.

The researcher had originally wished to measure patient's spirituality or religious scores by means of either the Paloutzian and Ellison (1979) Spiritual Well-Being Index (SWB) or the Kass et al (1991) Index of Core Spiritual Experiences (INSPIRIT). However both tools were rejected by both participating hospices as they felt it essential to limit the patient questionnaire to no more than 16 questions. Consequently the researcher had to abandon the inclusion of a "spirituality / religiosity measurement" tool in exchange for confidential information extracted from the patient's files. This information included the patient's nominal religion and whether the patient practised his or her religious / spiritual beliefs. Information concerning the patient's illness and stage of disease was also supplied. The researcher requested that access to these files should not be available to her until completion of interviews in order to minimise criticism of bias towards any of the participants. Three categories of patient subjects were subsequently defined and henceforth represented the main nominal variables of interest. These were recorded as, -

1. Believers and practising church members (BPCM).
2. Believers, but non-practising church members (B-NPCM).
3. Non-believers, non-practising (NBNP).

The MQOL-SV measuring instrument contained 16 questions. The initial 3 questions labelled A, B and C were existential questions, which were not included in score totals or sub-scale totals. This also applied to number 13. Although these 4 questions were not included within total scores or sub-scale scores, respondent's answers were nonetheless examined in order to discover possible relationships. For example a potential relationship between questions A and C was investigated together with whether results of all 4 questions corresponded with religious / spirituality orientation declared within the Patient Files.

Twelve of the questions on the MQOL-SV were based closely on the original MQOL although potential score totals now ranged between 12 and 60 points (higher results being more desirable) instead of between 17 – 119. The four MQOL-SV sub-scales remained identical to those of the MQOL although an additional sub-scale had been included ("Total Scores") –

Physical Sub-Scale: - Number 1 (producing score range 1 – 5)

Psychological Sub-Scale: - Numbers: 2 – 5 (producing score range 4 – 20).

Meaningful Existence Sub-Scale: - Numbers: 6 – 8 (producing score range 3- 15).

Outlook on Life Sub-Scale: (Support) - Numbers 9 – 12 (producing score range 4- 20).

Total Scores Sub-Scale: - Numbers 1 – 12 (producing score range 12 – 60).



Before being presented to the Local Authority Medical Ethics Board, the “MQOL-SV Patient Research” study had to initially receive approval from the Director of Palliative Medicine at each of the 2 hospices involved in the research. Both consultants submitted their written approval of the study on the “Combined Form for Ethics Submission & Project Registration”.

#### Staff Questionnaire (refer to Appendix 1.4)

Staff at both hospices imposed little restriction on the contents of the Staff Questionnaire since research with staff members was not subject to investigation by Medical Ethics Boards. The MQOL (Cohen et al, 1995) had not included questions for staff but in order help account for possible result differences between hospice groups in the “Patient Research” study, a “Staff Questionnaire” entitled “Coping with Palliative Care Duties” (CPCD) was devised by the researcher. Its main objective was to investigate staff attitude towards spirituality issues within hospice policy, staff coping strategies and quality of life scores. It consisted of 22 questions, 20 of which were directed at overall hospice staff population. Question 21 targeted doctors / consultants and question 22 investigated the views of hospice chaplains / spiritual directors. Upon completion, results for both studies (Staff and Patient research) would then be compared.

The first 20 questions were designed to measure –

1. Personal spirituality – Numbers 1 – 4 (producing score range 0 – 8)
2. Attitude to spirituality issues as hospice policy – Numbers 6 – 8 (producing score range 0 - 10)
3. Attitude towards spirituality/religion as a coping mechanism – Number 9 (producing score range 0 – 4)
4. Coping with depression - Number 10 & 13 (producing score range 0 – 4)
5. Quality of Life measurement – Question 14 & 16 (producing score range 0 – 4)
6. Personal religiosity & ritual assessment – Questions 17 – 20 (producing score range 0 – 8)

Personal spirituality was assessed in questions 1 – 4 while the opinions of staff with no religious / spirituality beliefs were provided for in the open-ended question number 5 - “During your lifetime, what has helped sustain you during times of crisis?” Question 6 (a) and (b) assessed staff attitudes towards working with hospice chaplains and visiting clergy and questions 7 (a) & (b) & 8 explored staff attitudes towards the discussion of spirituality and religious issues and praying with patients. Whether spirituality and religious issues were assessed as worthy of being included as coping strategies for the terminally was assessed in question 9 (a) and (b). Questions 10 and 11 were inserted to provide a comparison (depression) score total with the “psychological sub-scale”

in the patient questionnaire and question 12 provided an opportunity to gain insight into staff attitude towards “meaningful existence”. Questions 13 & 15 investigated the main research subject (coping-strategies) and question number 16 provided a comparison total for the I.V. (Quality of Life) in the Patient Questionnaire. Lastly questions 17 – 20 assessed personal religiosity.

Questions 21 investigated doctor’s attitude towards assessment of patient’s psychological status and coping abilities. In addition, it inquired whether doctors considered males or females to be more adept at coping with terminal illness and whether they informed their patients when they were close to death. Question 22, on the other hand, invited the chaplains / spiritual directors of Hospices A & B to outline the benefits to patients of the inclusion of pastoral care and “spiritual well-being” within palliative care. Questions 21 and 22 were included in order to compare and contrast the responses with results reported in recent literary reviews of palliative care / coping strategy research.

### Scoring Range

Questions numbered 1 – 4 were scored as follows,

Yes = 2; No = 0; Not sure = 1; Not appropriate = 0 (score range 0 – 8).

Question number 5 was an open-ended question.

Questions numbered 6 (a & b), 7(a & b) & 8 were scored as follows,

Yes = 2; No = 0; Sometimes = 1; Unsure = 1 (score range 0 – 10)

Question number 9 (a & b) was scored as follows,

Yes = 2; No = 1; Unsure = 0 (score range 0 – 4).

Question numbered 10 was scored as,

Yes = 0; Occasionally = 1; No = 2 (score range 0 – 2).

Question number 11 was an open-ended question.

Question number 12 was also open-ended and will be compared to question C in the Patient’s Questionnaire.

Question 13 and 14 were scored as follows,

Yes = 2; No = 0; Unsure = 1; Not appropriate = 0 (score range 0 – 4).

Question 15 was open-ended.

Question 16 was scored as,

Good = 2; Fair = 1; Poor = 0 (score range 0 – 2).

Questions 17 – 18 were scored as follows,

Yes = 1; No = 0 (score range 0 – 2)

Questions 19 – 20 were scored as,

Daily = 3; Weekly = 2; Monthly = 1; Never = 0 (score range 0 – 6).

Total overall score for staff participants ranged from 2– 38.

Question 21 was divided into 4 parts and was scored as follows,

- A. – Yes = 2; No = 1
- B. – Yes = 2; No = 1
- C. – Males = 3; Females = 2; About the same = 1; Can't appropriate = 0.
- D. – Always =3; Only = 2; Sometimes = 1; Never = 0.

Question 22 was an open-ended question. Questions 21 and 22 were not included in the overall total score range for staff participants since the answers to these questions were used solely as comparisons to previous published research results.

### Procedure

Approval for the study was obtained from North Glasgow University Hospital NHS Trust Research Ethics Committee (refer to Appendix 5).

### Patient Participants:

Initially, pilot tests were conducted with 2 patients from each hospice (not included in the final results) in order to acquire experience and confidence in empathetic communication techniques with patients and also to gain practise in data collection. The pilot tests also created the additional benefit of familiarisation with medical teams and general administrative policies prevalent within each hospice. Most importantly, the tests afforded valuable information concerning the amount of time needed to conduct each interview. On completion of the pilot study, discussions ensued concerning the times most suited to interviewing, once the main research programme with patients became scheduled to begin. Afternoon appointments between the hours of 2.00pm and 4.00pm were considered by staff to be most appropriate. Patients were considered to be at their most comfortable as all pain-controlling drugs were routinely administered during morning rounds. Patients were also predicted to feel relaxed (but not sleepy), having consumed their lunch. However, once empirical research commenced, this schedule was found not to be suitable as patient's relatives began visiting as soon as lunch was finished (1.00pm). Therefore in order not to interrupt patient / relative interactions, permission was obtained from medical staff to access patients from 11.00 am onwards on the appointed research days (normally 2 mornings each week).

Each hospice visit entailed the same procedure –

1. Check in at hospice security desk.
2. Receive name-identifier security tag.
3. Short meeting with staff research team, during which the names of any patients who were in the process of dying (and therefore not to be interviewed) were supplied.

Following the staff meeting, the researcher was afforded the opportunity to conduct a random selection of patients for interview. (No information from Patient's Files was supplied at this point in time in order to prevent "interviewer bias" criticism). Determining the whereabouts of resident patients was accomplished by looking at a map (provided by the research team) in which the bays, patient's names, rooms and bed numbers were highlighted in fluorescent ink. Some patients were confined to their beds whereas others were able to achieve short periods either sitting in their bedside chair or being transported to veranda or conservatory areas by means of hospice wheelchairs. Approaching a patient concerning research participation was conducted in a polite but methodological manner irrespective of the fact that they had previously read the Information sheet and that a favourable response regarding questionnaire participation may have been given to one of the research team earlier that day. In every instance, information detailing the nature and aims of the study was discussed and ample time was given for decision making. If permission to conduct the interview was granted, the patient was asked to sign the Consent Form and a copy of the Patient Questionnaire (see Appendix 1) was then given for reference. He / she was reminded that the questions would be read aloud, and that there was no right or wrong answer – only their own opinions. Once the patient was ready to begin, the 16 MQOL-SV questions were read to the participant and the appropriate self-rated score assessment chosen by the patient, was recorded by the researcher onto the Questionnaire Form.

With reference to questions numbered A B C and 13, examples of answers most likely to be expressed by patients had been prepared. These had been pencilled into allocated spaces within the Interviewer's Questionnaire sheet. If the patient mentioned any of these answers, a circle was drawn around it. Extra space was provided however for the inclusion of alternative patient responses. For example, with regard to question A –

"During your lifetime, what has helped sustain you during times of crisis?" - Examples of responses were, – "family members, friends, religion, personal resilience, fellow church members" etc.

Once all questions had been answered and scored, the patient was again thanked for her / his assistance and for taking time to make their valuable contributions towards the research study. The reference copy of the Patient Questionnaire was left with the patient while the completed questionnaire and Consent Form was placed within a secure folder before the procedure was repeated in exactly the same manner with the next patient volunteer.

The amount of time devoted to each interview was determined by individual patient's preference. Some patients preferred to spend time answering the questions, giving details and opinions, while others preferred to answer without supplying explanations for their answers. In general, Patient Questionnaires took between 20 and 40 minutes to conduct, however repeating the rationale of the research to each participating patient before every interview added an additional 10 minutes to the overall procedure. As the amount of time involved in the initial pilot tests had indicated "face to face interviewing" as a time-consuming procedure, a total of 6 months (3 months for each hospice) had been allocated for "Patient Research". Once empirical research began however, it became apparent that only 4 – 6 interviews on average were being achieved per week. Thus the amount of time devoted to each interview ultimately determined the population sample. During 3 months of "Patient Research" within the first participating hospice (Hospice A) the study attained 60 completed questionnaires. The same amount of responses were targeted in the second participating hospice, Hospice B. Interviews within this hospice progressed slightly quicker, attaining a total of 60 completed questionnaires in just under 3 months (10 weeks). Due to these methods, a total of 120 patients participated in the Patient Research programme.

#### Staff Participants:

The staff questionnaires although self-administering had nonetheless to be made known to hospice staff members. Four possible options were available to the researcher –

1. Placing notices in advertising boards within both hospices explaining the object of the research.
2. Staff meetings would be arranged in order to explain the research and appeal for participants.
3. Chaplain / spiritual director would distribute the questionnaires, together with a written explanation of the study aims and objectives, within routine staff mailings.
4. The researcher would distribute the questionnaires to members of staff while explaining the objectives of the research study on a one to one approach.

Following a meeting, in which the pros and cons of the four options were discussed, it was decided that number 3 would give the research the best chance of completion returns. Staff members, (comprising medical staff and non-medical staff) were set a time limit of 2-3 weeks for questionnaire completion (see Appendix 1.4). Each staff member was given a copy of the Staff Information Sheet and Consent Form (see Appendix 1.5). Participants were requested to deposit completed questionnaires and consent forms into a box situated in a secure part of the hospice or to return them personally to the hospice chaplain/spiritual director. The 2-3 week time limit had been chosen on the advice of the research team whose experience with previous studies had noted a general cessation of returns following three weeks of distribution.

Following the allotted period, 48 staff returns were collected from Hospice A and 42 from Hospice B. However, during the “Patient Research” study, 2 staff members from Hospice A and 8 from Hospice B returned questionnaires which they had earlier completed but forgotten to deposit in the box. Due to these methods, the Staff Research population attained 100 participants (50 from each hospice).

#### Presentation of Results for Patient and Staff Research Studies.

Of prime interest to the “collaborative team” was the possibility of significant result differences between the populations of Hospices A and B.

Since “Patient Research” and “Staff Research” took place within 2 separate hospices, Descriptive Statistics results and One-Way ANOVA results for each hospice were presented separately within Chapter 4 in order to illustrate resulting differences.

“Two Way Between Groups” ANOVA (employing a 3 x 2 factorial design) was the main statistical test utilised for the 5 hypotheses relating to MQOL-SV Patient Research. For CPCD Staff Research, “Two Way Between Groups” ANOVA (6 x 2 factorial design) was employed. A detailed presentation of these results may be accessed within Appendices 2.1 – 2.5 & 4.1 – 4.4 (see Table of Contents).

## Chapter 4

## Descriptive Statistics and One-Way ANOVA Results

Table A - Descriptive Sample Data for Patients in Hospices A &amp; B (N = 120)

<b>HOSPICE A – (N = 60)</b>		<b>HOSPICE B – (N = 60)</b>	
<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Sex</b>		<b>Sex</b>	
Male	29 (49%)	Male	22 (36.7%)
Female	31 (51%)	Female	38 (66.3%)
Total	60 – 100%	Total	60 – 100%
<b>Ethnicity</b>		<b>Ethnicity</b>	
White	60 (100%)	White	60 (100%)
Total	60 – 100%	Total	60 – 100%
<b>Age</b>		<b>Age</b>	
Under 50 years	04 (06.6%)	Under 50 years	04 (06.6%)
Between 50 & 60 years	10 (16.4%)	Between 50 & 60 years	09 (15.1%)
Over 60 years	46 (77.0%)	Over 60 years	47 (78.3%)
Total	60 – 100%	Total	60 – 100%
<b>Religious Status</b>		<b>Religious Status</b>	
Believing & practising church members	18 (30%)	Believing & practising church members	20 (33.3%)
Believing but non-practising church members	16 (27%)	Believing but non-practising church members	19 (31.7%)
Non-believers / non-practising	26 (43%)	Non-believers / non-practising	21 (35.0%)
Total	60 – 100%	Total	60 – 100%
<b>Disease</b>		<b>Disease</b>	
Cancer	58 (96.7%)	Cancer	58 (96.7%)
Other	02 (03.3%)	Other	03 (03.3%)
Total	60 – 100%	Total	60 – 100%
<b>Stage of Disease</b>		<b>Stage of Disease</b>	
Rehabilitation	20 (33.3%)	Rehabilitation	14 (23.3%)
Symptom Control	32 (53.4%)	Symptom Control	29 (48.4%)
End of Life	08 (13.3%)	End of Life	17 (28.3%)
Total	60 – 100%	Total	60 – 100%
<b>Physical Health (Qu. 1)</b>		<b>Physical Health (Qu. 1)</b>	
Very well	06 (10.0%)	Very well	17 (28.3%)
Well	19 (31.7%)	Well	29 (48.3%)
Neutral	01 (01.7%)	Neutral	0
Unwell	26 (43.3%)	Unwell	11 (18.3%)
Very unwell	08 (13.3%)	Very Unwell	03 (05.0%)
Total	60 – 100%	Total	60 – 100%

<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Anxiety (Qu.2)</b>		<b>Anxiety (Qu.2)</b>	
Very anxious	07 (11.7%)	Very anxious	0
Anxious	18 (30.0%)	Anxious	30 (50.0%)
Neutral	01 (01.6%)	Neutral	0
Slightly anxious	19 (31.7%)	Slightly anxious	14 (23.3%)
Not anxious	15 (25.0%)	Not anxious	16 (26.7%)
Total	60 – 100%	Total	60 – 100%
<b>Depression (Qu.3)</b>		<b>Depression (Qu.3)</b>	
Very depressed	04 (06.7%)	Very depressed	0
Quite depressed	13 (21.7%)	Quite depressed	23 (38.3%)
Neutral	01 (01.7 %)	Neutral	01 (01.7%)
Slightly depressed	20 (33.3%)	Slightly depressed	17 (28.3%)
Not at all depressed	22 (36.6%)	Not at all depressed	19 (31.7%)
Total	60 – 100%	Total	60 – 100%
<b>Sadness (Qu.4)</b>		<b>Sadness (Qu.4)</b>	
All the time	03 (05.1%)	All the time	0
Quite often	14 (23.3%)	Quite often	18 (30.0%)
Neutral	02 (03.3%)	Neutral	04 (06.7%)
Somewhat	27 (45.0%)	Somewhat	18 (30.0%)
Not at all	14 (23.3%)	Not at all	20 (33.3%)
Total	60 – 100%	Total	60 – 100%
<b>Frightened of Future (Qu.5)</b>		<b>Frightened of Future (Qu.5)</b>	
All the time	01 (1.6%)	All the time	01 (01.7%)
Quite often	07 (11.7%)	Quite often	14 (23.3%)
Neutral	01 (01.6%)	Neutral	02 (03.3%)
Somewhat	29 (49.5%)	Somewhat	23 (38.3%)
Not at all	21 (36.1%)	Not at all	20 (33.3%)
Total	60 – 100%	Total	60 – 100%
<b>Achieve Life Goals (Qu.6)</b>		<b>Achieve Life Goals (Qu.6)</b>	
Failed miserably	01 (01.7%)	Failed miserably	0
Could have achieved more	09 (15.1%)	Could have achieved more	07 (11.7%)
Neutral	04 (06.6%)	Neutral	06 (10.0%)
Achieved a certain amount	29 (48.3%)	Achieved a certain amount	25 (41.7%)
Achieved a lot	17 (28.3%)	Achieved a lot	22 (36.6%)
Total	60 – 100%	Total	60 – 100%
<b>Meaningful Life (Qu.7)</b>		<b>Meaningful Life (Qu.7)</b>	
Decidedly meaningless	0	Decidedly meaningless	0
Meaningless	06 (10.0%)	Meaningless	09 (15.0%)
Neutral	05 (08.5%)	Neutral	07 (11.7%)
Fairly meaningful	32 (53.6%)	Fairly meaningful	26 (43.3%)
Very meaningful	17 (27.9%)	Very meaningful	18 (30.0%)
Total	60 – 100%	Total	60 – 100%



<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>In Control (Qu.8)</b>		<b>In Control (Qu.8)</b>	
Very out of control	0	Very out of control	0
Out of control	19 (31.7%)	Out of control	13 (21.7%)
Neutral	04 (06.7%)	Neutral	04 (06.7%)
Fairly in control	21 (35.0%)	Fairly in control	26 (43.3%)
Very much in control	16 (26.6%)	Very much in control	17 (28.3%)
Total	60 – 100%	Total	60 – 100%
<b>Close to People (Qu.9)</b>		<b>Close to People (Qu.9)</b>	
Very close	25 (41.7%)	Very close	35 (58.3%)
Fairly close	18 (30.0%)	Fairly close	15 (25.0%)
Neutral	02 (03.3%)	Neutral	01 (01.7%)
Quite distant	12 (20.0%)	Quite distant	09 (15.0%)
Very distant	03 (05.0%)	Very distant	0
Total	60 – 100%	Total	60 – 100%
<b>Feel Good About Self (Qu.10)</b>		<b>Feel Good About Self Qu.10)</b>	
Decidedly bad	01 (01.7%)	Decidedly bad	01 (01.7%)
Not very good	08 (13.3%)	Not very good	07 (11.7%)
Neutral	03 (05.0%)	Neutral	05 (08.3%)
Fairly good	26 (43.3%)	Fairly good	18 (30.0%)
Very good	22 (36.7%)	Very good	29 (48.3%)
Total	60 – 100%	Total	60 – 100%
<b>Each Day Joy or Burden Q.11</b>		<b>Each Day Joy or Burden</b>	
Very burdensome	03 (05.0%)	Very burdensome	02 (03.3%)
Burdensome	15 (25.0%)	Burdensome	13 (21.7%)
Neutral	02 (03.3%)	Neutral	05 (08.3%)
Quite joyous	30 (50.0%)	Quite joyous	15 (25.0%)
Very joyous	10 (16.7%)	Very joyous	25 (41.7%)
Total	60 – 100%	Total	
<b>Quality of Life (Past 2 Days) (Qu.12)</b>		<b>Quality of Life (Past 2 Days) (Qu.12)</b>	
Very good	28 (48.0%)	Very good	51 (85.0%)
Good	23 (39.0%)	Good	07 (11.7%)
Neutral	01 (01.6%)	Neutral	01 (01.6%)
Fairly bad	05 (08.5%)	Fairly bad	01 (01.7%)
Very bad	03 (04.9%)	Very bad	0
Total	60 – 100%	Total	60 – 100%
<b>Total Scores</b>		<b>Total Scores</b>	
Good	14 (23.3%)	Good	26 (43.3%)
Fair	42 (70.0%)	Fair	33 (55.1%)
Poor	04 (06.7%)	Poor	01 (01.6%)
Total	60- 100%	Total	60- 100%

<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Physical Sub-Scale</b>		<b>Physical Sub-Scale</b>	
Very Good Physically	06 (10.0%)	Very Good Physically	16 (26.7%)
Fairly Good Physically	19 (32.1%)	Fairly Good Physically	29 (48.3%)
Fairly Poor Physically	27 (45.8%)	Fairly Poor Physically	11 (18.3%)
Poor Physical Health	08 (12.1%)	Poor Physical Health	04 (06.7%)
Total	60 – 100%	Total	60 – 100%
<b>Psychological Sub-Scale</b>		<b>Psychological Sub-Scale</b>	
Poor Psychological Health	05 (08.3%)	Poor Psychological Health	14 (22.6%)
Fairly Poor Psychological Health	17 (28.3%)	Fairly Poor Psychological Health	11 (18.3%)
Fairly Good Psychological Health	12 (20.1%)	Fairly Good Psychological Health	12 (20.1%)
Good Psychological Health	26 (43.3%)	Good Psychological Health	23 (39.0%)
Total	60 – 100%	Total	60 – 100%
<b>Meaningful Existence Sub-Scale (Existential)</b>		<b>Meaningful Existence Sub-Scale (Existential)</b>	
Very Meaningful Existence	12 (20.6%)	Very Meaningful Existence	26 (43.3%)
Meaningful Existence	23 (39.0%)	Meaningful Existence	21 (35.0%)
Fairly Meaningless Existence	17 (28.3%)	Fairly Meaningless Existence	09 (15.0%)
Utterly Meaningless Existence	08 (12.1%)	Utterly Meaningless Existence	04 (06.7%)
Total	60 – 100%	Total	60 – 100%
<b>Outlook In Life Sub-Scale (Support)</b>		<b>Outlook In Life Sub-Scale (Support)</b>	
Poor Outlook	04 (06.7%)	Poor Outlook	0
Fair Outlook	14 (23.3%)	Fair Outlook	15 (25.0%)
Good Outlook	26 (43.0%)	Good Outlook	13 (21.7%)
Very Good Outlook	16 (27.0%)	Very Good Outlook	32 (53.3%)
Total	60 – 100%	Total	60 – 100%
<b>Willing to have Prayers said for you (Qu.13)</b>		<b>Willing to have Prayers said for you (Qu.13)</b>	
Very unwilling	06 (10.0%)	Very unwilling	04 (06.7%)
Fairly unwilling	03 (05.0%)	Fairly unwilling	0
Neutral	03 (05.0%)	Neutral	03 (05.0%)
Fairly willing	06 (10.0%)	Fairly willing	06 (10.0%)
Very willing	42 (70.0%)	Very willing	47 (78.3%)
Total	60 – 100%	Total	60 – 100%
<b>Time Between Interview &amp; Death</b>		<b>Time Between Interview &amp; Death</b>	
Less than 1 week	12 (20.6%)	Less than 1 week	06 (10.0%)
Between 1 – 4 weeks	19 (31.1%)	Between 1 – 4 weeks	12 (20.0%)
Between 1 – 3 months	07 (11.7%)	Between 1 – 3 months	06 (10.0%)
Between 4 – 6 months	20 (33.3%)	Between 4 – 6 months	06 (10.0%)
Still alive at present (29.03.03)	02 (03.3%)	Still alive at present (30.07.03)	30 (50%)
Total	60 (100%)	Total	60 (100%)

<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>What has Sustained During Crisis (Qu.A)</b>		<b>What has Sustained During Crisis (Qu.A)</b>	
Religious belief / Spirituality	22 (36.7%)	Religious belief / Spirituality	27 (45.0%)
Family / Self	26 (43.3%)	Family / Self	20 (43.3%)
Other Answer	12 (20.0%).	Other Answer	13 (21.7%)
Total	60 – 100%	Total	60 – 100%
<b>What Has Been On Mind (Qu.B)</b>		<b>What Has Been On Mind (Qu.B)</b>	
Religious belief / Spirituality	06 (10.0%)	Religious belief / Spirituality	09 (01.7%)
Family / Self	30 (50.0%)	Family / Self	26 (50.0%)
Other Answer	24 (40.0%)	Other Answer	25 (36.7%)
Total	60 – 100%	Total	60 – 100%
<b>What Gives Meaning to Life (Qu.C)</b>		<b>What Gives Meaning to Life (Qu.C)</b>	
Religious / Spirituality Concerns	24 (40.0%)	Religious / Spirituality Concerns	25 (36.7%)
Issues Concerning Family / Self	14 (23.3%)	Issues Concerning Family / Self	16 (26.7%)
Other Answer	22 (36.7%)	Other Answer	19 (20.0%)
Total	60 – 100%	Total	60 – 100%

**Table B – Descriptive Sample Data for Volunteer Staff in Hospices A & B (N = 100)**

<b>Hospice A -</b>		<b>Hospice B -</b>	
<b>Variables</b>	<b>N = 50</b>	<b>Variables</b>	<b>N =50</b>
<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Sex</b>		<b>Sex</b>	
Male	14 (28.0%)	Male	07 (14%)
Female	36 (72.0%)	Female	43 (86 %)
Total	50 –100%	Total	50 (100%)
<b>Age</b>		<b>Age</b>	
Under 40	30 (60.0%)	Under 40	26 (52%)
Forty or Over	20 (40.0%)	Forty or Over	24 (48%)
Total	50 – 100%	Total	50 (100%)

<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Occupation</b>		<b>Occupation</b>	
Nurse	21 (42.0%)	Nurse	38 (76%)
Doctor	08 (16.0%)	Doctor	04 (08%)
Other Job	21 (42.0%)	Other Job	08 (16%)
Total	50 – 100%	Total	50 (100%)
<b>Ethnicity</b>		<b>Ethnicity</b>	
White	50 (100%)	White	50 (100%)
Total	50 – 100%	Total	50 – 100%
<b>Personal Spirituality</b>		<b>Personal Spirituality</b>	
High	35 (70.0%)	High	40 (80%)
Medium	11 (22.0%)	Medium	09 (18%)
Low	04 (08.0%)	Low	01 (02%)
Total	50 – 100%	Total	50 (100%)
<b>Spiritual Assessment Scores</b>		<b>Spiritual Assessment Scores</b>	
Good	37 (74.0%)	Good	34 (68%)
Fair	10 (20.0%)	Fair	14 (28%)
Poor	03 (06.0%)	Poor	02 (04%)
Total	50 – 100%	Total	50 (100%)
<b>Category Inclusion Assessment</b>		<b>Category Inclusion Assessment</b>	
Worthy of Inclusion	45 (90.0%)	Worthy of Inclusion	45 (90%)
Not Worthy of Inclusion	05 (10.0%)	Not Worthy of Inclusion	05 (10%)
Total	50 – 100%	Total	50 (100%)
<b>Personal Coping With Work Ability</b>		<b>Personal Coping With Work Ability</b>	
Good	24 (48.0%)	Good	20 (40%)
Fair	25 (50.0%)	Fair	24 (48%)
Poor	01 (02.0%)	Poor	05 (12%)
Total		Total	50 (100%)
<b>Quality of Life</b>		<b>Quality of Life</b>	
Good	36 (72.0%)	Good	33 (66%)
Fair	11 (22.0%)	Fair	13 (26%)
Poor	03 (06.0%)	Poor	04 (08%)
Total	50 – 100%	Total	50 (100%)
<b>Religiosity Total Scores</b>		<b>Religiosity Total Scores</b>	
High	22 (44.0%)	High	37 (74%)
Medium	04 (08.0%)	Medium	05 (10%)
Low	24 (48.0%)	Low	08 (08%)
Total	50 – 100%	Total	50 (100%)
<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>

<b>Spiritual Measurement Scores (SMS)</b>		<b>Spiritual Measurement Score Totals (SMS)</b>	
High	10 (20%)	High	14 (28%)
Medium	15 (30%)	Medium	22 (44%)
Low	25 (50%)	Low	14 (28%)
Total	50 – 100%	Total	50 – 100%
<b>Spiritual Person? (Qu.1)</b>		<b>Spiritual Person? (Qu.1)</b>	
Yes	36 (72.0%)	Yes	44 (88%)
No	14 (28.0%)	No	06 (12%)
Total	50 – 100%	Total	50 – 100%
<b>Spirituality Important? (Qu.2)</b>		<b>Spirituality Important? (Qu.2)</b>	
Yes	34 (68.0%)	Yes	44 (88%)
No	03 (06.0%)	No	06 (12%)
Not Sure	13 (26.0%)	Not Sure	0
Total	50 – 100%	Total	50 – 100%
<b>More Important Now? (Qu.3)</b>		<b>More Important Now? (Qu.3)</b>	
Yes	22 (44.0%)	Yes	21 (42%)
No	14 (28.0%)	No	10 (20%)
Not Sure	14 (28.05)	Not Sure	19 (38%)
Total	50 – 100%	Total	50 – 100%
<b>Life After Death? (Qu.4)</b>		<b>Life After Death? (Qu.4)</b>	
Yes	29 (58.0%)	Yes	40 (80%)
No	03 (06.0%)	No	02 (04%)
Not Sure	18 (36.0%)	Not Sure	08 (16%)
Total	50 – 100%	Total	50 – 100%
<b>Comfortable With Hospice Chaplain? (Qu.6A)</b>		<b>Comfortable With Spiritual Director? (Qu.6A)</b>	
Yes	44 (88.0%)	Yes	41 (82%)
No	02 (04.0%)	No	03 (06%)
Sometimes	04 (08.0%)	Sometimes	06 (12%)
Total	50 – 100%	Total	50 – 100%
<b>Comfortable With Clergy? (Qu.6B)</b>		<b>Comfortable With Clergy? (Qu.6B)</b>	
Yes	39 (78.0%)	Yes	32 (64%)
No	02 (04.0%)	No	10 (20%)
Sometimes	09 (18.0%)	Sometimes	08 (16%)
Total	50 – 100%	Total	50 – 100%
<b>Discuss Spirituality Issues (Qu.7A)</b>		<b>Discuss Spirituality Issues (Qu.7A)</b>	
Yes	36 (72.0%)	Yes	47 (94%)
No	03 (06.0%)	No	01 (02%)
Unsure	11 (22.0%)	Unsure	02 (04%)
Total	50 – 100%	Total	50 – 100%

<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Discuss Religious Issues? (Qu.7B)</b>		<b>Discuss Religious Issues (Qu.7B)</b>	
Yes	28 (56.0%)	Yes	32 (64%)
No	05 (10.0%)	No	09 (18%)
Unsure	17 (34.0%)	Unsure	09 (18%)
Total		Total	50 – 100%
<b>Pray With Patient?(Qu.8)</b>		<b>Pray With Patient?(Qu.8)</b>	
Yes	30 (60.0%)	Yes	40 (80%)
No	12 (24.0%)	No	06 (12%)
Unsure	08 (16.0%)	Unsure	04 (08%)
Total	50 – 100%	Total	50 – 100%
<b>Spirituality Issues Worthy? (Qu.9A)</b>		<b>Spirituality Issues Worthy? (Qu.9A)</b>	
Yes	48 (96.0%)	Yes	44 (88%)
No	02 (04.0%)	No	0
Unsure	00 (00.0%)	Unsure	06 (12%)
Total	50 – 100%	Total	50 – 100%
<b>Religious Issues Worthy? (Qu.9B)</b>		<b>Religious Issues Worthy? (Qu.9B)</b>	
Yes	42 (84.0%)	Yes	40 (80%)
No	02 (04.0%)	No	01 (02%)
Unsure	06 (12.0%)	Unsure	09 (18%)
Total	50 – 100%	Total	50 – 100%
<b>Struggle Emotionally (Qu.10)</b>		<b>Struggle Emotionally?Q.10</b>	
Yes	12 (24.0%)	Yes	15 (30%)
No	22 (44.0%)	No	06 (12%)
Occasionally	16 (32.0%)	Occasionally	29 (58%)
Total	50 – 100%	Total	50 – 100%
<b>Cope With Job (Qu.13)</b>		<b>Cope With Job (Qu.13)</b>	
Yes	47 (94.0%)	Yes	38 (76%)
No	01 (02.0%)	No	01 (02%)
Unsure	02 (04.0%)	Unsure	11 (22%)
Total	50 – 100%	Total	50 – 100%
<b>Developed Coping Strategy? (Qu.14)</b>		<b>Developed Coping Strategy? (Qu.14)</b>	
Yes	30 (60.0%)	Yes	33 (66%)
No	14 (28.0%)	No	14 (28%)
Unsure	06 (12.0%)	Unsure	04 (06%)
Total	50 – 100%	Total	50 – 100%
<b>Quality Of Life? (Qu.16)</b>		<b>Quality Of Life? (Qu.16)</b>	
Good	33 (66.0%)	Good	33 (66%)
Fair	13 (26.0%)	Fair	13 (26%)
Poor	04 (08.0%)	Poor	04 (08%)
Total	50 – 100%	Total	50 – 100%

<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Ever Been Church Member?</b> (Qu.17)		<b>Ever Been Church Member?</b> (Qu.17)	
Yes	41 (82.0%)	Yes	46 (92%)
No	09 (18.0%)	No	04 (08%)
Total	50 – 100%	Total	50 – 100%
<b>Still Church Member(Qu.18)</b>		<b>Still Church Member (Qu.18)</b>	
Yes	26 (52.0%)	Yes	38 (76%)
No	24 (48.0%)	No	12 (24%)
Total	50 – 100%	Total	50 – 100%
<b>How Often Worship? (Qu.19)</b>		<b>How Often Worship? (Qu.19)</b>	
Daily	05 (10.0%)	Daily	07 (14%)
Weekly	16 (32.0%)	Weekly	27 (54%)
Monthly	03 (06.0%)	Monthly	04 (08%)
Never	26 (52.0%)	Never	12 (24%)
Total	50 – 100%	Total	50 – 100%
<b>How Often Pray? (Qu.20)</b>		<b>How Often Pray? (Qu.20)</b>	
Daily	21 (42.0%)	Daily	31 (62%)
Weekly	09 (18.0%)	Weekly	13 (26%)
Monthly	05 (10.0%)	Monthly	0
Never	15 (30.0%)	Never	06 (12%)
Total	50 – 100%	Total	50 – 100%
<b>Total Scores</b>		<b>Total Scores</b>	
Low	16 (32.0%)	Low	08 (16%)
Medium	16 (32.0%)	Medium	23 (46%)
High	18 (36.0%)	High	19 (38%)
Total	50 – 100%	Total	50 – 100%

**Table C - Descriptive Sample Data for Doctors in Hospices A & B**

<b>Hospice A - N = 8</b>		<b>Hospice B - N = 4</b>	
<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Sex</b>		<b>Sex</b>	
Male	4	Male	2
Female	4	Female	2
Total	8	Total	4
<b>Age</b>		<b>Age</b>	
Under 40	7	Under 40	2
Forty or Over	1	Forty or Over	2
Total	8	Total	4
Variables	Values	Variables	Values

<b>Do you assess your patient's anxiety or stress levels?</b>		<b>Do you assess your patient's anxiety or stress levels?</b>	
Yes	7	Yes	2
No	1	No	2
Total	8	Total	4
<b>Do you assess your patient's level of coping with illness.</b>		<b>Do you assess your patient's level of coping with illness</b>	
Yes	6	Yes	2
No	2	No	2
Total	8	Total	4
<b>Which gender copes better with terminal illness?</b>		<b>Which gender copes better with terminal illness?</b>	
Males	0	Males	0
Females	2	Females	2
About the same	5	About the same	2
Can't Answer	1	Can't Answer	0
Total	8	Total	4

<b>Do you inform your patients when they are close to death?</b>		<b>Do you inform your patients when they are close to death?</b>	
Always	0	Always	0
Only if they themselves ask	2	Only if they themselves ask	2
Sometimes if considered appropriate	6	Sometimes if considered appropriate	2
Never	0	Never	0
Total	8	Total	4
<b>Variables</b>	<b>Values</b>	<b>Variables</b>	<b>Values</b>
<b>Do you believe in a spiritual life after death?</b>		<b>Do you believe in a spiritual life after death?</b>	
Yes	3	Yes	2
No	0	No	0
Not Sure	5	Not Sure	2
Total	8	Total	4
<b>How often pray?</b>		<b>How Often Pray?</b>	
Daily	1	Daily	1
Weekly	2	Weekly	1
Monthly	1	Monthly	0
Never	4	Never	2
Total	8	Total	4



<b>Spiritual / Religious Orientation</b>		<b>Spiritual / Religious Orientation</b>	
Believer & Church Attendee	2	Believer & Church Attendee	2
Believer but non-practiser	2	Believer but non-practiser	0
Non-believer	4	Non-believer	2
Total	8	Total	4
<b>Do you consider religiosity/ spirituality issues worthy of inclusion in a category entitled "coping strategies of the terminal ill?"</b>		<b>Do you consider religiosity/ spirituality issues worthy of inclusion in a category entitled "coping strategies of the terminal ill?"</b>	
Yes	8	Yes	4
No	0	No	0
Not Sure	0	Not Sure	0
Not Appropriate	0	Not Appropriate	0
Total	8	Total	4
<b>Do you ever get depressed due to the duties connected to your occupation?</b>		<b>Do you ever get depressed due to the duties connected to your occupation?</b>	
Yes	0	Yes	2
No	3	No	0
Occasionally	5	Occasionally	2
Total	8	Total	4
<b>Do you employ a coping strategy?</b>		<b>Do you employ a coping strategy?</b>	
Yes	5	Yes	2
No	2	No	2
Not Appropriate	1	Not Appropriate	0

## Inferential Statistics

### Patients in Hospice A – (n = 60)

#### Hypothesis 1

##### Analysis-of-Variance **Table 1: Physical Status by Religious Orientation Status**

Distribution of F ( $p = 0.05$ ).

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	0.754	2	.377	.459	.634
Within Groups	46.846	57	.822		
Total	47.600	59			

Physical Sub-Scale: Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05 1
Believer and practising church member	18	1.6667
Believing but non-practising church member	16	1.7500
Non-believing / non-practising church member	26	1.9231
Sig.		.658

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 1 displays an  $F$  value of .477,  $p = .634$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) must be retained.

#### Hypothesis 2

##### Analysis-of-Variance **Table 2: Psychological Status by Religious Orientation Status**

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	2.828	2	1.414	2.456	.095
Within Groups	32.822	57	.576		
Total	35.650	59			

Psychological Sub-Scale: Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05 1
Believer and practising church member	18	2.3333
Believing but non-practising church member	16	2.6875
Non-believing / non-practising church member	26	2.1538
Sig.		.084

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 2 displays an  $F$  value of 2.456,  $p = .095$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) must be retained.

### Hypothesis 3

#### Analysis-of-Variance Table 3: Meaningful Existence Status by Religious Orientation Status

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.945	2	.472	.960	.389
Within Groups	28.038	57	.492		
Total	28.983	59			

Meaningful Existence Sub-Scale: Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05 1
Believer and practising church member	18	2.1667
Believing but non-practising church member	16	2.0000
Non-believing / non-practising church member	26	2.3077
Sig.		.370

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 3 displays an  $F$  value of .960,  $p = .389$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) should be retained.

## Hypothesis 4

### Analysis-of-Variance Table 4: (Outlook in Life) Support by Religious Orientation Status

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	4.944	2	2.472	4.547	.015
Within Groups	30.989	57	.544		
Total	35.933	59			

Outlook in Life Sub-Scale Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05	Subset for alpha = .05
		1	2
Believer and practising church member	18	2.6111	2.6111
Believing but non-practising church member	16		2.6250
Non-believing / non-practising church member	26	2.0385	
Sig.		.050	.998

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 4 displays an  $F$  value of 4.547,  $p = .015$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.980 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently within this population sample,  $p$  just falls below the significant level and it may therefore be acceptable to retain the null hypothesis ( $H_0$ ).

## Hypothesis 5

### Analysis-of-Variance Table 5: Total Scores by Religious Orientation Status

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.318	2	.159	.567	.571
Within Groups	16.015	57	.281		
Total	16.333	59			

Total Scores: Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05 1
Believer and practising church member	18	2.3333
Believing but non-practising church member	16	2.1250
Non-believing / non-practising church member	26	2.0769
Sig.		.612

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 5 displays an  $F$  value of .567,  $p = 0.571$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 3.150 to reach  $p < 0.05$  (Bonferroni adjustment). Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) should be retained.

## Hypothesis 6

### Analysis-of-Variance Table 6: Intercessory Prayer Response by Religious Orientation Status

Distribution of  $F$  ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	0.246	2	.123	.498	.610
Within Groups	14.087	57	.247		
Total	14.333	59			

Intercessory Prayer Response Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05 1
Believer and practising church member	18	1.2222
Believing but non-practising church member	16	1.0625
Non-believing / non-practising church member	26	1.1923
Sig.		.583

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 6 displays an  $F$  value of .498,  $p = .610$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 3.150 to reach  $p < 0.05$ . Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) should be retained.

## Hypothesis 7 (See Appendices 3.2).

**Patients in Hospice B – (n = 60)**

### Hypothesis 1

**Analysis-of-Variance Table 8: Physical Status by Religious Orientation Status**

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	10.142	2	5.071	8.293	.001
Within Groups	34.858	57	.612		
Total	45.000	59			

Physical Sub-Scale: Tukey HSD (a,b)

Religious Status	N	Subset for alpha	
		1	2
Believer and practising church member	20		2.9000
Believing but non-practising church member	19		2.6842
Non-believing / non-practising church member	21	1.9524	
Sig.		1.000	.660

Means for groups in homogeneous subsets are displayed.

- c. Uses Harmonic Mean Sample Size = 19.967  
 d. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 8 displays an  $F$  value of 8.293,  $p = .001$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is significant and it may be acceptable to reject the null hypothesis ( $H_0$ ) in favour of the alternative hypothesis ( $H_1$ ).

### Hypothesis 2

**Analysis-of-Variance Table 9: Psychological Status by Religious Orientation Status**

Distribution of F ( $p = 0.05$ ).

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	3.694	2	1.847	2.591	.084
Within Groups	40.639	57	.713		
Total	41.924	59			

Psychological Sub-Scale: Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05
		1
Believer and practising church member	20	1.9500
Believing but non-practising church member	19	2.5263
Non-believing / non-practising church member	21	2.0476
Sig.		.088

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 9 displays an  $F$  value of 2.591,  $p = .084$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) must be retained.

### Hypothesis 3

**Analysis-of-Variance Table 10: Meaningful Existence Status by Religious Orientation Status**  
Distribution of  $F$  ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	13.376	2	6.688	16.714	.000
Within Groups	22.808	57	.400		
Total	36.184	59			

Meaningful Existence Sub-Scale: Tukey HSD (a,b)

Religious Status	N	Subset for alpha	= 0.05
		1	2
Believer and practising church member	20		2.7500
Believing but non-practising church member	19		2.3158
Non-believing / non-practising church member	21	1.6190	
Sig.		1.000	.085

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 10 displays an  $F$  value of 16.714,  $p = .000$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is significant and it may be acceptable to reject the null hypothesis ( $H_0$ ) in favour of the alternative hypothesis ( $H_1$ ).

## Hypothesis 4

### Analysis-of-Variance Table 11: Outlook in Life / Support by Religious Orientation Status

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	4.527	2	2.263	11.067	.000
Within Groups	11.657	57	.205		
Total	16.183	59			

### Outlook in Life Sub-Scale Tukey HSD (a,b)

Religious Status	N	Subset for alpha	
		1	= 0.05 2
Believer and practising church member	20		2.9500
Believing but non-practising church member	19		2.6316
Non-believing / non-practising church member	21	2.2857	
Sig.		1.000	.153

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 11 displays an  $F$  value of 11.067,  $p = .000$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is significant and it may be acceptable to reject the null hypothesis ( $H_0$ ) in favour of the alternative hypothesis ( $H_1$ ).

## Hypothesis 5

### Analysis-of-Variance Table 12: Total Scores (Quality of Life) by Religious Orientation Status

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	6.646	2	3.323	19.063	.000
Within Groups	9.937	57	.174		
Total	16.583	59			



Total Scores (Quality of Life): Tukey HSD (a,b)

	N	Subset for alpha = .05		
		1	2	3
Believer and practising church member	20			2.7500
Believing but non-practising church member	19		2.3158	
Non-believing / non-practising	21	2.1429		
Sig.		1.000	1.000	1.000

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 12 displays an  $F$  value of 19.063,  $p = .000$ , which is well above the  $F$  sig. / probability table, with  $df = (2,57)$ , where  $F$  must be at least 4.98 to reach  $p < 0.01$  (Bonferroni adjustment). It may be acceptable to conclude therefore that  $p$  is significant within this population sample and that the null hypothesis ( $H_0$ ) may be rejected in favour of the research hypothesis ( $H_1$ ).

## Hypothesis 6

### Analysis-of-Variance Table 13: Intercessory Prayer Response by Religious Orientation Status

Distribution of  $F$  ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	1.064	2	.532	1.935	.154
Within Groups	15.670	57	.275		
Total	16.733	59			

Intercessory Prayer Response Tukey HSD (a,b)

Religious Status	N	Subset for alpha = .05
		1
Believer and practising church member	20	1.1000
Believing but non-practising church member	19	1.1905
Non-believing / non-practising church member	21	1.4211
Sig.		..138

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 19.167

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 13 displays an  $F$  value of 1.935,  $p = .154$ . According to the  $F$  sig. / probability table, with  $df = (2,57)$ ,  $F$  must be at least 3.150 to reach  $p < 0.05$ . Consequently  $p$  is not significant within this population sample and the null hypothesis ( $H_0$ ) should be retained.

## Staff in Hospice A – (n = 100)

### Hypothesis 8

**Analysis-of-Variance Table 14: Attitude to Spirituality Issues by Spirituality Measurement Score-** Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	13.040	2	6.520	1.851	.168
Within Groups	165.540	47	3.533		
Total	178.580	49			

Attitude to Spirituality Issues Tukey HSD (a,b)

Spirituality Scores.	Measurement	N	Subset for alpha = .05 I
High		10	8.9000
Medium		15	8.6000
Low		25	7.7200
Sig.			.218

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 14.516

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 14 displays an  $F$  value of 1.851,  $p = .168$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 4.980 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

**Analysis-of-Variance Table 15: Attitude to Spirituality Issues by Occupation of Staff Member.** Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	8.234	2	4.162	1.149	.326
Within Groups	170.256	47	3.622		
Total	178.580	49			

Attitude to Spirituality Issues Tukey HSD (a,b)

Occupation of Staff Member.	N	Subset for alpha = .05 I
Doctor	08	7.3750
Other Occupation	21	8.1905
Nurse	21	8.5714
Sig.		.239

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 13.622

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 15 displays an  $F$  value of 1.149,  $p = .326$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 4.980 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

## Hypothesis 9

### Analysis-of-Variance Table 16: Category Inclusion by Spirituality Measurement Score

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.047	2	.023	.056	.946
Within Groups	19.573	47	.461		
Total	19.620	49			

#### Category Inclusion Sub-Scale Tukey HSD (a,b)

Spirituality Scores.	Measurement	N	Subset for alpha = .02 1
HIGH		10	3.8000
MEDIUM		15	3.7333
LOW		25	3.7200
Sig.			.940

Means for groups in homogeneous subsets are displayed

a. Uses Harmonic Mean Sample Size = 14.516

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 16 displays an  $F$  value of .056,  $p = .946$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

### Analysis-of-Variance Table 17: Category Inclusion by Occupation of Staff Member.

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.668	2	.334	.828	.443
Within Groups	18.952	47	.403		
Total	19.620	49			

#### Category Inclusion Sub-Scale Tukey HSD (a,b)

Occupation of Staff Member	N	Subset for alpha = .02 1
Doctor	08	4.0000
Other Occupation	21	3.7143
Nurse	21	3.6667
Sig.		.365

Means for groups in homogeneous subsets are displayed

a. Uses Harmonic Mean Sample Size = 13.622

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 17 displays an  $F$  value of .828,  $p = .443$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

## Hypothesis 10

**Analysis-of-Variance Table 18: Coping with Occupation by Spirituality Measurement Score**

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	5.147	2	2.573	3.210	.049
Within Groups	37.673	47	.802		
Total	42.820	49			

Coping with Occupation: Tukey HSD (a,b)

Spirituality Scores.	Measurement	N	Subset for alpha = .02 1
High		10	8.9000
Medium		15	8.6000
Low		25	7.7200
Sig.			.218

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 14.516

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 18 displays an  $F$  value of 3.210,  $p = .049$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 4.980 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

**Analysis-of-Variance Table 19: Coping with Occupation by Occupation of Staff Member.** \_\_

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	1.802	2	.901	1.032	.364
Within Groups	41.018	49	.873		
Total	42.820				

Coping with Occupation Sub-Scale Tukey HSD (a,b)

Occupation of Staff Member	N	Subset for alpha = .02 1
Doctor	08	3.3750
Other Occupation	21	3.1429
Nurse	21	2.8571
Sig.		.326

Means for groups in homogeneous subsets are displayed

a. Uses Harmonic Mean Sample Size = 13.622

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 19 displays an  $F$  value of 1.032,  $p = .364$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 4.980 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

## Hypothesis 11

### Analysis-of-Variance Table 20: Quality of Life by Spirituality Measurement Score

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	2.940	2	1.470	1.170	.319
Within Groups	59.060	47	1.257		
Total	62.000	49			

Quality of Life: Tukey HSD (a,b)

Spirituality Scores.	Measurement	N	Subset for alpha = .02 I
High		10	3.3000
Medium		15	3.2000
Low		25	2.7600
Sig.			.403

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 14.516

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 20 displays an  $F$  value of 1.170  $p = .319$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

### Analysis-of-Variance Table 21: Quality of Life by Occupation of Staff Member.

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	2.077	2	1.039	.815	.449
Within Groups	59.923	47	1.275		
Total	62.000	49			

Quality of Life: Tukey HSD (a,b)

Occupation of Staff Member	N	Subset for alpha = .02 I
Doctor	08	3.1250
Other Occupation	21	2.7619
Nurse	21	3.1905
Sig.		.586

Means for groups in homogeneous subsets are displayed

a. Uses Harmonic Mean Sample Size = 13.622

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 21 displays an  $F$  value of .815,  $p = .449$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is significant and it may be acceptable to reject the null hypothesis ( $H_0$ ) in favour of the alternative hypothesis ( $H_1$ ).

### Staff in Hospice B – (n = 100).

#### Hypothesis 8

**Analysis-of-Variance Table 22: Attitude to Spirituality Issues by Spirituality Measurement Score**  
Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	10.201	2	5.100	1.374	.263
Within Groups	174.519	47	3.713		
Total	184.720	49			

Attitude to Spirituality Issues: Tukey HSD (a,b)

Spirituality Scores.	Measurement	N	Subset for alpha = .02 1
High		14	8.0000
Medium		22	8.6364
Low		14	7.5714
Sig.			.273

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 14.516

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 22 displays an  $F$  value of 1.374,  $p = .263$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 4.980 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

**Analysis-of-Variance Table 23: Attitude to Spirituality Issues by Occupation of Staff Member.** Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	2.200	2	1.100	.283	.755
Within Groups	182.520	47	3.883		
Total	184.720	49			

Occupation of Staff Member: Tukey HSD (a,b)

Occupation of Staff Member.	N	Subset for alpha = .05 1
Doctor	04	8.0526
Other Occupation	08	8.2500
Nurse	38	8.6250
Sig.		.841

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 7.475

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 23 displays an  $F$  value of .283,  $p = .755$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 4.980 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

## Hypothesis 9

Analysis-of-Variance Table 24: Category Inclusion by Spirituality Measurement Score

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.774	2	.387	.586	.560
Within Groups	31.006	47	.660		
Total	31.780	49			

Category Inclusion :Tukey HSD (a,b)

Spirituality Measurement Scores.	N	Subset for alpha = .02 1
HIGH	14	3.6429
MEDIUM	22	3.7273
LOW	14	3.4286
Sig.		.557

Means for groups in homogeneous subsets are displayed

a. Uses Harmonic Mean Sample Size = 15.931

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 24 displays an  $F$  value of .586,  $p = .560$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

Analysis-of-Variance Table 25: Category Inclusion by Occupation of Staff Member

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.819	2	.410	.622	.541
Within Groups	30.961	47	.659		
Total	31.780	49			

Table 25 displays an  $F$  value of .662,  $p = .541$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

Occupation of Staff Member: Tukey HSD (a,b)

Occupation of Staff Member.	N	Subset for alpha = .05 1
Doctor	04	3.2500
Other Occupation	08	3.5000
Nurse	38	3.6842
Sig.		..559

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 7.475

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

### Hypothesis 10

Analysis-of-Variance **Table 26: Coping with Occupation by Spirituality Measurement Score**

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum Squares	df	Mean Square	F	Sig
Between Groups	2.436	2	1.218	2.093	.135
Within Groups	27.344	47	.582		
Total	29.780	49			

Coping with Occupation: Tukey HSD (a,b)

Spirituality Measurement Scores.	N	Subset for alpha = .02 1
HIGH	14	2.2857
MEDIUM	22	2.8182
LOW	14	2.8182
Sig.		.131

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 14.516

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 26 displays an  $F$  value of, 2.093  $p = .135$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

Analysis-of-Variance **Table 27: Coping with Occupation by Occupation of Staff Member**

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum Squares	df	Mean Square	F	Sig
Between Groups	.267	2	.133	.212	.809
Within Groups	29.513	47	.628		
Total	29.780	49			



Occupation of Staff Member: Tukey HSD (a,b)

Occupation of Staff Member.	N	Subset for alpha = .05 1
Doctor	04	2.7500
Other Occupation	08	2.7500
Nurse	38	2.7589
Sig.		.909

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 7.475

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 27 displays an  $F$  value of .212,  $p = .809$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

### Hypothesis 11

Analysis-of-Variance Table 28: Quality of Life by Spirituality Measurement Score

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.675	2	.337	.292	.748
Within Groups	54.305	47	1.155		
Total	54.980	49			

Quality of Life Tukey HSD (a,b)

Spirituality Measurement Scores.	N	Subset for alpha = .02 1
HIGH	14	3.0000
MEDIUM	22	2.8636
LOW	14	3.1429
Sig.		

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 15.931

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Table 28 displays an  $F$  value of, .292  $p = .748$  According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

Analysis-of-Variance Table 29: Quality of Life by Occupation of Staff Member

Distribution of F ( $p = 0.05$ )

Source of Variation	Sum of Squares	df	Mean Square	F	Sig
Between Groups	.335	2	.168	.144	.866
Within Groups	54.645	47	1.163		
Total	54.980	49			

Occupation of Staff Member.	N	Subset for alpha = .05 1
Doctor	04	3.2500
Other Occupation	08	3.0000
Nurse	38	2.9474
Sig.		.851

Means for groups in homogeneous subsets are displayed.

a. Uses Harmonic Mean Sample Size = 7.475

b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.

Table 29 displays an  $F$  value of .144,  $p = .866$ . According to the  $F$  sig. / probability table, with  $df = (2,47)$ ,  $F$  must be at least 3.150 to reach  $p < 0.012$  (Bonferroni adjustment). Consequently within this population sample,  $p$  is not significant and the null hypothesis ( $H_0$ ) must be retained.

## Chapter 5

### Discussion

Patient Research - Hypotheses 1, 2, 3, 4 & 5: (For Univariate Analysis of Variance Results – See Appendices 2.1 – 2.5)

The first 5 hypotheses were concerned with determining score totals for the 5 MQOL-SV sub-scales (Physical, Psychological, Meaningful Existence, Outlook (Support) and Total Scores respectively). “Two Way Between Groups factorial ANOVA” were employed (utilising a 3 x 2 factorial design). Since all 120 patient participants had previously been measured on each of the 5 MQOL-SV sub-scales variables of “Physical”, “Psychological”, “Meaningful Existence”, “Outlook in Life” and “Total Scores”, the latter now served as 5 separate dependent variables (DV’s). As stated in Chapter 3 (p.119) a Bonferroni adjustment was applied to all test results. Since the MQOL-SV contained 5 tests, a p level of .01 was set as determining statistical significance.

Tests of “Between-Subjects Effects” within Univariate Analysis of Variance did in fact record statistically significant results. Examination of Post Hoc tests (Multiple Comparisons) together with subsequent One-way ANOVA revealed result differences between both hospices. Notably, for Hospice A, the null hypothesis seemed to be retained in all 5 Hypotheses. For Hospice B however, the alternative hypothesis seemed to be supported in Hypotheses 1, 3, 4 & 5 while the null hypothesis was retained only in Hypotheses 2. An account of the specific tests utilised are described below, beginning with Hypothesis 1.

Hypothesis 1 proposed that,

“Believers and Practising Church Members (BPCM) together with Believers but Non-Practising Church Members (B-NPCM) would achieve higher scores totals for the “Physical Sub-scale” (physical health status) than Non-Believers / Non practising participants (NBNP)”.

Result differences between patients in hospices A & B could initially be detected in the Descriptive Statistics Tables (Chapter 4, p.135). In hospice A, 42.1% of patients assessed themselves to be “Physically well” or “Physically very well”, whereas in hospice B, the same assessment rose to 75%. Similarly, 57.9% of patients in hospice A assessed themselves to be

“Physically unwell” or “Physically very unwell”, whereas the same self-assessment in hospice B decreased to approximately 25%.

Turning to inferential statistics, a 3 (Religious Orientation: BPCM vs. B-NPCM vs. NBNP) x 2 (Hospice: A vs. B) between groups factorial ANOVA was conducted to explore the impact of “Hospice” and “Religious orientation” on levels of “Physical Status” as measured by the MQOL-SV. (Results of this experiment may be viewed in Appendix 2.1). Tests of Between Subjects Effects (p.2) showed that the main effect of “Hospice” (VAR34) was significant. The effect size was large (eta squared = .14). Religious Orientation (VAR03) was not significant. “Tests of Between Subjects Effects” showed the main effect to be qualified by a significant interaction effect. The existence of this interaction indicated that it was the effect of “Hospice” on “Religious Orientation” which was influencing patient’s assessment of “Physical status”. (Subsequent one-way ANOVA identified significant results within Hospice B (Chapter 4, p.p.143 & 149).

Investigation of the interaction began by consulting post hoc tests. The graph (p.4) illustrated the higher means of BPCM (2.9) & B-NPCM (2.68) for Hospice B in comparison to BPCM (1.66) & B-NPCM (1.75) for Hospice A. Means for NBNP patients, on the other hand were recorded as 1.95 for Hospice B and 1.92 for Hospice A. An obvious feature of the graph was that mean scores in Hospice B developed a downward trend - (2.9 for BPCM to 2.6 for B-NPCM to 1.95 for NBNP), while mean scores in Hospice A produced an upward trend (1.6 (BPCM) to 1.7 (B-NPCM) to 1.92 (NBNP)).

Tukey HSD test (p.4) revealed the overall highest mean of 2.31 for BPCM (n=38) a slightly lower mean of 2.25 for B-NPCM (n=35) and the lowest overall mean of 1.93 for patients who were NBNP (n=47).

According to the graph, BPCM patients in Hospice B produced the highest personal assessment of physical health. A slightly lower assessment occurred in the B-NPCM patients followed by a considerably lower personal assessment of physical health by NBNP patients. On the other hand BPCM patients in Hospice A seemed to have the lowest personal assessment of physical health. A slightly higher assessment occurred in B-NPCM while the highest self-assessment of physical status was to be found in the NBNP category of patients.

In an attempt to unravel these intriguing results still further, a One-way ANOVA was conducted using Physical Sub-Scale as DV and a new variable - “Cellcode” as IV with levels 1-6. (The 6 cell levels used are identical to those recorded in the Descriptive Statistics table (Appendix 2.1 p.1).

The ANOVA (p.5) was significant. The homogeneous subsets (p.6) show that the following groups did not differ from each other –

- |                       |                       |
|-----------------------|-----------------------|
| 1. BPCM – Hospice A   | 3. B-NPCM – Hospice A |
| 5. NBNP – Hospice A   | 6. NBNP – Hospice B   |
|                       |                       |
| 4. B-NPCM – Hospice B |                       |
| 2. BPCM – Hospice B   |                       |

Hence the significant differences occurred between groups,

- 1 & 2 – BPCM – Hospice A & BPCM –Hospice B
- 1 & 4 – BPCM – Hospice A & B-NPCM – Hospice B
- 2 & 3 – BPCM – Hospice B & B-NPCM – Hospice A
- 4 & 3 – B-NPCM – Hospice B & B-NPCM – Hospice A
- 2 & 5 – BPCM – Hospice B & NBNP – Hospice A
- 2 & 6 – BPCM – Hospice B & NBNP – Hospice B

With reference to Hospice B, BPCM & B-NPCM attained statistically significant score totals for physical status whereas NBNP patients attained the lowest overall scores among the 6 groups. For Hospice A, although NBNP patients attained marginally higher scores than BPCM & B-NPCM, the subset above revealed that these results were not statistically significant. Therefore, patients in all 3 categories of religious orientation in Hospice A, together with the NBNP patients in Hospice B assessed their physical health to be at a similar level. The homogeneous subsets (above) clearly demonstrate that BPCM & B-NPCM in Hospice B also attained significant higher physical status scores than the other 4 groups. Yet ultimately the question of why Hospice B seemed to have had the effect of producing higher “Physical status” self-assessment scores in their BPCM & B-NPCM in comparison to their NBNP patients could not be answered solely by statistical analysis.

However, as the design of this study had afforded the researcher personal access to both patients and hospice policy, some explanations will now be offered.

Hospice B had originally been founded by a religious order although little outward sign of this fact would be obvious to today's patients and visitors. Nevertheless, while staffed by individuals of all denominations (and none), the ethos of the hospice retained fundamental aspects of traditional Christian teaching – i.e. holistic care of spirit, mind and body – which were actively promoted by the spiritual director. Numerous staff training courses dedicated to the promotion of spiritual awareness and spiritual care have resulted in an obviously attentive nursing staff whose care for their patients extends beyond solely medical and physical needs. Whenever possible (i.e. when awake and without visitors) nursing staff engaged in communication with their patients (refer to O'Brien, 1982 study, Chapter 2, p.106). As mentioned in the Methods section (Chapter 3) there was a daily mass (open to all) and social activities within the Day Centre area of the hospice (for all patients well enough to attend). These areas together with the dedicated nursing practice promoted a sense of community and self-esteem within their BPCB & B-NPCM. Without being consciously aware of it, BPCM & B-NPCM may have been bolstered by the ethos of the hospice to the extent that they assess themselves at a higher level of physical fitness than they in fact actually were. To an extent, this theory is reinforced by patient responses to MQOL-SV question 12 (Chapter 4). When asked to “describe their quality of life within the hospice”, 96% of patients in Hospice B assessed it to be “good” or “very good”. In other words, 96% of patients thought that the care and attention they received by medical staff was of the highest quality. Consequently, as 35% of the patient population of Hospice B categorised themselves as NBNP, it could not follow that the latter considered themselves less physically well because they felt less well cared for by hospice staff. The spirituality centred hospice policy may have unintentionally promoted a sense of disorientation in their NBNP patients, making them feel “outsiders” in a comfortable yet unfamiliar environment. One additional explanation of why BPCM & B-NPCM in Hospice B assessed their “Physical status” more highly than all other groups may have been due to a sense of obligation and a desire to publicly acknowledge a hospice to which they felt not only gratitude but a large amount of affiliation.

Another interesting fact to note was that NBNP scores for “Physical status” in Hospice B were the same (statistically) as those within all 3 categories of Hospice A – (BPCM, B-NPCM & NBNP). It is possible to conclude that these sample score levels were more representative of a terminally ill hospice population. But this does not explain why the BPCM & B-NPCM

populations in Hospice A seemed to feel slightly worse (physically) than the NBNP patients. It begs the question as to whether this may have occurred because little mention concerning their spirituality or religious beliefs was made to patients by hospice staff. In other words, the BPCM & NPCM in Hospice A did not receive the same “bolstering effect” as those within the same categories in Hospice B because spirituality hospice policies were not in operation within this hospice. Spirituality issues were, for the most part, assigned solely to the hospice chaplain. Certainly, descriptive statistics (Chapter 4, p134, Qu.12) recorded that 87% of patients within Hospice A described themselves as having a “good” or “very good” quality of life because of medical treatment. Since half of this population (43%) categorised themselves as NBNP patients it followed therefore, that BPCM & B-NPCM (who constituted 44% of the hospice population), assessed themselves as having lower physical health scores than those of the NBNP patients. (This follows a similar type of pattern to Hospice B). Even although they assessed their quality of life to be high, BPCM & B-NPCM in Hospice A nonetheless felt less physically well than the NBNP patients. Crucially their scores were also much lower than the scores of those within the same categories (BPCM & B-NPCM) in Hospice B.

In summary, all 3 categories of religious orientation (BPCM, B-NPCM & NBNP) within Hospice A, together with the NBNP patient category in Hospice B recorded similar score assessment totals which this research study proposes may be characteristic of score totals recorded in similar published studies. (Refer to Chapter 1, p.23 – Lo et al, 2002). A complicating factor within this conclusion is that Hospice A, BPCM & B-NPCM may have attained higher scores had a spirituality policy been in operation within this hospice. Notably, physical status score assessments for BPCM & B-NPCM patients in Hospice B were considerably higher than in all other categories in both hospices. This research proposes that these higher results occurred due to a “bolstering influence” created by the spirituality ethos prevailing in Hospice B, which had the effect of helping their BPCM & B-NPCM feel physically better than they in fact actually were. (Refer to Chapter 1, p 21 – studies by Dull and Skokan 1995 and Ramaswami and Sheik 1989 & Pargament et al (1990), p.41 - Hill, Butler and Eric, 1995. Also Chapter 2, p.70 Averill, O’Brian and De Witt (1977), p.82 Tyler, (1978) p.108 Greach (1987) and p.109 Highfield and Carson, 1983).

It may be worthwhile to point out that all patients taking part in the study were, in fact, physically very seriously ill. Recorded times between interviews and death (Chapter 4, p.135) showed that

50% of volunteer patients in Hospice A had died within 4 weeks of interview and 30% were dead within the same time period for Hospice B.

Hypothesis 2 proposed that,

“NBNP patients will attain lower scores totals for the Psychological Sub-scale (anxiety, sadness, fear and depression symptoms) than BPCM and B-NPCM”.

On inspection of the Descriptive Statistics Tables (Chapter 4) it became obvious that result differences between patients in hospices A & B were not as pronounced for Hypothesis 2 as they had been for Hypothesis 1. In hospice A for example, 63.4% of patients assessed themselves to be “Psychologically well” or “Psychologically very well”, while in hospice B, the same assessment fell only slightly to 59.1%. Similarly, 36.6% of patients in hospice A assessed themselves to be “Psychologically unwell” or “Psychologically very unwell”, while for the same self-assessment in hospice B, scores increased only slightly to 40.9%.

A 3 (Religious Orientation: BPCM vs. B-NPCM vs. NBNP) x 2 (Hospice: A vs. B) between subjects factorial ANOVA was conducted to explore the impact of “Hospice” and “Religious Orientation” on levels of “Psychological Status” as measured by the MQOL-SV. (Results of this experiment may be viewed in Appendix 2.2). Tests of Between Subjects Effects (p.2) showed that “Hospice” (VAR34) was non-significant. The main effect - Religious Orientation (VAR03) was significant although the effect size was moderate (eta squared = .07). Subsequent reference to the “Tests of Between Subjects Effects” showed that the main effect was not qualified by a significant interaction.

The significant main effect of “Religious Orientation” nonetheless justifies reference to and discussion of the graph and Post Hoc Tests. The graph (p.5) displays an almost identical pattern of mean assessments for both hospice populations and religious orientation categories. The most striking feature of this graph was that both hospice populations were represented in an arrow formation in which the B-NPCM constituted the apex of the arrow. Thus for Hospices A & B, the B-NPCM assessed themselves to have the highest scores in the “Psychological Sub-scale”. In other words, the B-NPCM felt less depressed, less anxious, less worried and less fearful of the future than the BPCM & NBNP patients within their respective hospices.



An explanation of why this occurred will now be attempted. As previously stated, empirical research design had provided the researcher 6 months access to patients. Throughout this time, it became apparent that when interviewing all 120 volunteers, most patients answered the “Psychological Sub-scale” questions in 2 distinct ways -

1. Thoughtfully, following several moments of deliberation
2. Glibly, with little depth of consideration.

The more the researcher became familiar with these occurrences, the more it became apparent that some patients were displaying signs of denial with regard to their terminal state. Since access to patient files did not occur until after interview completion, it was impossible to distinguish between the 3 categories of religious / spirituality orientation while the interviews were taking place. However answers to “General Questions”, A, B & C tended to reflect the religious or spiritual belief system of most patients (this will be discussed in detail in Hypotheses 6). Thus the researcher began to realise that those patients who did not make reference to “spirituality” or religiosity in question A, B & C also seemed to spend the least time deliberating when answering the “psychological” questions and that their answers tended to be less positive. In other words, they assessed themselves to be more depressed, more anxious, more sad and more fearful of the future than patients in the other categories.

Those patients who did make mention of spirituality or religiosity in answer to questions A, B & C were more difficult to assimilate. Some patients would assess themselves as having no depression, anxiety, sadness or fear of the future, while others would admit to having spells of depression, anxiety, fear and sadness. This ambiguity is illustrated most clearly in the graph. For both hospices, the B-NPCM attained higher mean scores than those of the BPCM. These results can also be detected within the Descriptive Statistics and Multiple Comparison Post Hoc Tests. Together they offer interesting possibilities for conjecture.

It is possible that the BPCM may have experienced guilt had they attempted to assess answers in a dishonest fashion. Or, it may have been that they understood and accepted the seriousness of their terminal condition even if they had concealed this fact from friends and relatives. Most interestingly, the mean scores (within both hospices) of the BPCM (2.13) were almost identical to the means of the NBNP (2.10). This factor leads to two possible conclusions. The latter scores represented a more truthful assessment of psychological status and that the BPCM & NBNP

patients may have accepted the reality of their terminal status better than the B-NPCM who may have been exhibiting signs of denial. (Refer to Chapter 1, p.26 – research by Holden, 1978 & research by Carver, Scheir and Weintraub, 1989). It is also possible that some patients within all 3 categories experienced actual clinical depression, which according to published data is present in up to 25% of terminally ill patients. (Refer to Chapter 1, p.36 - Chochinov, Wilson and Enns 1994, Le Fevre, Devereux and Smith 1999 and Holtom and Barraclough, 2000. Also p.38, Koenig and colleagues studies conducted in 1992,1994 & 1998.

The reasons why the B-NPCM in both hospices exhibited denial towards their serious condition are complex (refer to Chapter 1, p.28 – Silver & Wortman 1980 study) but are presented below.

The B-NPCM category of religious / spirituality orientation was composed of patients who believed in a God and life after death. However most had not attended church, or any kind of religious ritual, for many years. During the course of the interview many expressed the view that they had experienced guilt because of this, as attending church had been a way of life especially in their youth. Others had remarked that on several occasions during their lifetime they had considered making the effort to return to attending ceremonies and rituals connected to their former belief system. Invariably, other factors took precedence over these intentions, and their aim had not been achieved up to the point in time in which they found themselves occupying a bed in a hospice. The serious status of their illness would have been explained to them before arriving in the hospice, however accepting the reality of their physical status may have become unacceptable precisely for the reason referred to above. Thinking themselves unable to become reconciled to their former church affiliations - especially within a short period of time - may have resulted in the adoption of a state of denial towards their terminal state. Adherence to the hope that they would either recover from their illness or at least remain in the same physical status may have given the B-NPCM hope of accomplishing changes in the near future (Glaser & Glaser, 1995 - Chapter 1, p.19). These factors are offered by the researcher as contributing to the reasons why B-NPCM populations within both hospices assessed themselves as having little depression, anxiety, sadness or fear of the future.

In conclusion it is important to keep in mind that results recorded in the “Psychological Sub-Scale” may have been due to unconscious as well as conscious assessments on the part of patient participants and that “denial” was undoubtedly also adopted by some patients within the BPCM & NBNP sample populations.

Hypothesis 3 proposed that,

“BPCM and B-NPCM will achieve higher scores totals for the Meaningful Existence Sub-Scale (lifetime goals, meaning in life, control) than NBNP participants”.

Result differences between patients in hospices A & B could initially be detected in the descriptive statistics tables (Chapter 4, p.135). In hospice A, 59.6% of patients self-assessed as having a “Meaningful” or “Very meaningful” existence, whereas in hospice B, the same assessment rose to approximately 78.3%. Similarly, 40.4% of patients in hospice A assessed themselves as having a “Fairly meaningless” or “Very meaningless” existence, whereas the same self-assessment in hospice B decreased to approximately 21.7%.

A, 3 (Religious Orientation: BPCM vs. B-NPCM vs. NBNP) x 2 (Hospice: A vs. B) between subjects factorial ANOVA was conducted to explore the impact of “Hospice” and “Religious Orientation” on levels of “Meaningful Existence” as measured by the MQOL-SV (See Appendix 2.3). Tests of Between Subjects Effects showed that the main effect of “Religious Orientation” (VAR03) was significant with a moderate effect size (eta squared = .09). “Hospice” (VAR34) was non-significant. Reference to the “Tests of Between Subjects Effects” also showed that the main effect was qualified by a significant interaction effect. The existence of this interaction indicated that the effect of “Religious Orientation” on patients was being influenced by “Hospice” with regard to “Meaningful Existence” assessment scores. (Subsequent one-way ANOVA confirmed significant results within Hospice B - refer to p.p.144 & 156).

Investigation of the interaction began by consulting post hoc tests and graph. The latter (p.4) recorded the higher means of BPCM (2.75) & B-NPCM (2.31) for Hospice B which then fell sharply to the NBNP (1.61) patient scores within the same hospice. A different pattern of mean scores was illustrated in Hospice A. The BPCM (2.16) were slightly higher than the B-NPCM (2.00), but the NBNP patients recorded the highest mean of 2.30.

The most striking feature of the graph was that mean scores for patients in both hospices (with the exception of the BPCM in Hospice A) followed an almost identical pattern to the mean scores recorded in Hypothesis 1 (“Physical Sub-Scale”).

As in Hypothesis 1, Hospice B scores developed a downward trend – (2.7 for BPCM to 2.3 for B-NPCM to 1.6 for NBNP), while mean scores in Hospice A produced an upward trend (2.1 (BPCM) to 2.0 (B-NPCM) to 2.3 (NBNP)).

Tukey HSD test (p.4) revealed the overall highest mean of 2.47 for BPCM (n=38) a lower mean of 2.17 for B-NPCM (n=35) and the lowest mean score of 2.0 for patients within the NBNP (47) category. Thus at this point, it seemed as if Hypothesis 3 was upheld in so far as the BPCM together with the B-NPCM did appear to score more highly in the “Meaningful Existence Sub-Scale” than the NBNP patients.

In order to further investigate these results, a One-way ANOVA was conducted using “Meaningful Existence Sub-Scale” (DV) and “Cellcode” as IV with levels 1-6. Tukey was chosen as the post hoc test.

The ANOVA was significant (p.5). The homogeneous subsets (p.6) recorded that the following groups did not differ from each other

1. BPCM – Hospice A
3. B-NPCM – Hospice A
6. NBNP – Hospice B
  
2. BPCM – Hospice B.
4. B-NPCM – Hospice B.
5. NBNP – Hospice A.

Hence the significant differences occurred between groups,

- 3 & 2 - B-NPCM – Hospice A & BPCM – Hospice B
- 6 & 2 - NBNP – Hospice B & BPCM – Hospice B
- 6 & 4 - NBNP – Hospice B & B-NPCM – Hospice B
- 6 & 5 - NBNP – Hospice B & NBNP – Hospice A.

The above results together with those illustrated in the graph underlined an interesting pattern within the population means of both hospices. BPCM in Hospice B attained the highest means (2.7), which subsequently decreased to 2.3 for the B-NPCM, decreasing still further to 1.6 for the NBNP patients. Interestingly, referral to the homogeneous subset (above) clearly revealed these

NBNP patients (Hospice B) to be in the same sub-set as the BPCM & B-NPCM population of Hospice A. The same trend is repeated for results in Hospice A. BPCM attained the highest means (2.1) decreasing slightly to 2.0 for the B-NPCM, but, at this point, instead of decreasing yet further, the NBNP population broke the pattern by an increase in means to 2.3. Once again, referral to the homogeneous subset revealed the NBNP patients (Hospice A) to be in the same sub-set as Hospice B. Consequently, an interesting factor within this hypothesis was that the NBNP populations (within both hospices) appeared to have attained similar means to those in the opposite hospice. It was therefore necessary to speculate upon 2 questions.

1. Why did NBNP patients in Hospice B produce lower scores than the NBNP & B-NPCM patients in Hospice A as well as the lowest overall scores?
2. Why did NBNP patients in Hospice A self-assess similar scores to those of the B-NPCM patients in Hospice B?

Beginning with question 1, the low “Meaningful Existence” score of NBNP patients (Hospice B) was shown to record the lowest evaluation of all 6 groups. It was also shown to be within the same sub-set grouping as the BPCM & B-NPCM patients in Hospice A. As previously discussed, the holistic, spirituality centred policy of Hospice B, may have unintentionally caused a lowering of self-confidence in their NBNP patients due to a sense of isolation from the more overtly ritualistic practises experienced by the BPCM patients, e.g. prayer & visits from clergy. (The statistically significant interaction lends support to this assessment). On several occasions during interviews, the researcher was aware of receiving answers such as, “I’ve never thought of my life being meaningful before” or “I’ve never answered a question like this before”. It is most likely that responses such as these were given predominantly by NBNP patients. In addition, anxiety / depression towards their illness coupled with an inability to provide confident responses to “meaningful existence” would also account for the low scores recorded by Hospice B, NBNP patients. Interestingly, while there may be justification in proposing that BPCM & B-NPCM patients in Hospice A may also have experienced a similar state of mind to NBNP Hospice B patients, their scores were undoubtedly higher. An explanation for this may have been that although they did not receive the reinforcement of their beliefs which they may have consciously or unconsciously desired (see Chapter 1, p. 48, Martin, Burrows and Pomilio 1983 study & Gartner et al 1990 research), religious belief was nevertheless important to them. In addition Tests of Between Subjects Effects had shown “Religious Orientation” as the statistically significant “main effect”. To religiously orientated individuals, the latter is very often the

principal reason for existence, even although family or occupation may also be important to them (Axelsson and Sjoden 1998, p.75). Thus while not receiving the “bolstering effect” of the holistic policies of Hospice B, religiously orientated Hospice A patients would probably still have accessed their belief system when assessing how meaningful their lives had been (p.51, Frankl, 1963). “Krivohlavý’s (2001) assertion that, “we are not too far from the Viktor E. Frankl’s vision relating meaningfulness of life to health”(p.3) is most appropriate to this cohort.

With regard to question 2, the reasons why NBNP patients (Hospice A) attained similar scores to those of B-NPCM patients in Hospice B will now be considered. Unlike the same grouping in Hospice B, NBNP patients in Hospice A, while also not possessing a belief system, were uninfluenced by spirituality policies such as staff / patient communication of spirituality issues. Thus their assessment of “Meaningful Existence” would have no religious / spirituality connotation and would be based mainly on family, work or other concerns (See Hypothesis 7, p.179). These factors seemed to raise their assessments slightly higher than those of the BPCM & B-NPCM (Hospice A) although results for Hospice A groups were non-significant. The fact that NBNP patients in Hospice A achieved the same score as B-NPCM in Hospice B was most probably coincidence. As previously discussed, the latter attained lower scores than Hospice B BPCM because some experienced symptoms of denial or depression (see results -Hypothesis 2).

In conclusion, BPCM & B-NPCM (Hospice B) attained the highest mean scores in this existential sub-scale -“Meaningful Existence” because these patients related meaningful existence to their religious / spirituality beliefs. (See p.51, Foglio and Brody 1988, and p.56, Holland et al 1999). In addition, these beliefs received reinforcement because of the ethos within the hospice, which in turn helped bolster their confidence and self-esteem. (Tests of Between Subjects Effects had revealed a significant interaction effect). This research is also proposing that the mean scores for BPCM, B-NPCM (Hospice A) & NPNB (Hospice B) were the result of a lowering of self-esteem and self-confidence due to the different policies operating within each hospice (Caddell, 2003a). NBNP (Hospice A) patients were the only group whose self assessed “Meaningful Existence” scores were uninfluenced by either “Religious Orientation” or hospice policy.

Hypothesis 4 proposed that,

“BPCM and B-NPCM will achieve higher scores for the Outlook in Life Sub-Scale, (Support) - (closeness to others / self-love / joyful or burdensome life / quality of life) than NBNP participants”.

Reference to the Descriptive Statistics Tables (Chapter 4, p.135) revealed little differences in results between both hospices. For example, in Hospice A, 70 % of patients assessed themselves to have a “Good” or a “Very good” outlook in life which was similar to the Hospice B assessment of 75% within the same category. Similarly, 30% of patients in Hospice A assessed themselves as having a “Fair / Poor” outlook while 25% in Hospice B included themselves in the same category.

A, 3 (Religious Orientation: BPCM vs. B-NPCM vs. NBNP) x 2 (Hospice: A vs. B) between subjects factorial ANOVA was conducted to explore the impact of “Hospice” and “Religious Orientation” on levels of “Support” as measured by the MQOL-SV. (Results of this experiment may be viewed in Appendix 2.4). Tests of Between Subjects Effects (p.2) showed that the main effect of Religious Orientation (VAR03) was significant with a large effect size (eta squared = .19). The main effect for “Hospice” (VAR34) and the interaction effect did not reach statistical significance.

The significant main effect of “Religious Orientation” justified reference to and discussion of the graph and Post Hoc Tests. The graph (p 4) illustrated an interesting pattern of results for the 3 categories of religious / spirituality orientation within both hospices. The BPCM in Hospice B attained the highest mean (2.9), decreasing for the B-NPCM to (2.63) then yet further to 2.28 for the NBNP patients. On the other hand, the means for the BPCM in Hospice A (2.61) were much lower than in Hospice B, but interestingly were almost identical to scores for the B-NPCM (2.62) in both hospices. Similar to Hospice B, the mean scores for the NBNP patients in Hospice A comprised the lowest scores. These results can also be detected within the Descriptive Statistics and Multiple Comparisons Post Hoc Tests.

As was mentioned in Chapter 3, the “Outlook in Life Sub-Scale” had been renamed “Support” in a revised addition of the MQOL (Cohen et al, 1997). Interestingly, the concept of “Support” provided clearer insight into the aims of this sub-scale, which was thereby shown to concern present, rather than future assessments. Specifically, areas of investigation concerned 4 evaluations. Patients were asked to,

1. Assess how close or distant they felt towards other people.
2. Assess their feelings towards themselves.

3. Judge whether their daily lives included moments of joy, or whether they perceived them to be devoid of any of the pleasures enjoyed by the general population.
4. Assess overall "quality of life" within their respective hospice.

(Subsequent One-way ANOVA (Chapter 4, pp 144 & 150) revealed significant results for Hospice B. For Hospice A however, One-way ANOVA produced an *F* value which was just below the *F* sig. / probability table.

The main question to arise from Hypothesis 4 results was why NBNP patient scores in both hospices were so much lower than the scores of the BPCM & B-NPCM. During researcher / patient interviews with all 120 patients, a frequent assessment recorded by patients was that their level of care within their respective hospice compared to that received in a 5 star hotel. When answering questions within this particular MQOL-SV Sub-Scale, palliative care assessment nonetheless constituted only a small part of overall assessment. Other aspects such as "closeness to others / self-love / joyful or burdensome life" were also to be considered. Averill, O'Brien and DeWitt 's 1977 assertion (p70) that successful coping depended on the individual's personality, background, experiences and beliefs are undoubtedly important to the results, as are the 4 types of coping processes associated with positive psychological states (Folkman, 1997 p.68). Kellehear's "Situational" element of spiritual coping and his "Connectedness" theory of hospice aid "triggering" deeper reflections of the consequences of illness (p.96) also give support to the highly significant Tests of Between Effects "main effect" result. "Religious orientation" was found to be of prime importance to results, reinforcing previous research findings (Lynch, 1999, p.96) whereby serious illness often resulted in solitude and loneliness for patients unable to undergo a "spiritual journey".

Another concept which may be of particular significance to these findings is "Ontological Insecurity" (Tillich, 1952 p.63). For example, the NBNP patients in both hospices (A & B) may have experienced less self-esteem and assessed life more burdensome (than the BPCM & B-NPCM) due to the fact that their own lives were drawing to a close - a fact which, to this population, signalled the end of existence. The concept of hope (as defined in the form of trust in an eternal future (Muyskens, 1979 p.56) would have been absent in NBNP patients. Conversely, hope may have provided the BPCM & B-NPCM populations with an active cognitive framework with which to face their future. (Holland et al 1999, & Post, 1995 p.56). Factors such as these would inevitably influence an individual's assessment of self-esteem, their relationship with



others and most particularly, their levels of “death distress”. (Chapter 1, p.42 Lifton 1973; p.50 Chibnall, 2002, Gibbs & Achterberg-Lawis, 1978, Miller, 1985, and O'Brien 1982: Chapter 2 p.73, Parker & Brown 1981).

Results to Hypothesis, 4 also offered interesting speculations as to whether the NBNP populations may have been subject to “spiritual distress” (See Chapter 2, p.105 Speck, 1992 and O'Brien, 1982 & p.109 Highfield & Carson, 1983) which according to the authors manifested in patients becoming listless, withdrawn, lonely and uncommunicative. However, during interviews with those patients who revealed that they were not religious and did not believe in God, the researcher was surprised at the numerous occasions in which they would remark that their long-held assertions could have been wrong and that they may be in for “a pleasant surprise”. (Refer to Chapter 2, p.96 Kellehear 2000). Most of these patients also revealed that the latter assertion was an intimate one which they would not wish to share with friends or family. The numerous occasions in which thoughts such as these were conveyed by some NBNP patients during interviews, led the present researcher to the conclusion that some patients may indeed have been suffering from a degree of spiritual distress which would more than likely remain unresolved. Being unable to find the necessary resources required to discuss thoughts of death and religion with friends, family or staff would most probably cause some patients within the NBNP populations to feel less supported than their overtly religious / spiritual fellow patients. (Chapter 1, p.21 Pargament et al, 1990 and p.48, Pargament, 1997 and to Chapter 2, p.81 LePoidevin's 1989 “dimensions of loss” – i.e. family and communications difficulties). However in retrospect, the intimate revelations confided to the researcher during the interviews nonetheless seemed to be insufficiently impacted upon the belief system of those involved to impinge upon their assessments of questions within this “Support Sub-Scale”.

Hypothesis 5 proposed that,

“Believers and Practising Church Members (BPCM) together with Believers but Non-Practising Church Members (B-NPCM) will achieve higher overall Quality of Life (i.e.- Total Scores) than Non-Believers, Non-Practising (NBNP) participants”.

Hypothesis 5 considered patient's overall “Quality of Life” (QOL) within the sub-scale “Total Scores” and was the final sub-scale relating to the MQOL-SV. Result differences between patients in hospices A & B could initially be detected in the Descriptive Statistics Tables (refer to Chapter 4, p.134). In hospice A, 23.3% of patients had score totals within the category labelled

“Good”, whereas in hospice B, the same category contained 43% of patients. Category labelled “Fair” contained 70% of patients in hospice A while the same category in Hospice B decreased in patient number to 55%. Only a very small percentage of patient scores in both hospices (6.7% in Hospice A and 1.6% in Hospice B) fell within the category labelled “Poor”. The high level of score results within the “Fair / Good” categories for the MQOL-SV “Total Scores Sub-Scale”, supports Cohen et al’s (1995) original assertion that terminally ill patients can experience high levels of quality of life even during the last phase of life (Chapter 1, p.23).

Turning to inferential statistics, a 3 (Religious Orientation: BPCM vs. B-NPCM vs. NBNP) x 2 (Hospice: A vs. B) between subjects factorial ANOVA was conducted to explore the impact of “Hospice” and “Religious orientation” on levels of “Total Scores”. (Results of this experiment may be viewed in Appendix 2.5). Tests of Between Subjects Effects (p.2) showed that the main effect of “Religious Orientation” (VAR03) was significant producing a large effect size (eta square = .12). “Hospice” (VAR34) just failed to reach significance level. The latter occurred because, in common with the 4 previous MQOL-SV sub-scales, a Bonferroni adjustment with p level of < .01 had been applied. “Tests of Between Subjects Effects” showed that the main effects were not qualified by a significant interaction effect.

However, the main effect of Religious Orientation justifies discussion of Post Hoc Tests. Multiple Comparisons confirmed that a significant difference occurred in mean score totals of BPCM patients and all other groupings (B-NPCM & NBNP).

Subsequent “One-Way ANOVA” tests produced non-significant results for Hospice A, but significant results for Hospice B (Chapter 4, pp 145 & 151). Investigation of the Post Hoc Tests (Multiple Comparisons, p.3) and “Homogeneous Subsets” within One-Way ANOVA (Chapter 4, pp. 146 150) illustrated that there were significant differences in mean score totals between all 3 groups in Hospice B (BPCM, B-NPCM & NBNP patients). Whereas for Hospice A, results indicated that there was no significant difference in quality of life Total Scores for BPCM, B-NPCM or NBNP patients (all findings are also illustrated within the graph, p4).

“Total Scores” results provided a measurement of overall “Quality of Life” levels for patients within Hospices A & B. Results to Hypothesis 5 supported the findings of the previous 4 MQOL-SV hypotheses results (the implications of which have been previously discussed). It is perhaps worthwhile to point out that the difference in mean scores between the B-NPCM in Hospice B

and the B-NPCM in Hospice A was very slight but did in effect, make the difference between significant and non-significant results. This small difference also meant that B-NPCM in Hospice A were excluded from the higher quality of life levels of BPCM (Hospice B), BPCM (Hospice A) and B-NPCM (Hospice B). Nonetheless, the attainment of high QOL score totals by BPCM within both hospices concurred with the previous research of Jenkins & Pargament, 1988, Pargament, 1992 and Koenig, 1992 (Chapter 1, p.4), Pargament, 1997 (p.5) and Pargament et al, 1990 (p.21 & 48).

#### Hypotheses 6 and 7:

The design of this research study had originally included Hypotheses 6 and 7 in order to compare their results with those obtained in previously published studies. In particular, the researcher wished to investigate whether psychosocial variables (Schnoll, R.A., Harlow, L.L., Brower, L, 2000, Chapter 1, p.5) in the form of spirituality / religious beliefs could be shown to mediate the emotional and social impact of serious illness. However, during statistical analysis of Hypotheses 1- 4, some interesting and significant results began to emerge and it became apparent that the inclusion of these hypotheses would not only provide comparisons to previous studies, but would generated support for the concepts and aims of the present research investigation.

Consideration of the influences of an individual's faith / religious beliefs or spirituality formed the subject matter of Hypothesis 7, while these beliefs (or superstitions) were further examined in Hypothesis 6 (below).

#### Hypothesis 6 proposed that,

"NBNP participants will attain similar score ratios to BPCM and B-NPCM participants with reference to intercessory prayer".

Descriptive results (Chapter 4, p.135) were fairly similar but not identical. 80% of patients in Hospice A & 88.3% in Hospice B reported to be "Very / Fairly willing to have prayers said for them. Consequently 20% of patients in Hospice A and 11.7% in Hospices B were either "Neutral" or "Unwilling" to have intercessory prayers. Inferential results (One-way Analysis of Variance) were, as expected, non-significant for both hospices (Refer to Chapter 4, pp.146 & 150). Results for Tau b may be accessed in Appendix 3.1. The latter also revealed non-significant findings. All results supported previous research (Hall 1986, and McGlaughlin and Malony 1984, Chapter 1, p.47) which stated that there would be no significant differences between NBNP

patients and BPCM & B-NPCM patients who were willing to have prayers said for them. (Consequently, there was no need for further statistical examination of these results).

Interestingly, one of the qualities of greatest significance to the coping process regarding the relationship of BPCM & B-NPCM with their God may have been faith in communication through prayer. Having practised prayer rituals throughout their lives, questions concerning intercessory prayer would not have seemed alien to them and were, for the most part, received with enthusiasm. Of course, statistics cannot interpret whether “believing” patients accepted the proposal of intercessory prayer as a plea for recovery from serious illness due to the belief that anything can be achieved, including changing reality, if it is prayed for intensely by themselves or by others on their behalf. On the other hand, they perhaps embraced it as a mechanism for obtaining “a good death”(Bradshaw, 1996, Chapter 1, p.12). The proposal that intercessory prayer derives from the concept of transcendence (Chapter 1, p.47, Chinen, 1984, Labouvie-Vief, 1980, Moberg, 1982, Neugarten, 1979 and Conrad, 1985,) would apply to the NBNP patients as much as it would to the BPCM & B-NPCM. For those patients who did not adopt “denial” as a coping strategy, acceptance of their illness as being associated with the end of life would, as in other developmental phases in life, produce characteristic changes (Reed, 1986 Chapter 1, p.126). One of these changes may be the gradual acceptance of the possibility of other dimensions beyond the physical constraints of this world. Another change (particularly for NBNP patients) may be their attitude towards spirituality and religious belief. (Refer to Chapter 1 p.47, Hall, 1986 and McGlaughlin & Malony, 1984; p.48 Hood, Spilka, Hunsberger & Gorsuch, 1996). Consequently, for some NBNP patients, character changes may have produced a favourable response to the possibility of prayers being said for them, while for others, a favourable response may have been cited without changes in attitude and for completely different reasons. Prominent among the latter may be the possibility of attaining a miracle (examples being, an extension of pain free time with their family) even if it was accomplished by means normally alien to their principles. Other reasons may have included superstitious elements or the conception that intercessory prayer was provided as a type of “alternative therapy” treatment (Chapter 1, p 48, Eissen, Kessler et al, 1993). Whatever reasons were paramount in the minds of respondents must remain a matter of conjecture but ultimately no statistically significant differences were recorded between patient scores in both hospices. The large percentage of patients (78.3%) within each hospice willing to consent to intercessory prayer provides support for previous research findings (Refer to Chapter 1, p.5, Maltby, Lewis & Day, 1999, Pargament, 1997, and to the findings of the research study

conducted by the present researcher, Caddell, 2000. Also p.41 Oxman, Freeman, and Manheimer, 1995 and Hill, Butler and Eric, 1995: Also Chapter 2, p.97, Kellehear 2002).

Hypothesis 7 proposed that,

“Responses given by “believing patients” to questions A, B and C will be more spiritually or religiously orientated than the responses given by “non-believing patients”.

(Chi-Square results may be accessed in Appendix 3.2)

Question A

“Descriptive statistics” (Chapter 4, p.136) provided interesting reading for question A, “During your lifetime, what has helped sustain you during times of crisis?” Category “Religious Belief or Spirituality” was chosen by 36.7% of patients in Hospice A and 46.7% in Hospice B. Category “Family / Self” attained 43.3% in Hospice A and 31.7% in Hospice B and the third category, “Other Answer” attained 20% in Hospice A & 21.6% in Hospice B.

As stated in the Methods chapter, scores were combined and a chi-square applied in order to test the hypothesis (refer to Appendices 3.2). Chi-Square Tests (p.1, Table 7B) revealed a significant result and indicated that the responses of BPCM & B-NPCM within both hospices were more spiritually and religiously orientated than the responses given by “non-believing patients”. Reference to Table 7(A) reveals that 24 BPCM and 13 B-NPCM reported turning to their faith / belief system as a coping aid during stressful circumstances. This supports Pargament’s (1997) assertion that for the most part religious people cope with the tools which are most accessible to them and most familiar to their orienting system (Chapter 1, p.50). A small number (12) of NBNP patients purported turning to “spirituality” during times of stress. During the interviews, NBNP patients tended to use phrases such as, “There may be something out there that we can’t understand” or “ There may be something greater than ourselves”. Statements such as these indicated that although they did not conform to a conventional religion, in times of crises they nonetheless chose to believe in a spiritual or mystical dimension (see Chapter 2, p.106 – research by Banks 1980, Colliton 1981 and Ellison 1983).

Referring again to Table 7(A), it is interesting to note that 25 “believing” patients as well as 21 “non-believers” turned to “family and friends”. This meant that for some “believing” patients, support from family superseded that of their belief system in times of stress.

For the third category in Table 7A, “Other Answer”, examples of alternative answers offered by the 11 “believers” and 14 “non-believers” were recorded as,

“Own ability / self-confidence”

“Sense of humour”

“Friends”

“Optimism”.

### Question B

The question, “What has been on your mind recently?” presented patients with the task of having to think about the reality of their present condition and the consequences of their serious illness. Chi-Square Tests (p.2, Table 7D) revealed a non-significant result. Reference to Table 7C confirmed that for category, “Religious Belief / Spirituality”, only 11 “believers” and 4 “non-believers” chose it as the subject most recently on their mind. Thus the responses of BPCM & B-NPCM within both hospices were not more spiritually or religiously orientated than the responses given by “non-believing patients”.

Certainly it would seem logical to conceive that receiving palliative care within a hospice unit may result in the vast majority of patients worrying about their illness and directing their thoughts towards their physical condition. However, although category “Family / Self” had been chosen by half of patients in both hospices, personal interviews with patients were able to establish that none of the 33 “believing” and 23 “non-believing” patients were concerned about themselves. On the contrary, it was their family members, particularly their spouse / partner, who had been on their minds. This is an interesting result and illustrates that patients in terminal decline, who remain relatively pain free, can demonstrate concern or interest for family members or for other topics unrelated to themselves. These instances of altruism give support to the studies by Rose, 1997 and George et al, 1990 (Chapter 1, p.61). They also support Cohen et al’s (1995) conclusions that quality of life among the terminally ill need not necessarily decline drastically and that some patients can remain lucid in thought until the end (p.23).

Within the category labelled “Other Answer”, it is interesting to note that among the most frequently generated answers given by the 29 “believing” and 20 “non-believing” patients were,

“I am concerned about the patient beside me”

“I can’t seem to concentrate on anything”

"I don't think that I will be able to sleep tonight?"

"I don't think I will be able to go home again".

### Question C

The question, "What do you think gives meaning to life?" produced the following findings. Table 7E (p.3) revealed that 41 "believing" and 8 "non-believing" patients chose category "Religious Belief or Spirituality" as denoting "meaning to life". 17 "believers" and 12 "non-believers" chose category "Family or Self" and 15 "believing" patients together with 26 "non-believers" opted for "Other Answer".

Chi-Square Tests (p.1, Table 7F) revealed a significant result and indicated that the responses of BPCM & B-NPCM within both hospices were more spiritually and religiously orientated than the responses given by "non-believing patients". Descriptive Statistics (Chapter 4, p.136) were also worth noting since they revealed that 40% of patients in Hospice A, purported "Religious / Spirituality Concerns" as giving meaning to their lives, while a slightly lower percentage (35%) in Hospice B included themselves within the same category. The latter result is important to this present research since MQOL results had indicated that BPCM & B-NPCM in Hospice A may have been disappointed and somewhat depressed at the exclusion of their spirituality / religious beliefs in conversations with staff.

It is also interesting to note that 17 "believing" and 13 "non-believing" patients chose category "Family / Self" as denoting "meaning to life". Reference to Table 7E (p.3) revealed that 13.3% of patients in Hospice A as opposed to 26% in Hospice B made it their first choice. This result once again supported the assumption stated in the paragraph above.

Within the category "Other Answer", only 15 "believing" patients opted for this choice as opposed to 26 "non-believers". Examples of their recorded answers were,

"Work / Occupation"

"Nature"

"Helping People"

"Achieving Goals".

In conclusion, results to questions A and C supported the alternative hypothesis (HI) and are advantageous to this present research since they offer supporting evidence that spiritually or

religiously orientated individuals tend to turn to their belief systems during times of stress and non-stress situations. They are also consistent with results recorded in Pargament's 1997 research (Chapter 1, p.48), the Spilka, Shaver and Kirkpatrick 1985 study p.44 & the Pargament and Park 1995 research, p.45. Results to question B supported the null hypothesis (Ho). These findings illustrate that within these sample populations, BPCM & B-NPCM were not mentally deranged (Moszczyńska and Beit-Hallahmi 1996, Chapter 1, p.45) or obsessed with their religious / spirituality beliefs to the extent that they consistently ranked paramount in their thoughts. On the contrary, BPCM & B-NPCM were shown to think about family, friends and a host of other subjects as much as did NBNP patients. These results support those of Hood Spilka, Hunsberger and Gorsuch 1985 (p.48).

This concludes discussion of the section concerning statistical analysis of the first 5 hypotheses relating to the main area of investigative study within this research – MQOL-SV (Patient Questionnaire) results and the 2 additional hypotheses (6 & 7) included as comparisons to results in previously published studies.

The remainder of this Discussion Chapter concerns Hypotheses 8 – 11, which relate to the secondary area of study research – “Staff Questionnaire” results.

Staff Research - Hypotheses 8, 9, 10 & 11: (For Univariate Analysis of Variance results, refer to Appendices 4.1 – 4.4).

The “Staff Questionnaire” (CPCD), had been devised by the researcher in order to investigate attitudes towards spirituality issues within hospice policy, coping strategies and quality of life levels among staff within Hospices A & B. (Refer to Chapter 3, p.119). Specific demographics relating to the individuals involved in this empirical research may be accessed by consulting Chapter 4, pp.136 - 140. Hypotheses 8 – 11 were concerned with determining score totals for the 4 CPDC sub-scales (SIA, CCI, CDO & QOL). “Two Way Between Groups factorial ANOVA” were employed (utilising a 6 x 2 factorial design). Since all 100 staff had previously been measured on each of the 4 CPCD sub-scales variables of “Spirituality Issues Attitude”, “Coping Category Inclusion”, “Coping with Occupational Depression” and “Quality of Life”, the latter now served as 4 separate dependent variables (DV's). The factorial design incorporated “Spirituality Measurement Scores” (SMS) and “Occupation” with 3 levels and “Hospice” with 2 levels. In common with the “Patient Research”, a Bonferroni adjustment was applied and since



the Staff Questionnaire (CPCD) contained 4 tests, a p level of 0.012 was set for all statistically significant results.

Although statistical test results did not reveal significant differences for staff CPCD scores in either hospice, they nonetheless provided indications that the majority of staff within both hospices recorded a favourable attitude towards spirituality policies. A detailed account of the specific statistical tests applied are described below, beginning with Hypothesis 8.

Hypothesis 8 proposed that,

“Hospice staff with “High” SMS, will claim to feel more comfortable working with hospice chaplains / visiting clergy, discussing spirituality / religious issues and praying with patients than those staff with lower SMS”.

Descriptive Statistics (Chapter 4) had revealed little score differences within the categories of “Hospice Chaplain”, “Discussing spirituality / religious issues” and “Praying with patients”. It was only within the “Comfortable with visiting clergy” category that some discrepancies arose. Interestingly, it was staff in Hospice B that claimed to be slightly less favourable towards visiting clergy. 36% of staff claimed to be “uncomfortable” or “sometimes uncomfortable” in their attitude towards visiting clergy in Hospice B, in contrast to 22% in Hospice A.

A, 6 (Spiritual Measurement Score: High vs. Medium vs. Low x Occupations: Nurse vs. Doctor vs. Other) x 2 (Hospice: A vs. B) between groups factorial ANOVA was conducted to explore the impact of “SMS,” “Hospice” and “Occupation” on levels of “Spirituality Issues Attitude” as measured by the CPCD. (Results of this experiment may be viewed in Appendix 4.1). Tests of Between Subjects Effects (p.3) showed that there were no significant results within the main effects of “SMS” (VAR01), “Hospice” (VAR06) and “Occupation” (VAR 07). “Tests of Between Subjects Effects” showed the main effects were not qualified by a significant interaction effect.

Reference to the graphs (pp 8-9) revealed that nursing staff in Hospice A appeared to be slightly more favourable towards spirituality policies than nurses in Hospice B. Interestingly, doctors in Hospice B with “Medium” & “Low” SMS scores were more favourable than doctors in Hospice A. The “Other Occupation” category recorded mixed results. “Descriptive statistics” (Chapter 4, p.138) revealed a noticeable discrepancy in scores for “Comfortable with visiting clergy” and it is

interesting to speculate why nurses in Hospice B (with “High” SMS) scored lower than “High” SMS nurses in Hospice A. It is possible that nurses in Hospice B may have had unresolved personal grudges or grievances arising from more frequent contact with clergy than nurses in Hospice A. Overall however, staff with “Low” SMS (in both hospices) appeared to be slightly less unfavourable towards spirituality policies but as previously stated, no statistical differences were found.

Thus, for Hypothesis 8, results determined that the H1 could not be supported and that the Ho should be retained. Findings such as these concur with the ethos of the 1991 survey by Maugans and Wadland (Chapter 1, p.13) and the Ehman et al 1999 research (p.13) and with the Kellehear, 2000 research (Chapter 2, p.96).

Hypothesis 9 proposed that,

“Hospice staff with “High” SMS will record higher scores in judging spirituality and religious issues worthy of inclusion in a category entitled “coping strategies for patients with life-threatening illness”, than staff with lower SMS”.

Inspection of “Descriptive Statistics”(Chapter 4) revealed a slight difference in score totals between Hospices A & B regarding the attitude of staff towards “Spirituality and Religious Issues” being worthy of inclusion into a category entitled “coping strategies of the terminally ill”. Interestingly, it was Hospice A staff who attained slightly higher scores in both categories. However the differences were so slight that Inferential Statistics recorded no significant results.

A, 6 (Spiritual Measurement Score: High vs. Medium vs. Low x Occupations: Nurse vs. Doctor vs. Other) x 2 (Hospice: A vs. B) between groups factorial ANOVA was conducted in order to explore the impact of “SMS,” “Hospice” and “Occupation” on levels of “Category Inclusion” as measured by the CPCD. (Results of this experiment may be viewed in Appendix 4.2). Tests of Between Subjects Effects (p.3) showed that there were no significant results within the main effects of “SMS”, “Hospice” and “Occupation”. Reference to the “Tests of Between Subjects Effects” showed the main effects were not qualified by a significant interaction effect.

Reference to the graphs (pp 8-9) revealed that nursing staff in Hospice A appeared to be slightly more favourable towards spirituality as a coping strategy than nurses in Hospice B. Interestingly,

doctors in Hospice B with “Medium” & “Low” SMS scores were more favourable than doctors in Hospice A. The “Other Occupation” category recorded mixed results.

Thus, the alternative hypothesis was once again rejected as no significant results emerged to indicate that staff with “High” SMS recorded higher scores in judging spirituality / religious issues worthy of being included within a category entitled “coping strategies for patients with life-threatening illness”. This is an extremely note-worthy but surprising result since it revealed that within both hospices, an average 90% of staff (irrespective of SMS) considered spirituality / religiosity issues to be suitable for inclusion as possible “coping strategy” aids. This finding gives support to Koenig (1994) research (Chapter 1, p.16).

Hypothesis 10 proposed that,

“Hospice staff with “High” SMS will be less depressed (struggle emotionally) with duties connected to their work than those respondents with lower SMS”.

Inspection of “Descriptive Statistics”(Chapter 4) revealed differences in score totals between Hospices A & B regarding the emotional impact experienced by staff due to the stresses involved in day to day caring of patients with life-threatening illnesses. 88% of staff in Hospice B compared to 56% in Hospice A (p.139, Qu.10) declared that they were always or occasionally subject to emotional distress when caring for their terminally ill patients. Interestingly, only 12% in Hospice B claimed that they did not struggle emotionally compared to 44% in Hospice A. With regard to “Cope with Job” (Qu.13) 24% of Hospice B staff felt that they struggled to cope compared to only 6% in Hospice A.

Turning to inferential statistics, A, 6 (Spiritual Measurement Score: High vs. Medium vs. Low x Occupations: Nurse vs. Doctor vs. Other) x 2 (Hospice: A vs. B) between groups factorial ANOVA was conducted in order to explore the impact of “SMS,” “Hospice” and “Occupation” on levels of “Coping with Occupational Depression” as measured by the CPCD. (Results of this experiment may be viewed in Appendix 4.3). Tests of Between Subjects Effects (p.3) showed that there were no significant results within the main effects of SMS”, “Hospice” and “Occupation” Reference to the “Tests of Between Subjects Effects” showed that the main effects were not qualified by a significant interaction effect.

Although results did not reach statistical significance, reference once again to Descriptive Statistics offered interesting speculations. Hospice B staff seemed to struggle more with the

impact of occupational duties and cope less with their job than staff in Hospice A. The question must therefore be asked why Hospice A staff recorded less emotional upset when assessing occupational duties. Was it feasible that almost half of the staff in Hospice A declared no emotional ties with any of their patients because they genuinely had no feelings for them? Or could it be that the constant witnessing of dying and death had resulted in this particular portion of the sample populating adoption (consciously or unconsciously) a type of denial of reality (similar to that encountered within concentration camp studies - refer to Chapter 1, p.54 Bettelheim 1986). There is of course no way of specifically knowing why 44% of staff in Hospice A distanced themselves emotionally from both duties and patients. Perhaps they felt more comfortable concentrating solely on physical care responsibilities or perhaps they were comprised of less experienced or younger members of palliative care staff. Inevitably, some explanations may be found in the Vachon, 1979 study (Chapter 1, p.13). Also, because a larger proportion of Hospice B staff gained higher overall SMS (Chapter 4, p.138), it is possible that they regarded their work as a vocation and as such, may have been more motivated to truth telling in the sense of confessing their innermost emotions.

The design of the “Staff Research” had allowed for the inclusion of some qualitative research (refer to Chapter, 3). With regard to “emotional upset”, Question 11 (see Appendix 1.4) gave participants who did experience emotional distress, an opportunity to write down (on the questionnaire sheet) anything in their lives which helped them cope with this distress. The findings are recorded below -

Question 11: (Emotional upset)

Hospice A:

Speak to colleagues.  
Spiritual meditation.  
Strength in own ability  
Support from spouse / partner.

Hospice B:

Prayer / Faith / Meditation.  
Speak to colleagues / Family.  
Inner strength.  
Seek support / Counselling.

Ultimately however, with regard to Hypothesis 10, the alternative hypothesis must be rejected in favour of the null hypothesis.

Hypothesis 11 proposed that,

“Hospice staff with “High” “SMS” will attain a higher “Quality of Life” scores than staff with lower SMS”.

Inspection of “Descriptive Statistics”(Chapter 4) revealed that there were no differences in score totals between Hospices A & B regarding “Quality of Life” score totals. Staff QOL personal assessment scores were identical in both hospices. This was an interesting but unexpected finding, which suggested statistically insignificant inferential results. Overall, “Descriptive Statistics” indicated that 66% of staff in both hospices assessed their quality of life to be “Good”, while 26% described it as “Fair”. As “Coping Strategy” was the main area of research within the “Patient Research”, it was also considered of prime importance to the “Staff Research” programme and was included within QOL assessments. “Descriptive Statistics” revealed a slight difference in score totals between Hospices A & B. Interesting, while 60% in Hospice A and 66% in Hospice B declared that they had developed a coping strategy, 28% in each hospice declared that they had not developed a coping strategy. (12% in Hospice A & 6% in Hospice B were unsure).

Turning to inferential statistics, A, 6 (Spiritual Measurement Score: High vs. Medium vs. Low x Occupations: Nurse vs. Doctor vs. Other) x 2 (Hospice: A vs. B) between groups factorial ANOVA was conducted in order to explore the impact of “SMS,” “Hospice” and “Occupation” on levels of “Category Inclusion” as measured by the CPCD. (Results of this experiment may be viewed in Appendix 4.4). Tests of Between Subjects Effects (p.3) showed that there were no significant results within the main effects of “SMS”, “Hospice” and “Occupation”. Reference to the “Tests of Between Subjects Effects” showed the main effects were not qualified by a significant interaction effect.

As in Hypothesis 10, “Staff Research” design had allowed for the inclusion of some qualitative research with regard to “Developed a coping strategy?”(see Appendix 1.4). Staff participants who had developed coping strategies were encouraged to record what they were. Examples of the findings are detailed below.

#### Question 15 (Coping strategies)

##### Hospice A:

Positive Thinking.  
Talk to colleagues.

##### Hospice B:

Prayer / Meditation.  
Take time for reflection.

Forget about work when at home.

Relax or socialise.

Resist emotional involvement.

Talk to colleagues.

Only 4% of staff in both hospices rated their QOL as “Poor” despite the emotional distress alluded to in hypothesis 10. The occurrence of such high “Quality of Life” scores may have been due to the fact that, as well as assessing their working environment, participants also included life outside the hospice environment in their evaluations. This is an interesting finding especially since 56% in Hospice A and 88% in Hospice B reported having “struggled” or “occasionally struggled” with emotional upset. Thus 22% of staff in Hospice B and 4% in Hospice A were struggling emotionally with the duties connected to their occupation, but had not thought to develop a coping strategy.

Overall, results for Hypothesis 11 were non-significant and did not reveal “SMS” to be a determining factor in staff QOL assessments. Thus the alternative hypothesis must be rejected in favour of the null hypothesis.

This completes discussion of the 4 “Staff Research” hypotheses.

Although questions 21 and 22 were not included within the research hypotheses, they are included within this thesis as a part of its “Staff Research” programme.

Question 21 was directed at doctors and Question 22 at the hospice chaplain / spiritual director in both hospices. Question 21 was divided into 4 parts. Parts A & B concerned whether doctors assessed and measured their patient’s anxiety / stress levels and coping abilities. Part C explored gender differences in coping with life-threatening illness and Part D inquired into doctor’s disclosure to their patients of nearness to death (Chapter 4, pp. 140 -142). Throughout the 3 months spent by the researcher in Hospice A, 8 doctors were employed on either a full-time or part-time capacity. All 8 doctors (100%) agreed to complete the questionnaire. Within Hospice B, 6 doctors were employed during the 3 months that the researcher was involved in staff research. During that period, 4 doctors (67%) agreed to complete the Staff Questionnaire.

It is interesting to note that the demographics of each hospice produced a 50% ratio of male to female participants. However, with regard to age, while 2 members of staff in Hospice B were over 40 years and 2 under 40 years, only 1 of the 8 participants in Hospice A was over 40 years.

Consequently, of all 12 participating doctors, only 3 were above 40 years of age. Although the sample populations from each hospice was very small, the information supplied is nonetheless worthy of note especially in view of the fact that it reflected the opinions of 100% of the doctor population from one hospice and 67% from the other.

In answer to the question 21(A) regarding assessment of patient's anxiety or stress levels 7 doctors in Hospice A reported that they conducted assessments, while only 1 stated they did not. In Hospice B, 2 doctors assessed their patient's stress or anxiety levels while 2 did not. The statements recorded below represented the measures undertaken by those doctors who routinely assessed their patient's stress / anxiety levels.

Hospice A:

1. Ask them outright.
2. Direct questions, plus physical examination.
3. Clinical judgement, plus view of other colleagues.
4. Occasionally use HADS but more usually assess by physical symptoms.

Hospice B

1. Occasionally use HADS, but more often use observation plus informal questioning.
2. Informal questioning.

In answer to the question 21(B) regarding assessment of patient's levels of coping with their illness 6 doctors from Hospice A reported that they assessed coping ability, while 2 did not. In Hospice B, 2 doctors assessed their patients coping levels while 2 did not. The following statements (below) represented examples of the measures undertaken by those doctors who reported that they did routinely measure stress / anxiety levels.

Hospice A:

1. Ask patient / family outright.
2. Judge by patient's ability to talk about their diagnosis.

3. No formal rating-scale – use own judgement.
4. Clinical judgement, plus opinions of other staff.

Hospice B:

1. Gradual questioning over a period of time.
2. Use own judgement.

Interestingly, only 3 out of 9 doctors who claimed to assess anxiety, depression and coping skills reported using a reliable and validated “psychological measuring scale”(e.g. HADS). In addition to direct questioning, the remainder relied on their clinical judgements of patient’s physical symptoms. This finding concurred with research referred to in the Literature Review indicating that doctors seemed to prefer remaining within their own familiar spheres of clinical judgements rather than embarking upon time consuming psychological domains (refer to p.36 Holtom & Barraclough, 2000).

Question 21(C) asked doctors to consider whether, in their opinion, males or females tended to cope better with terminal illness. Interestingly, none of the doctors thought that males tended to cope better, whereas 2 doctors in both hospices considered females to be more competent. This result supported the Monet and Lazarus (1991) study (Chapter 1 p.27). However, 5 doctors in Hospice A and 2 in Hospice B proposed that, between the sexes, coping strategies seemed to be “About the same” and 1 doctor in Hospice A declined to answer. There are two possible explanations for these particular assessments. Either, they were using their clinical judgement and experience to make a decisive choice, or they opted for the “About the same” category because coping ability assessment was not routinely conducted.

Question 21(D) asked doctors to disclose whether they informed their patients when they were close to death. None of the doctors in either hospice chose the “Always” or “Never” option, whereas 2 doctors in both hospices opted for “Only if they themselves ask” category. This latter choice is often difficult for doctors to deal with, particularly if there has been little or no assessment of the patient’s psychological status or coping ability. Interestingly, 6 doctors from Hospice A and 2 from Hospice B chose the option “Sometimes if considered appropriate”. But inevitably the question must be asked as to the criteria involved in determining “appropriate” timing. Disclosing nearness of death to patients (irrespective of whether they ask or not) may catapult some patients into a state of anxiety or even denial, whereas others may use the last phase of their life for closure and reconciliation with family and friends. The issue of truthful



disclosure was highlighted in the Meredith et al 1996 study (Chapter 1, p.23) and research by Fallowfield & Jenkins, 2002 (p.24). Further considerations of question 21(D) answers will be discussed in the Conclusions Chapter (Hypothesis 2).

Finally, additional descriptive statistics extracted from the doctor's individual "Staff Questionnaires" (Chapter 4, pp 140 – 142) were included to register any religious or spirituality orientation represented within this population and also as a comparison to overall staff findings.

10: Doctors who do not get depressed due to the duties connected to their occupation-

Hospice A (3): Hospice B (0)

11: Doctors who consciously employed a coping strategy in order to decrease emotional stress -

Hospice A - Yes (6): No – (2)

Hospice B - Yes (3): No – (1)

Although these findings (above) were from a very small sample population, they were nonetheless extremely relevant to the main areas of interest within this present research and provided findings which tended to differ somewhat from general trends of opinion in previous studies. (Refer to Chapter 1, p.32 Koenig, Pargament, & Neilson, 1998).

Interestingly, exactly half of the doctors in both hospices adhered to a religious belief (Christian) while half did not and the same amount stated that they prayed / did not pray fairly regularly. But the most interesting result was to be found in answer to the "Belief in spiritual life after death" question. While half of doctors in Hospice B and just under half in Hospice A stated that they did believe in life after death, none of the remainder were prepared to state that they did not believe in a spiritual after-life, preferring to opt instead for the "Unsure" option. This result indicated that just over half of the sample population were "open" to a recognition of spirituality if not religiosity and supported the recommendations of the study by Wright, 2002 (Chapter 1, p.35). Perhaps the most remarkable finding from the doctors questionnaire was that, irrespective of personal spirituality / religiosity orientation, all 12 respondents considered "Spirituality / Religiosity Issues" worthy of inclusion within a category entitled "Coping Strategies in Terminal Illness". Opinions such as these strongly indicated that within both hospices, physicians had encountered patients who's coping abilities tended to be positively rather than negatively influenced by their spirituality / religious beliefs. Results for this question also contrasted starkly

with the findings reported in the Koenig, Pargament, and Neilson's (1998) investigative study into the same topic (refer to Chapter 1, p.32).

Finally, the question of whether doctors in Hospices A and B were aware of the fact that they struggled emotionally due to the pressures of their job and that they either consciously or subconsciously relied on a coping strategy, was investigated. Only 3 doctors from Hospice A declared that they never struggled emotionally, while 5 from Hospice A and all 4 participating doctors from Hospice B admitted to experiencing degrees of depression due to the emotive nature of their occupation. However only 2 of the 4 doctors from Hospice B reported that they employed a coping strategy, whereas 5 doctors from Hospice A stated that they consciously employed a coping strategy in the hope of coping emotionally. These results indicated that at least 5 of the 12 participating doctors were sensitive to the emotive nature of their occupation and cognisant of the importance of coping with not only their own physical needs and those of their patients, but with the psychological issues which encompass terminal decline. Further considerations of doctor's responses will be presented in the Conclusions Chapter.

To complete the "Staff Questionnaire" responses, question 22 addressed the issues of "spirituality" and was directed solely at hospice chaplains / spiritual directors (refer to Chapter 3). During the period of research, Hospice A employed 2 chaplains, while 1 spiritual director was employed in Hospice B. Extracts from their answers illustrating their interpretation of how spirituality and pastoral care impacted patients with life-threatening illnesses are presented below.

1. "It allows patients to look beyond their illness and the effect it is having on their families. It allows them to explore their thoughts, feelings, hopes and fears and to try to make sense and meaning of their life as it is. They gain confidence in the knowledge that pastoral care extends not only to them but to their families and will continue even into bereavement"
2. "Spirituality is an integration of mind, body and spirit in order to experience "wholeness". Spirituality and pastoral care enables patients to achieve a degree of peace and serenity in the last stage of their journey towards death.
3. "As people approach death, they are at their most vulnerable. Spirituality and pastoral care helps them to feel less alone and to gain a level of comfort and support during the last phase of their life".

This completes the discussion chapter. Final conclusions relating to both Patient and Staff research studies are presented in Chapter 6.

## Chapter 6

### Conclusions and Recommendations

#### Patient Research:

As with previously published research, this present study highlighted the premise that when cure is not an option, the primary goal of palliative care must be to improve the quality of life (QOL) remaining to terminally ill patients. MQOL-SV results gave overall support to Cohen et al's (1995) principal assertion that good palliative care produces high quality of life (QOL) self-report assessments which can be maintained throughout the disease trajectory of end-of-life patients. Univariate ANOVA "Tests of Between Subjects" indicated significant main effects for each of the 5 Hypotheses. "Religious Orientation" constituted the significant main effect for Hypotheses 2, 3, 4 and 5 while "Hospice" was denoted for Hypothesis 1. It is important to point out that Hypotheses 1 & 3 were also qualified by a significant interaction effect. Overall MQOL-SV findings suggested that the existence or non-existence of spirituality hospice policies played an influential role in the self-rated QOL assessments of 5 of the 6 patient groups participating in the study. The nature and direction of this influence produced interesting speculations (See Chapter 5, pp. 162 - 164).

Conclusions to be drawn from Hypothesis 1 results were that physical status may not depend solely on drug and medical interventions, but may be interconnected with psychological issues such as self-esteem, self-confidence, and self-belief. If findings such as these were replicated within other studies, issues such as patient's spirituality beliefs (or non-belief) may begin to be more fully addressed by hospice staff. Studies by Geffen, (2000) & Searle (1991) purported that when a patient's support network included not only family and friends, but hospice counselling sessions and group therapy (which incorporated the context of faith), their pain management was controlled more easily and drug intervention lessened. Overall "Physical Status" results highlighted the fact that "spirituality concerns" among policy makers, continue to be one of the most over-looked aspects of pain management within the medical profession.

Hypothesis 2 MQOL-SV results highlighted the interesting fact that most of the B-NPCM populations within both hospices claimed not to have experienced anxiety or depressive symptoms in the recent past. The best explanation for these results seemed to have been that due to guilty feelings surrounding the non-practise of their faith and the hope of making amends in the

future, B-NPCM populations were presenting signs of “denial” towards their terminal illness. (Refer to Farran et al 1989 study, Chapter 2, p.102). Denial is of course, one of the main strategies adopted by humans within any stressful situation (Holden, 1978: Carver, Scheir and Weintraub, 1989) and could not therefore be considered surprising if recorded within a study investigating patients with life-threatening illnesses. However, what was more surprising was the way in which patients within the same category grouping appeared to respond in a similar fashion to the Psychological Sub-Scale questions. BPCM within both hospices tended to use religious belief as a coping strategy in order to help control (but not entirely eradicate) their anxieties. (This type of coping strategy reliance could be compared to Tyler’s 1978 description of “effective-people”). BPCM patients together with NBNP within both hospices provided indicators of being cognisant to the reality of their situation. (This type of understanding could be attributed to “problem focused” people (Lazarus & Folkman, 1980) – i.e. trying to come to terms with the demise of their own life, settling affairs with family etc, but struggling with the physical and psychological strains of terminal illness). Interestingly, the BPCM & NBNP also seemed to be making use of the first 3 coping processes proposed by Folkman (1997)

1. Positive reappraisal
2. Goal-directed problem-focused coping
3. Spiritual beliefs and practices (for and against)

Another interesting feature of Hypothesis 2 was that choice of coping strategy within each of the 3 groupings helped strengthen the advocacy of personality differences proposed by Cassileth et al, 1985 & Lampic et al, 1994 (see p. 70). Certain personality types tend to be attracted to particular types of behaviour which in turn influence coping strategy choice. Importantly, although “denial” and “avoidance” may not be considered the most fruitful of strategies, particularly for the terminally ill, for certain personality types, “denial” may be inevitable and perhaps even beneficial for the individual concerned. Thus, consideration of whether patients could be taught to chose the correct or most appropriate strategy may not be appropriate to certain population groupings (refer to Chapter 2 pp. 71-72 -Spiegel and Yalom, 1978, Spiegel and Glafkides, 1983 and Telch and Telch (1983) and also p.76, Pequegnat 1998). On the other hand, the recognition that certain personality types may be attracted to “denial” (such as the B-NPCM in this study) may give extra support to the 1927 theories of Freud and Heidegger (p.42). The holistic approaches to “Forgiveness Therapy” such as those proposed by Philips and Osborne

(1989) and Krivohlavy 2000, (pp. 72/73) may encourage sharing experiences among group members leading to eventual catharsis and peace.

The Psychological Sub-Scale seemed to be the most difficult for patients to answer and promotes interesting speculations as to whether the context of these questions may have triggered an initial response of “denial” in a small number of patients within all 3 groupings (BPCM, B-NPCM & NBNP). Patients were forced to confront their illness and its frightening consequences from the more unusual aspect of mental rather than physical assessments. In addition they were placed in the uncomfortable position of having to address issues which were perhaps not normally discussed with either family or staff members.

Hypothesis 3 results were similar to those of Hypothesis 1, except that NBNP patients in Hospice A achieved high scores which placed them in the same sub-set as the BPCM & B-NPCM of Hospice B. The reasons for this however, continued to remain the same as those discussed for Hypothesis 1. NBNP Hospice B patient’s scores were lower than those of Hospice A, BPCM & B-NPCM for the reasons discussed in the Discussion Chapter (p.164). However, the basic premise that the spirituality policies of Hospice B unintentionally created a lowering of self esteem in the NBNP patients still prevailed. Interestingly the nature of the detrimental effect was most probably subconsciously induced since it has been established that all patients within Hospice B were afforded equal care and attention and all patients assessed their treatment by hospice staff as excellent. Results for Hypothesis 3 (Meaningful existence) highlighted the urgent need for physicians to include routine communication of existential issues and / or administer assessment of patient’s “psychological well-being” (Krivohlavy 2001).

Results for Hypothesis 4 introduced issues of “ontological insecurity” and death distress and re-introduced the subjects of depression and denial. Leventhal et al’s (1986) contention that unsuccessful coping serves only to increase distress by reducing the patient’s sense of control applied particularly to the NBNP patients within both hospices. Coping with “Support” issues was difficult for some patients especially those without religious or spiritual beliefs. Facing up to the reality of their situation was difficult for patients within all 3 groupings and most probably produced existential pain as they struggle to make sense of their thoughts and emotions. Those who were in denial or who found it impossible to discuss their plight with family or hospice staff members may have experienced a heightening of their sense of lack of control, resulting in feelings of exhaustion, fatigue and isolation. Results for Hypothesis 4 highlighted the need for

good support networks to be established within hospices in order to identify patients who may suffer existential pain, “ontological insecurity” or signs of isolation.

Results for Hypothesis 5 supported the findings of Hypotheses 1 – 4. “Religious Orientation” was important to “BPCM & B-NPCM” patients within both hospices but “Hospice” was also influential in results (particularly where a significant interaction was recorded). The latter most affected BPCM & B-NPCM in Hospice A and the NBNP patients in Hospice B.

Overall, the design of the MQOL-SV succeeded in its original intention of producing a comparison of QOL scores for the groups of BPCM, B-NPCM & NBNP patients within both hospices. Results indicated that patients within each of the 3 groups employed 4 main strategies in order to cope with the stress of terminal decline. These were “religious / spirituality belief”, “denial”, “resignation / fatalism” and “acceptance”.

The present study was initially instigated by several questions (see Chapter 1, p 6), which have now been addressed. The following responses to these questions are tentative and all require further research.

1. Do patients choose a coping strategy during terminal illness?

Results of the MQOL-SV indicated that there seemed to be both conscious & unconscious coping strategy choices made by most patients. Except for NBNP patients in Hospice A, coping strategy choices seemed to be influenced by the operation or non-operation of spirituality policies within both specialised care hospice units

2. If so, is this choice determined by personal attitudes or beliefs?

Coping choice seemed to be very much determined by both personal attitude and personal beliefs. For the non-believer, their view that death signified the end of “the self” tended to create feelings of depression, anxiety and death distress. Consequently NBNP patients tended to consciously and sometimes unconsciously chose the coping strategies of “resignation / fatalism” to the inevitable (death) in conjunction with “acceptance” of medical practitioner’s skills. For the “believer” (BPCM & B-NPCM), coping strategy choices depended principally

on personal “faith / spirituality beliefs” although as has been previously discussed, the latter seemed to be either “bolstered” or undermined policies operating within each hospice.

### 3. What are the most frequently employed coping strategies?

As stated above, most frequently employed coping strategies appeared to be “religious faith”, “resignation / fatalism”, “acceptance” and “denial”. The latter appeared to be most applicable to the B-NPCM populations. There were also indications that some individuals within each of the 3 groupings (BPCM, B-MPCM & NBNP) attempted to access “positive thinking” and “social networking” but overall, most patients were inclined towards “palliative” as opposed to “instrumental” coping strategies.

### 4. Are “coping strategies” analogous to “well-being” and “quality of life”?

MQOL-SV results indicated that in Hospice B, BPCM & B-NPCM patient’s coping strategies were analogous to well-being producing high QOL assessments. However, this did not apply to NBNP patients whose coping strategies tended to consist of “denial” and “resignation / fatalism”. Although Hospice A, BPCM & B-NPCM patient’s QOL scores were lower than those of the same grouping in Hospice B, results nonetheless indicated that their main coping strategy of “religious / spirituality beliefs” was analogous to “well-being” within the areas of “Meaningful Existence” and “Support”. However, the deterioration of self-esteem (engendered by the lack of spirituality hospice policies) lowered their QOL assessments within the “Physical” and “Psychological” components of the MQOL-SV. Interestingly, although NBNP patients in Hospice A attained higher QOL scores than the same grouping in Hospice B, findings indicated that their choice of coping strategies were less analogous to well-being and high QOL evaluations than those of the BPCM & B-NPCM in both hospices. Interestingly, within all 3 populations “denial” was apparent but undoubtedly it was most noticeable within B-NPCM “Psychological Sub-Scale” responses. In this specific instance, “denial” could perhaps be regarded as analogous to the well-being of B-NPCM who used it as a means of alleviating guilt and anxiety.

Interestingly, MQOL-SV results give support to the introduction of techniques such as the first 3 suggested by Pequegnat (see Chapter 2, p.76). Developing predictors of failure to cope may

identify some prevalent issues such as death distress and existential suffering which was most prevalent within the NBNP populations. This research has also identified the importance of hope and its impact upon the 3 category groupings. For BPCM & B-NPCM, hope in a belief of existence after death eased meaningful existence concerns and death distress. However for some B-NPCM, anxiety concerning their lack of “practise” produced feelings of guilt and the hope that they would return to ritual practise thus instigating “denial” towards their terminal decline. Parkes, Relf & Couldrick’s 1996 (p.81) proposal of “working through the pain of grief” with counselling sessions and LePoidevin’s (1989 unpublished) “dimensions of loss” sessions (p.81) may both be applicable techniques to aid recovery from self doubt and feelings of guilt and as such worthy of incorporation within palliative care policies. (The latter would be most applicable to the B-NPCM patients within this study).

MQOL-SV results may be surprising to staff within the hospices in which the research was conducted. The study highlighted that some patients had considerably lower self-reported assessments of Physical Status, Psychological Status, Meaningful Existence and Support than others within the same hospice. This research has identified a link between patient’s spirituality / religiosity orientation and high / low self-reported questionnaire scores. Most surprisingly, statistical analysis has identified the importance of spirituality care policies to both religiously and non-religiously orientated patients. The existence of spirituality policies within palliative care hospices appeared to be of greater importance to end-of-life “religiously orientated” patients than perhaps hitherto appreciated by health care administrators. Self-report Quality of Life questionnaires are therefore worthy measuring tools in the evaluation of patient’s mental and physical well-being. The MQOL-SV has indicated that for “believing” patients, the inclusion or non-inclusion of spirituality policies may be the determining factor in QOL evaluations. Faced with terminal decline, existential issues and meaning in life often become important to some patients for the first time in their lives. For others, these subjects are so important to their existence that they may become distressed if not included within end-of-life care. The MQOL-SV may be a reliable measuring tool with which to identify such patients especially those suffering anxiety and depressive symptoms, which inevitably affect pain management. Results of the MQOL-SV highlighted the necessity of continuous patient assessment in order to recognise their concerns, expectations and QOL throughout their treatment and of the necessity of re-adjustment and continual development of existing care policies.



Hypothesis 6 introduced interesting subjects such as the power of prayer, superstition and desire to recover, even in the face of serious illness. Results supported the findings of other researchers in this area (refer to p.47 - Neugarten, 1979, Labouvie-Vief, 1980, Moberg, 1982 Chinen, 1984 & Byrd 1988) that irrespective of religious / spirituality beliefs, non-believer were equally as willing as believers to partake in intercessory prayer. The reasons why each of the 3 groups (BPCM, B-NPCM & NBNP) within both hospices were overwhelmingly willing to condone intercessory prayer were discussed on p 177 (Chapter 5) and lead to one general conclusion. Despite life-long differences in attitudes and beliefs, patients classed as having life-threatening illness were not averse to the suggestion of having prayers said for them. This seemed to support Doyle's (1994) assertion that as patients become closer to death, thoughts of transcendence become more important to them (Chapter 1, p.15). Hypothesis 6 also highlighted the need for support networks within hospices that can offer assistance to those patients who have religious affiliations as well as those who have none. For the former, hospices could offer "prayer partners" to those who desire it and arrange visits from chaplains or clergy. Where the latter is not possible, patients could be offered intercessory prayer opportunities. The same could also be offered to patients with no religious affiliations who may regard it as a type of alternative therapy. Where appropriate, patients with no religious affiliation could be offered the techniques of positive thinking and positive imagery

Results to Hypothesis 7 supported the present researcher's original theory that patients with life-threatening illness tended to cope with it in the same way that they coped with any stressful circumstance throughout their lives. Those with strong religious convictions tended to access their belief system and partake in religious ritual to help alleviate the stress. Those with little or no spiritual or religious belief tended to rely on their tried and tested recourses amalgamated from a lifetime's experience. The findings from this particular hypothesis provided some of the most revealing insights into the minds of those patients well enough on the day of interview to respond to the questions. Overall, results to Hypothesis 7, supported the aims of the present research in that spirituality / religious beliefs seemed to be very important to some, if not the majority of patients and as such, should be recognised as a possible aid and coping mechanism during the last phase of life.

#### Staff Research:

CPCD results were non-significant thereby necessitating the retention of the null hypothesis in all 4 hypotheses. This is a surprising result indicating that despite the fact that staff in Hospice B had

higher overall SMS than staff in Hospice A, no statistical differences occurred in staff attitude towards the introduction of spirituality centred hospice policies. This finding may encourage hospice administrators to consider spirituality issues when introducing new policy agenda. American opinion polls consistently show that although approximately 60% of patients would like their medical practitioners to talk to them about faith or spirituality as a factor in health prognosis, only 10% have in fact reported this happening (p.13 Maugans and Wadland, 1991 & Ehman, 1999 and to p.52, Delbanco, 1991). CPCD findings nonetheless indicated that Hospice B staff with “High” SMS experienced higher emotional distress regarding occupational duties and that it was this factor which contributed to their lower scores concerning occupational capability. However, as was stated at the outset, although scoring differences were not robust enough to produce statistically significant results, they are interesting to note since they highlight areas for future research. To date, little investigation has been conducted into the adoption of coping strategies by hospice staff as a means of alleviating occupational stress.

One of the most surprising results (Descriptive Statistics) was that more than half of the staff in each hospice were willing to discuss spirituality and religious issues with patients and even pray with them. Perhaps the most surprising overall finding was that 96% of staff in Hospice A and 88% of staff in Hospice B considered spirituality issues worthy of inclusion within a category entitled, “Coping Strategies in Terminal Illness” while slightly less considered religiosity issues worthy of inclusion. These results are remarkable for 2 reasons. Firstly the researcher did not expect such a high percentage of staff members within both hospices to be so favourable towards spirituality and religiosity issues. Secondly, staff members within Hospice A (where spirituality and religiosity issues were not incorporated into the care regime policies to the same extent as they were in Hospice B), in fact recorded a higher score for discussing spirituality issues with patients. This result opens the way for spirituality / holistic policies to be introduced more fully into the palliative care policies of Hospice A.

Some discrepancies began to emerge between the scores of Hospices A and B (Staff Questionnaire) in connection with occupational stress and emotional upset, although ultimately, score differences were not statistically significant. Hospice B had a large amount of staff who admitted experiencing emotional upset with regard to their occupational duties in comparison to those who did not. The numbers who experienced emotional upset in Hospice A was smaller than Hospice B but nonetheless constituted more than half. The most noted difference in results was for Hospice A staff who claimed not to experience emotional upset. This result was more than

four times that of Hospice B. Overall conclusions to be drawn from these findings were that for the most part occupational duty carried a heavy burden of moral decision making. Whether the latter was linked to religious / spirituality orientation or not, staff were presented with the dilemma of either succumbing continually to the emotional distress associated with end-of-life care or of completely closing down their emotional reactions to the more distasteful and frightening aspects of terminal illness. Since death was a regular occurrence, staff repeatedly experienced the loss of an individual in whom large amounts of effort had been invested. It was not surprising therefore that some staff chose (consciously or unconsciously) to adopt coping strategies which would protect their emotional and psychological well-being from continual distress. An indication of the necessity of coping strategy adoption was revealed in results to question 13 - "Coping with Job" (Chapter 4, p.139). Staff in Hospice A were much more confident in their evaluation of how well they coped with occupational stress, in comparison to staff in Hospice B. This provided strong indications that staff within both hospices were aware of the potentially disastrous consequences of becoming too closely entangled in their patient's plight. For some staff (particularly in Hospice B) emotional closeness with patients was judged to be the correct decision even although it resulted in a degree of uncertainty concerning the efficiency of occupational capability. For other staff members (mainly within Hospice A), emotional distancing was judged to be the correct procedure in order to obtain maximum occupational efficiency. Most interestingly, results to questions 11 & 15 assessing "Development of Coping Strategy" and "Quality of Life" produced almost identical scoring for staff in both hospices. The high scores attained in both of these areas (Chapter 4, p.139) indicated that for most staff members, individual coping strategy choice of involvement with or distancing from patients appeared to fulfil its desired function – i.e. the alleviation of emotional and psychological distress relating to occupational duty.

In conclusion, results for "Staff Research" highlighted the fact that both participating hospices in the West of Scotland were staffed with predominantly young, dedicated professionals, committed to palliative care who carried out their stressful tasks in a conscientious manner, designed specifically to ameliorate the anguish of their vulnerable end-of-life patients. Results also indicated that both hospices were receptive to the introduction of spirituality policies but that staff with "High" SMS in Hospice B seemed to suffer greater emotional distress due to occupational duty. Most importantly, staff research results indicated that it was most probably the spirituality hospice policies already in operation within Hospice B that contributed to their BPCM & B-NPCM patients achieving higher MQOL-SV scores. Whereas, for Hospice A, although staff

results indicated that the majority of staff would be favourable to the introduction of spirituality policies, because none were in operation, communication of spirituality issues with their BPCM & B-NPCM patients were not routinely included. This may have contributed to their lower MQOL-SV scores.

Finally, to complete conclusions to the Staff Research, mention will now be made of the findings relating to the “Doctors Questionnaire”. Although population numbers in this survey were small, they are nonetheless noteworthy since they represented 100% of doctors in Hospice A and 67% in Hospice B. In addition, results may be compared to previous studies, such as those stating that 9% of doctors adhered to religious or spiritual beliefs (Chapter 1, p.32 - Koenig, Pargament, and Neilson, 1998).

In answer to whether assessments of patient’s anxiety or stress levels and of coping with their illness were considered, although most doctors claimed that they conducted these types of assessments, few reported using validated psychological measuring tools. Most tended to rely on clinical judgements or discussion with colleagues. In answer to whether males or females tended to cope better with terminal illness, it was interesting to note that the majority of doctors proposed that both sexes coped “about the same”. This result was difficult to interpret since there were previous indications that patient’s coping abilities with regard to issues of death and dying were not routinely addressed. Qualitative responses given by doctors revealed a strong dedication to the more traditional aspects of medical treatment, concentrating mainly on pain management, nausea, exhaustion and the administration of appropriate medicines. Treatments or assessments involving a psychological approach tended to be either ignored or judged on the basis of physical examinations, clinical judgements and consultations with colleagues. Thus when confronted by the survey question of whether they informed their patients when they were close to death, 8 doctors chose to select the response “sometimes if considered appropriate” and 4 “only if they themselves ask”. These responses lend support to the conjecture that doctors prefer not to combine the more traditional fields of medicine (directed towards the treatment of physical illnesses) with psychological assessment and measurement tests. To a degree, this is completely understandable since doctors have only limited time with each patient, and communications concerning the realities of their medical status may cause alarm to some patients, impairing their quality of life. On the other hand, concealing truthful medical diagnosis from patients may also cause increased uncertainty, anxiety and distress which will affect not only QOL but relationships and communications with family and hospice staff. Doctors may fear an impending explosion of

emotional turmoil if patients were to face the full knowledge of the stages of their illness without hope of a cure. They may also be concerned that this knowledge would place an added burden on nursing staff who, in addition to administering medical procedures, may have to adopt counselling techniques. Nevertheless, if hospice staff are to address all the issues relating to palliative care, doctors may need to undertake continual training in the breaking of bad news and its consequential psychological effects. This proposal could be achieved with course modules focusing on previous studies of patient's ability to cope with truthful disclosure, leading eventually to standard practise in which patients possessed enough knowledge to enable them to act as partners in the management of their own situation.

The questionnaire also investigated whether doctor's ability to cope with occupational stress was aided by the adoption of coping strategy techniques. While 3 doctors in Hospice A reported never being emotionally depressed and 3 claimed not to employ a coping strategy, the remaining 9 doctors reported being either usually or occasionally depressed due to occupational duties. Within this last grouping, 7 claimed to consciously adopt a coping strategy in order to alleviate the stress. In keeping with overall "Staff Research" results, although 5 doctors in Hospice A admitted to being occasionally depressed, none reported being depressed on a regular basis whereas in Hospice B, 2 of the 4 doctors admitted to being frequently depressed. Results of whether doctors considered spirituality / religiosity issues to be considered important enough to patients to be included in a category of "coping strategies in terminal illness" were in fact higher than those within the general staff research findings with all 12 doctors choosing the "yes" option. This latter result, although within a small cohort, presents opinions contrary to most of those recorded within previous research. Finally, although adherence to religious ritual was high and therefore again contrary to the trend in previously published findings, small population numbers within this part of the research study prevents further speculation as to whether there may have been a link between religious / spirituality orientation and doctor's responses.

Before presenting recommendations for future palliative care research, the researcher wishes to provide answers for the last of the "investigative questions / outcomes" originally mooted in the Introduction Section (Chapter 1, p.6 and p.10).

Investigative Questions (p.6)

1. Are policies in operation, which encourage assessment of patient's depression or anxiety symptoms?

Results of the “Doctor’s Questionnaire” suggested that there were no official guidelines as to the assessment of patient’s psychological status. Some staff did assess their patient’s anxiety and coping abilities but few employed reliable and validated psychological tests.

2. Do staff consider religion or spirituality issues worthy of inclusion within the category “coping strategies of patients with life-threatening illness”

More than 87% of staff considered spirituality issues worthy of inclusion within the category “coping strategies of patients with life-threatening illness”. More than 79% of staff considered religious issues worthy of inclusion within the category “coping strategies of patients with life-threatening illness”.

#### Desired Outcomes (p.10)

1. Help reduce patient's mental anguish by the recommendation of improved “quality of life” assessments. –

MQOL-SV results highlighted the need for communications relating to religious or spirituality issues for “believing” patients which were not only of vital importance to their well-being but seemed to increase QOL self-report scores. In the light of these findings, this study recommends the inclusion of spirituality / religiosity issues in all QOL assessments which may lead to the reduction of mental anguish and a boosting of self-esteem for religiously / spiritually orientated patients. Most importantly however, these measures will identify non-religiously orientated patients who may benefit from either coping-skills instruction or counselling sessions in order to minimise feelings of isolation or disorientation arising from the introduction of spirituality issues / policies.

2. Increase medical practitioner’s awareness and support of their patient’s spiritual / religious concerns resulting in better medical control of patient’s symptoms. –

MQOL-SV results indicated that where patient’s religious / spirituality concerns were incorporated into the ethos and communication policies of the hospice, “believing” patients could experience a psychological boost to their self-worth and self-esteem which may result in better control of physical symptoms. Importantly, possible detrimental effects upon “non-believers” of such policies should also be addressed in order to benefit all patients

undertaking end-of-life care. Overall, MQOL-SV results highlighted a need for medical staff to be aware of the importance of religious / spirituality issues to religiously / spirituality orientated patients. Results for “Staff Research” yielded high support for the inclusion of religious / spirituality issues within palliative care policies and for the recognition that these issues were worthy coping strategy aids. Staff results recorded awareness of the maxim that in order to maximise therapeutic efficacy, respect must be paid to the religious / spirituality beliefs of those patients who hold these issues as critical life factors. The latter may aid the coping abilities of some patients thereby contributing to increased medical control of symptoms.

3. Result in the inclusion of “psychological measuring scales” within healthcare assessment of patients, which may further increase their overall QOL and end-of-life care.

MQOL results together with results from the “Doctor’s Questionnaire” provided strong evidence for the necessity of regular patient QOL assessments incorporating reliable and validated psychological measuring scales. As previously stated, depression is often frequently undiagnosed in end-of-life patients and other states such as anxiety, isolation and denial similarly overlooked. This study has highlighted the need for reliable and validated psychological tests which should be conducted on a regular basis throughout the disease trajectory of end-of-life patients.

## Recommendations

1. Routine inquiry relating to patient’s spirituality / religiosity orientation should be included in initial interviews conducted with patients entering hospice care. This could be either self-report status or a more in-depth disclosure by means of a spiritual well-being test (eg Paloutzian & Ellison Spiritual Well-Being Scale). Such information has clinical relevance since it establishes the patient as a unique person and not merely a person with a symptom.
2. Medical staff committed to good quality of life standards should recognise that patient’s spirituality / religiosity orientation is of importance to patient autonomy and can provide a helpful active cognitive framework from which to face life-threatening illness. It can also

provide hospice staff with useful information regarding requests for visits from clergy, participation in religious services or referrals to hospice chaplains.

3. The introduction of spirituality / religiously related policies within palliative care should be given serious consideration. These policies should encompass respect for rituals such as prayer or intercessory prayer and regular communication of spirituality / religious issues with patients who indicate a desire for such dialogue. The outcome of such policies would be the promotion and enrichment of patient / staff relationships.
4. In order to recognise Frankl's proposal that the sense of "quality of life" depended on the perception of personal meaning, existential problems should be addressed within palliative care agenda.
5. Pain management should include psychological as well as physical assessments since pain may result from existential / spiritual distress as well as physical ailment.
6. Psychological tests should be conducted on a routine basis throughout the disease trajectory of the terminally ill patient. Several potential screening tools exist, for example, the ICD 10 Tests or HADS.
7. Medical students should be trained in the administration and interpretation of psychological tests.
8. Patients experiencing excessive anxiety or depressive symptoms should be seen by a visiting clinical psychologist assigned for this specific purpose by Local Authority Health Boards.
9. Where the patient is shown to be free of psychological illness, a contract should be negotiated between physician and patient whereby all communication between them should be honest in matters concerning disease status and disease prognosis. The patient would be free to sign agreement to this contract if they felt it would relieve them of uncertainty and anguish regarding their illness. On the other hand, where a patient decided that entering into this type of agreement would create more anguish, the contract could be left unsigned. Both actions would provide physicians and medical staff with important insight into their patient's mental



status regarding their illness. Policies such as these would also demonstrate flexibility and respect for individual patient's coping strategies and information choices.

10. All concerned with the care and medical treatment of hospice patients should recognise spirituality / religiosity to be a normal part of work with end-of-life patients. Thus nurses, doctors, social workers, chaplains, psychologists and medical directors would share equal responsibility in this undertaking. The question of whether resident chaplains should be included along with the house staff during patient's rounds should also be addressed. Incorporating such a system would increase the exposure of physicians to chaplains (and vice versa) thus increasing comfort levels with each other.
11. The 10 recommendations (above) should be integrated into a framework of standard practise in order to provide future palliative care services with continual updating of "standard of excellence" proposals.

#### Future Research:

- (A) The MQOL-SV and CPCD questionnaires should be repeated in other similarly matched specialised care hospice units in order to test reliability.
- (B) Where similar results occurred, research should concentrate on establishing the reasons why NBNP patient's scores were lower within "spirituality / holistically centred" hospices.
- (C) Future palliative care research should aim to provide new ways of diagnosing anxiety and depression disorders with the least amount of unnecessary disturbance to the dying patient. New interventions incorporating patient interviews could be piloted by suitably trained staff with the objective of compiling a list of unacceptable stress levels relating to all aspects of end-of-life care.
- (D) Investigations should assess whether age, gender or cultural differences affect attitude towards pain, suffering and death distress.
- (E) Other domains which may affect patient's QOL should be explored, for example loss of privacy, inability to do as one wants, immobility and separation from spouse / partner.

- (F) The concept of religious belief could be further explored. For example, MQOL-SV questionnaire results could distinguish between those patients who considered God as loving, fair and just as opposed to punishing and vengeful. Results may shed light on whether both populations chose or did not choose religious belief / faith as coping strategy aids and which aspects of their beliefs determined successful outcomes.
- (G) Research into end-of-life coping-strategy adoption and its association with QOL assessment scores should be further investigated in order to provide comprehensive insight into the concerns and fears of the dying patient.
- (H) Investigation of why certain patients opt for the coping strategy of “denial” should be explored more fully in order to establish whether the choice involves conscious or unconscious processes.
- (I) The opinions and concerns of hospice staff members should be further explored and investigated. Consideration should be given to their mental health status, particularly in areas of anxiety and emotional distress related to occupational duties.
- (J) More research should also be directed towards the coping strategies of hospice staff and whether they contribute to high / low assessments of job capability.
- (K) Future research should investigate whether staff who are attracted to palliative medicine are more spirituality / religiosity orientated than other sections of the medical community and what implications results may have for future palliative care spirituality / holistic policies.
- (L) Staff should be informed of the importance of religious / spirituality issues to religiously / spirituality orientated patients experiencing terminal decline.
- (M) Longitudinal studies into the processes involved in the management of pain, anxiety and death distress would maximise the ability of research to provide fluid and continuous information to palliative care practitioners.

- (N) Longitudinal studies would also provide important information regarding the coping strategies of “non-believers” and the processes involved in the management of their life-threatening illnesses.
- (O) Finally, longitudinal studies should also be directed towards the impact of terminal illness upon hospice staff. Research should concentrate on their concerns and anxieties regarding occupational duty and the effect it has on quality of life assessment.

In conclusion, research into “the coping strategies of hospice patients with life-threatening illnesses” has provided the present researcher with a privileged insight into the hopes, fears and desires of end-of-life patients within two specialised palliative care units in the West of Scotland. MQOL-SV results have shown, as Schultz and Schlarb (1991) attested, that studies investigation death and dying provide valuable opportunities to develop the existing theories about coping with stress (Chapter 1, p.65). In addition, it has also generated new proposals for future palliative care treatment and hospice policies. Most importantly, however, this research has been a testimony to the resilience and resoluteness of terminally ill patients who, despite being very close to death, were determined to leave some trace of themselves within their MQOL-SV questionnaire responses.

### Research Limitations / Strengths

1. The “questionnaire” technique of methodology has been criticised from the perspectives of judgement and assessment of truthful responses from participants and from incomplete questionnaire forms. However with reference to the MQOL-SV, criticisms of this nature may be counterbalanced by the following arguments: Although the “Patient Research” programme was presented in questionnaire format, patient responses were not received by the usual methods (i.e. telephone or postal replies). Due to ethical considerations and poor physical status of participants, the “Patient Research” study was conducted by interview technique. In so doing, face to face contact promoted patient / researcher empathetic communication,

emotive conversations, opportunity for tactile expressions and confiding opinions. The fragile physical status of each patient was also accounted for by responses being recorded by the researcher. It also meant that their energy was channelled into verbally answering the questions, not physically writing them into a questionnaire sheet. This method also provided patients with an “outside contact” in whom they could confide (if they so wished). Finally, since the researcher personally interviewed all 120 patient volunteers, queries concerning comprehension difficulties could be promptly addressed. By so doing, the immediacy of the patient / researcher interview helped promote truthful responses and importantly, one of the biggest criticisms of the questionnaire technique was avoided i.e. incomplete questionnaire returns.

2. Both hospices involved in the study were not the result of a random choice. However, as explained in the Methods Chapter, because this research study investigated patients with life-threatening illness, approval by the Local Authority Medical Ethics Board stood little chance of being granted unless it obtained backing by at least 1 palliative care hospice. Consequently, having received the backing of 2 hospices, the researcher gratefully acknowledged the support offered by both centres in the full realisation that the alternative to this support would have been refusal by the Ethics Committee of any access to patients in terminal decline. However, although ethical limitations were imposed, it is important to point out that selection of patient volunteers was completely randomised. The latter also applied to participating staff populations (to whom no ethical limitations had been imposed). The catchment areas for patients within both hospices was fairly large, encompassing the whole of Greater Glasgow North towards Kilsyth, west towards the Clyde Tunnel and east towards Baillieston and yet further east towards North and South Lanarkshire. Staff employed at both hospices travelled from approximately the same areas. Consequently results obtained from “Patient” and “Staff” research represented opinions from a wide geographical area of Greater Glasgow, North and South Lanarkshire.
3. Ethical procedures imposed by the Local Authority Medical Ethics Board together with “Collaborative Team” limitations did change the researcher’s original methodological intentions. However, the limiting of the questionnaire to 16 questions plus the request for questionnaires to be conducted by interview technique did not produce detrimental results – indeed the limitations generate positive and constructive outcomes. Ultimately, by personally conducting 120 interviews during the six months period, the researcher grew to appreciate

completely the collaborative team's initial anxieties towards potential patient exhaustion and concentration difficulties. Accordingly, the 16 question limitation meant that it became crucial to target each question directly towards the research study's main objectives, i.e. – an investigation of the quality of life and coping strategies of hospice patients from physical, psychological, existential, support and spirituality perspectives.

4. The decision to abandon the “Spiritual Well-Being / Religiosity” measuring tool in order to comply with the collaborative team's principal decision concerning questionnaire brevity initially caused the researcher a degree of concern. However the team's alternative suggestion (following interview completion) of consultation of the Patient's Files for self declaration of adherence to a religious or spirituality belief turned out well and resulted in the instigation of the 3 sample populations (BPCM, B-NPCM & NBNP). To include a religiosity / spirituality measuring tool within the Patient Research Programme may indeed have been problematic as often during the course of answering the 16 questions, interviews had to be interrupted for the administration of pain killing drugs or other medical proceedings. Consequently, patients would most probably have been too exhausted to follow completion of the 16 MQOL-SV questions, with a “Spiritual Well-Being” instrument. What remained constant throughout was their determined effort to complete the questionnaire even although interviews averaged between 20 and 50 minutes. For the researcher to insist on the inclusion of a spirituality measuring tools would have necessitated the arranging of a repeat appointment with each patient. Apart from doubling the length of stay in each hospice, this procedure would not have been feasible due to the high mortality rates (refer to Chapter 4, p.135). In summary, although patient declaration of religious / spirituality orientation could not be accessed by the researcher until completion of interviews, the MQOL-SV questionnaire was designed to include questions which provided the researcher with indications of religious / spirituality orientation (Appendix 1 questions, A, B, & C). Subsequently, once Patients Files were accessed, responses to the latter questions tended to match with their declared religious / spirituality orientation.
5. As mentioned above, this research study was conducted with patients who were close to death. Official hospice files recorded 3 stages of terminal disease i.e. – Rehabilitation, Symptom Control and End of Life, in order to determine appropriate palliative care treatment. It is interesting to note the actual death occurrences for patients taking part in empirical research. For Hospice A, only 8 of the 60 participating patients (13.3%) were classed as “End

of Life” (September 2002) yet within 1 month of being interviewed 31 (51.6%) had died. Six months later only 2 (0.03%) remained alive. For Hospice B, 17 out of 60 patients (28.3%) were classed as “End of Life” (December 2002). Within 4 weeks of interview 17 (28.3%) had died yet six months later 30 (50%) were still living. The fact that 50% of patients in Hospice A and 30% in Hospice B died between 1 day and 28 days of interview provides evidence with which to address one of the most frequently quoted criticisms directed towards research with terminally ill patients. That is that most results must relate only to patients in the early stages of terminal decline. This is a reasonable accusation particularly during circumstances in which patients undertake a self-report questionnaire programme. The design of this present research is thus fairly unique in its design and operation. Another area which could instigate research criticism is that significant result differences between patients in Hospices A and B occurred because Hospice A patients must have been older and frailer than those of Hospice B. The latter however, would be discounted by information held within official records. Each hospice adhered to strict criteria concerning the level of physical decline necessary to attain a short-stay bed within those units classed as “Specialised Care” centres. The average length of stay within both hospices was 2 – 3 weeks for “In-Bed” patients while the existence of “day-care” units also allowed seriously ill patients to be administered to medically. Consequently, severity of illness levels between volunteer patients within Hospices A & B were subject to identical criteria.

6. Because research design had ensured that access to patient’s files should not be permitted until completion of interviews (in order to counteract interviewer bias criticisms) the researcher could not control group sizes within the 3 categories of religious orientation (BPCM, B-NPCM & NBNP). This could have presented problems within inferential statistics if sizes had been extremely unequal. However if empirical research was to be conducted in an honest manner, the researcher had to precede with all 120 interviews in the hope that data recordings would generate robust analysis. Groups within Two-way Between Groups ANOVA were recorded as,

BPCM – 38

B-NPCM – 35

NBNP – 47

These ratios were within the limits advocated by Stevens, 1996 (i.e. largest/smallest = 1.5). For One-way ANOVA (refer to Chapter 4) sample sizes for Hospice B were, by chance, almost identical (20: 19: 21) although this was not the case for Hospice A (18: 16: 26). Levene's Test of Equality of Error Variances identified the presence of inequality of error variances across group samples, but as Stevens purports (p.249), analysis of variance is reasonably robust to violations of this assumption. In addition the application of a Bonferroni adjustment restricted the likelihood of a Type 1 error. Despite this restriction, inferential statistics (Two-way Between Groups ANOVA) nonetheless identified significant "main effects" in all 5 MQOL-SV hypotheses (generating strong to moderate strengths of association). In addition, significant differences also occurred between Hospice A & Hospice B patient's scores (One-way ANOVA). In conclusion, despite being unable to manipulate group sizes within empirical research, data recordings within inferential statistics were robust enough to generate significant differences between groups both within and between Hospices A & Hospice B.

7. In Chapter 3 (Methodology) it was stated that sample populations within the Patient Research study reached in excess of 30% for both participating hospices (refer to p.120). In comparison to other survey / questionnaire research this is an average / good response rate and is above the "sampling error fraction" described by Weisberg et al (1989) -

"when the sampling fraction is above 30 percent, enough of the population has been sampled so public attitudes are likely to be very similar to those of the sample" (p.57).

It must be stressed however, that to attain an overall population of 120 terminally ill patients within a study programme is well in excess of average numbers within other similar terminal care research studies. Investigation of journals such as "Journal of Palliative Medicine" or "Journal of Clinical Oncology" will reveal average research populations of between 8 – 25 subjects per hospice / hospital unit. MQOL-SV Patient Research has provided an unusually high patient response contribution to coping with terminal illness and QOL assessment.

8. As mentioned in Chapter 3, the measuring tool used in the Staff Research programme (CPCD) was not yet a validated or reliable instrument. However, as a secondary area of interest within this research study, it had been composed purely for use in the event of significant differences occurring within Patient Research. The collaborative research team was keen to investigate staff attitude towards spirituality hospice policies since it would

provide findings for a hitherto unexplored area of palliative care research. Because significant results emerged within the MQOL-SV Patient Research study, the CPCD Staff Research programme was instigated.

In conclusion, the imposition of specific design and operational limitations upon the “Patient Research” study did not produce detrimental effects upon statistical results. On the contrary, the empirical study became specifically and succinctly tailored to the physical, social and cultural needs of this most fragile of volunteer groupings. Specifically, MQOL questions became completely focussed on the main areas of investigation within the research study producing results which ultimately indicated statistical differences between both hospice groups.

Finally, as all questions and information given to patients and staff adhered to the guidelines of the BPA and to those of the Glasgow Royal Infirmary Ethics Board, the dignity of all volunteers was preserved throughout the research programme.



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**Appendix 1.1 – MQOL- SV (McGill Quality of Life: Scottish Version) Page 1 of 1**

- A. During your lifetime, what has helped sustain you during times of crisis?  
 .....
- B. What has been on your mind recently?  
 .....
- C. What do you think gives meaning to life?  
 .....

(Please answer the following questions thinking about the last 2 days )

1. How well have you been feeling recently?  
 5      4      3      2      1
2. Have you been feeling anxious ?  
 1      2      3      4      5
3. Have you been feeling depressed?  
 1      2      3      4      5
4. How much of the time do you feel sad  
 5      4      3      2      1
5. How frightened are you of the future?  
 1      2      3      4      5
6. How far do you think you have come in achieving life goals?  
 5      4      3      2      1
7. Do you feel that your life has been meaningful or meaningless?  
 1      2      3      4      5
8. Do you feel that your life is in your hands and you have control of it?  
 5      4      3      2      1
9. Do you feel close to people or distant from them?  
 1      2      3      4      5
10. Do you feel good about yourself as a person?  
 5      4      3      2      1
11. Does each day seem a burden or a joy?  
 1      2      3      4      5
12. How would you describe your quality of life in the past two days?  
 5      4      3      2      1
13. Would you be willing to have prayers said for you?  
 Y ( ) N ( ) Unsure ( ).



1. **Study title** – “The Coping Strategies of Hospice Patients During Illness”.
2. **Invitation paragraph** -You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
3. **What is the purpose of the study?** - I am conducting research as part of my dissertation for a Ph.D. in psychology at the University of Glasgow. The research involves exploring the different ways hospice patients cope with life-threatening illnesses. The main area of investigation concentrates on patient’s quality of life and how they feel they are coping with emotional and spiritual concerns. As improving “quality of life” for patients is the goal of every treatment in palliative care, it is essential that there should be a valid and reliable means of measuring quality of life. This research study has modified a specially designed questionnaire for hospice patients in order to include questions on emotional and spiritual concerns. The cause of pain is sometimes more than physical. It can, for example, include psychological or spiritual elements. This research study seeks to examine whether the inclusion of psychological and “spiritual well-being” measurements into “Quality of Life” assessments will produce a means by which the quality of life of future palliative care patients will be increased. The study will be conducted in this hospice for a period of 3 months but individual patients wishing to take part in the research will be needed for one interview only, lasting between 20 – 40 minutes.
4. **Why have I been chosen?** – You are being given the choice to take part in this study because you are receiving treatment at this hospice. Every patient who is being cared for by this hospice will be given the opportunity to take part in the study.
5. **Do I have to take part?** – It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a Consent Form and you will be able to keep this Information Sheet. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.
6. **What will happen to me if I take part?** – If you decide to take part in this study, you will be informed of a day and a time when the researcher will come along to talk to you. A suitable room in which to carry out the study will be chosen by hospice staff. It may be your own room or another private area within the hospice. Please do not worry if you do not feel well enough to speak to the researcher on the day appointed as another appointment can easily be arranged. The research is in the form of an interview in which you will be asked to answer 16 questions from a questionnaire. It

is important for you to understand that there is not a “right” or a “wrong” answer to any of the questions. What is important to this research is that you give your own opinions and answer as truthfully as possible. The interview will take approximately 20 - 40 minutes but can be shortened or extended to suit the patient’s own pace in answering the questions.

7. **What do I have to do?** – After introducing herself to you, the researcher will ask you if you are feeling well enough to go ahead with the interview. If not, the study will be cancelled and you will be given the opportunity to arrange another appointment. If you do feel able to take part in the study, the researcher will explain that she will read out each question to you and that your answers will be recorded by her onto the questionnaire sheet. The researcher will hand you a copy of the questionnaire and you will be given time to read all the questions before the study begins. If there is anything on the questionnaire that you do not understand, the researcher will take time to explain it to you. As soon as you say you are ready to answer the first question, the researcher will start to read it out to you and the research study will begin. After each question is read to you, you are again free to ask for an explanation of anything you do not understand. The researcher will encourage you to give your own personal opinion when answering the questions as that is what will be of most help to the research study. She will also stress to you that no names are written on the questionnaire form so it is impossible to identify your name with your answers. When the study is completed, the researcher will thank you for taking part in the research and you will be able to keep your copy of the Questionnaire Sheet and your signed Consent Form.
8. **What is the drug or procedure that is being tested?** – There are no drugs involved in this study.
9. **What are the alternatives for diagnosis or treatment?** - This does not apply to this study.
10. **What are the side effects of taking part?** - This does not apply to this study.
11. **What are the possible disadvantages and risks of taking part?** – There are no physical disadvantages or risks in taking part in this study. There is the possible risk however that the patient may experience feelings of disappointment or guilt if unable to complete the study due to illness or tiredness.
12. **What are the possible benefits of taking part?** – A sense of achievement in being able to make a valuable contribution to research which may help improve the quality of life of future palliative care patients.
13. **What if new information becomes available?** – This does not apply as there are no medical treatments or drug applications involved in this research study.
14. **What happens when the research study stops?** – The information received in this study will be collected and analysed by the lead researcher. Results will be recorded and discussed in her Ph.D. thesis which is due to be completed in 2 years time. In the days following the research study, you will be free to discuss any opinions which may have arisen from the study with \*\*\*\*\* (hospice chaplain), Dr. \*\*\*\*\* (consultant in palliative medicine) or (Clare Caddell, lead researcher).

15. **What if something goes wrong?** – If you have any concerns about any aspect of the way you have been approached or treated during the course of this study, these concerns will be referred to the Centre chaplain (Mr. \*\*\*\*\*) to follow up. Any forthcoming complaints will be referred to the Centre Manager using the center’s Complaints Procedure.
16. **Will my taking part in this study be kept confidential?** – All information which is collected about you during the course of this research will be kept strictly confidential. Any information about you which leaves the hospice will have your name and address removed so that you cannot be recognised from it. Your own GP and doctors within this hospice will be notified of your decision to take part in this research.
17. **What will happen to the results of the research study?** – The results of the research study will be presented in a Ph.D. thesis, which will be kept in the “Special Collections” section of Glasgow University library. If, in the future, an article relating to this study is published in a Journal, no identifying names or places will be given.
18. **Who is organising and funding the research?** – This research is an academic one, the design of which has resulted from collaboration between staff in this hospice and the lead researcher (Glasgow University). The research is being funded by the lead researcher.
19. **Who has reviewed the study?** – This study has been reviewed by the Research Ethics Committee of Glasgow Royal Infirmary.
20. **Contact for Further Information.** – Further information can be attained from, -

Clare Caddell (Lead Researcher)  
D\*\*\*\* (Chaplain)  
Dr. S\*\*\*\*\* (Consultant in Palliative Medicine).

**Thank you for taking the time to read this Information Sheet. For those of you who choose to take part in the research study, thank you, and a copy of the Patient Information Sheet and signed Consent Form will be given to you to keep.**

Centre Number [ ]  
Study Number [ ]

Patient Identification Number for this trial [ ]

**CONSENT FORM**

**Title of Project:** "The Coping Strategies Of Hospice Patients During Illness".

Name of Researcher: Clare Caddell.

**Please initial box**

1. I confirm that I have read and understand the information sheet dated..... (version..... ) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from this academic research or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

**Appendix 1.3 - McGill Quality of Life Questionnaire (MQOL) Page 1 of 6**

Take a look at this list of physical symptoms, some of which may have been troubling you over the last 3 days.

PAIN:      TIREDFNESS:      WEAKNESS:      NAUSEA:      CONSTIPATION:  
 DIARRHOEA:      TROUBLE SLEEPING:      SHORTNESS OF BREATH:  
 LACK OF APPETITE:      SOME OTHER SYMPTOM (PLEASE STATE):

Which do you feel has been the most troublesome?

- A. My troublesome symptom today is: \_\_\_\_\_  
 Slight problem      1   2   3   4   5   6   7      tremendous problem
- B. My troublesome symptom yesterday was: \_\_\_\_\_  
 Slight problem      1   2   3   4   5   6   7      tremendous problem
- C. My troublesome symptom day before was: \_\_\_\_\_  
 Slight problem      1   2   3   4   5   6   7      tremendous problem

**How have you been feeling today / yesterday?**

1. Physically, I felt :  
 Terrible                      1   2   3   4   5   6   7                      Well
2. I was:  
 Not at all depressed      1   2   3   4   5   6   7                      Extremely depressed
3. I was  
 Not at all anxious or worried      1   2   3   4   5   6   7      Extremely anxious or worried

**The next group of questions concerns your feelings and thoughts**

4. How much of the time do you feel sad?  
 Never            1 2 3 4 5 6 7            Always
5. Rate the degree to which you are frightened of the future.  
 Not afraid            1 2 3 4 5 6 7            Constantly terrified
6. My personal existence is,  
 Utterly meaningless & without purpose.            1 2 3 4 5 6 7            Very purposeful & Meaningful
7. In achieving life goals I have,  
 Made no progress whatsoever            1 2 3 4 5 6 7            Progressed to complete fulfilment
8. My life to this point has been  
 Completely worthless            1 2 3 4 5 6 7            Very worthwhile
9. My life is,  
 Out of my hands & out of my control            1 2 3 4 5 6 7            In my hands & I am in control of it.
10. I feel close to people  
 Completely disagree            1 2 3 4 5 6 7            Completely agree
11. I feel good about myself as a person  
 Completely agree            1 2 3 4 5 6 7            Completely disagree
12. To me, every day seems to be a burden            1 2 3 4 5 6 7            A joy
13. The world is, an impersonal unfeeling place            1 2 3 4 5 6 7            Caring and responsive to my needs
14. Considering all the parts of my life – physical, emotional, social, spiritual & financial, my quality of life in the past two days was  
 Very bad            1 2 3 4 5 6 7            Excellent

The Questionnaire

Cohen et al (1995) highlighted the deficiencies of former measuring tools by producing the MQOL, which included the following components – psychological symptoms, meaningful existence (existential), outlook in life (support) as well as physical symptoms. The importance of measuring the existential domain was justified by the finding that in of all the MQOL sub-scales

and Spitzer items (Spitzer et al 1981) only the meaningful existence sub-scale correlated significantly with a single item scale rating overall quality of life. The MQOL is a single instrument, which provides a good measure of Quality of Life (QOL) at all stages of the disease trajectory. It consequently provides a means of enabling researchers to undertake longitudinal studies of quality of life from diagnosis to death (or cure). Of the 17 questions comprising the MQOL, 9 were selected based on quantitative results and qualitative impressions from a longitudinal study of 50 patients (unpublished data). In the preliminary study, a package of 3 established instruments were used. These were,

1. Functional Living Index – Cancer (FLIC).
2. Purpose in Life Test (PIL).
3. Edmonton Symptom Assessment (ESAS).

Together with questions devised by Cohen et al, these tests were administered and completed by patients with advanced cancer at two-week intervals for a period of 3 months and then once more 3 weeks later- or until the patient could no longer complete the questionnaires – whichever was shorter.

As a result, 9 questions were retained from this first study because they,

1. Represented conceptually relevant sub-scales (based on clinical experience, a literature review, and the qualitative information obtained).
2. Discriminated well among patients.
3. Were not redundant.

To complete the questionnaire, 3 questions were conceptually based on the Missoula-Vitas Quality of Life Index – Advanced Illness (Byock 1995) while 1 question was added from an earlier version of Byock, M. Pratt and B. Kinzbrunner, 1994 (personal communication). Another 3 questions concerned the perceived significance (rather than severity) of the patient's 3 most troublesome physical symptoms. Lastly a Single-Item Scale (MQOL-SIS) was incorporated in order to measure overall quality of life.

The Spitzer Quality of Life Index (QLI) was chosen by Cohen et al (1995) to assess convergent and divergent validity of the MQOL total and its sub-scales, mainly because it was much shorter than other well established instruments. It is a 5-item questionnaire measuring activities of daily

living, general health, outlook and support. Due to the physical condition of the patients, adding a much longer instrument to the MQOL would have resulted in a biased sample, as only the less severely ill palliative care patients would have been able to complete a long questionnaire. In addition, the Spitzer QLI “ Outlook” item measures a construct that is not assessed in most other quality of life questionnaires, but which is an important component of the MQOL.

Performance status was measured to determine its relationship to the MQOL and the MQOL SIS. The global performance status item from the Edmonton Functional Assessment Tool (EFAT-PS) was used because it was designed to assess performance status in the terminally ill, and was thought to be more sensitive to differences among this population than the more commonly used Karnofsky Performance Status Scale.

The MQOL data were screened for appropriateness for parametric statistics by examining for each question and each subscale, the mean, range, skewness, kurtosis, frequency distribution and box-whisker plot. Using the criterion of a significant Mahalanobis distance, multivariate outliers were detected using regression of all MQOL items plus the MQOL SIS on a dummy variable containing random numbers.

Principal components analysis with varimax orthogonal rotation was performed for the MQOL items. Eigenvalues, Cattell’s Scree Test and a criterion of the interpretability were used to select the appropriate number of components to be derived. Sub-scales for the MQOL were created by assigning each item to the component on which it loaded most highly. The degree of internal consistency of the items in each sub-scale was determined by calculating Cronbach’s alpha. Principal components analysis revealed four MQOL sub-scales. These were,

1. Physical symptoms.
2. Psychological symptoms.
3. Meaningful existence (Existential).
4. Outlook in Life (Support).

The 4 components had eigenvalues greater than 1.0. and the 4 factors accounted for 62% of the variance in the analysis. All 4 sub-scales showed acceptable internal consistency as measured by Cronbach’s alpha. The Physical Sub-scale had 4 items (alpha = 0.70). The Psychological Sub-scale had 3 items (alpha = 0.75). The Meaningful Existence sub-scale had 3 items (alpha = 0.80)



and the Support Sub-scale (Outlook in Life) had 5 items ( $\alpha = 0.77$ ) Moreover the McGill Quality of Life Questionnaire was found to be internally consistent ( $\alpha = 0.80$ ).

Each MQOL sub-scale had construct validity since each correlated with conceptually similar Spitzer items but not with dissimilar items. The Physical Symptoms Sub-scale correlated significantly with the Spitzer health item ( $p = 0.56, p = 0.0005$ ). The Outlook in Life sub-scale (Support) correlated significantly with the Spitzer outlook item ( $p = 0.76, p = 0.0001$ ). The Meaningful Existence sub-scale correlated significantly with the MQOL SIS and close to significantly with Spitzer's outlook item ( $p = 0.44, p = 0.007$ ) and the MQOL Outlook in Life sub-scale ( $p = 0.44, p = 0.02$ ). The psychological symptoms sub-scale did not correlate significantly with any of the other scales or items since none of the latter measured psychological problems.

The Meaningful Existence (Existential) Sub-scale comprises 3 questions concerning the respondent's sense of purpose and meaning in life. An example of a meaningful existence question is –

"In achieving life goals, I have made no progress whatsoever .....In achieving life goals, I have progressed to complete fulfilment".

The Outlook in Life Sub-scale (Support) comprises 5 questions concerning the respondent's self-esteem and emotions. An example of an outlook on life question is –

"I feel good about myself as a person – completely agree .....I feel good about myself – completely disagree.

The Psychological Sub-scale comprises 3 questions concerning the respondent's mood states. An example of a psychological symptom question is –

"I was not at all depressed .....I was extremely depressed (during the last 2 days).

The Physical Symptom Sub-scale comprises 4 questions concerning the respondent's physical health. An example of a physical symptom question is –

" A troublesome symptom (please choose from the list provided) is a slight problem ..... is a tremendous problem.

In order to assess the MQOL Single Item Scale (SIS), three separate runs of multiple regression were used to predict scores on the MQOL SIS from,

1. Each MQOL item entered as a separate variable.
2. The MQOL sub-scale scores.
3. The MQOL total score.

Further validation was obtained by examining the correlations between the MQOL total score, Spitzer total scores, sub-scales on the MQOL, Spitzer items and EFAT-PS. Cohen et al (1995) pointed out that validity is supported if conceptually related variables are significantly correlated (convergent validity) while variables not conceptually related do not show significant correlation (divergent validity). Since each item on the Spitzer QLI has three ordered response categories, this data was treated as ordinal and the correlations were evaluated using Spearman's rank correlation. A significance level of  $p < 0.005$  was used because of the relatively large numbers of correlations used. Examination of the mean, range of answers, skewness, kurtosis and frequency distribution within Cohen et al's original experiment, indicated that all of the MQOL questions were appropriate for parametric analysis.

The McGill Quality of Life Questionnaire (Cohen et al 1995) is a reliable and acceptable instrument for measuring quality of life in people with non-curable illnesses. It supports Cohen et al's hypothesis that addressing the existential domain improves the ability of observers to assess accurately the quality of life within this population. This is highlighted by the fact that the MQOL meaningful existence sub-scale was the only item among the MQOL and Spitzer sub-scales and total scores to correlate significantly with the patient's assessment of his or her quality of life as measured by the MQOL SIS. It also supports their other hypothesis that, as quality of life is subjective, it is best rated by patient's self-assessments. Answers for the MQOL questions were recorded on a Likert scale, so that a score of 1 indicated the least desirable, and 7 indicated the most desirable situation. Total scores for a respondent's quality of life answers could theoretically range from 17 to 119.

**Appendix 1.4 - Coping with Palliative Care Duties (CPCD) - Caddell (2002).Page 1 of 3**

**Please tick your appropriate age bracket:** - Are you, 30 years or under ( ) under 40 years ( ) 40 years or over ( ) 50 years or over ( ) 60 years or over ( )

**Please tick the appropriate box.** - Are you, **Male** ( ) or **Female** ( )

**Hospice Staff Questions.**

**Please tick your occupation or profession** - **Nurse** ( ) **Doctor** ( ) **Other occupation within hospice** ( ) **Volunteer within hospice** ( ) .

1. Do you consider yourself to be a spiritual person? Yes ( ) No ( ) .
2. Is spirituality important to you in your life? Yes ( ) No ( ) .
3. Is spirituality more important to you now that you are working with the terminally ill? Yes ( ) No ( ) Not sure ( ) Not appropriate ( ) .
4. Do you believe in a spiritual life after death? Yes ( ) No ( ) Not sure ( ) .
5. During your lifetime what has helped sustain you during times of crisis?  
.....
6. **(a).**Do you feel comfortable working with the hospice chaplain /spiritual director?  
Yes ( ) No ( ) Sometimes ( ) .  
  
**(b).**Do you feel comfortable working with visiting clergy?-Yes( )No( )Sometimes( ) .
7. **(a).**Would you feel comfortable discussing spirituality with those patients who wished you to do so? Yes ( ) No ( ) Unsure ( )  
  
**(b).**Would you feel comfortable discussing religious issues? Yes ( ) No ( )Unsure ( )
8. Would you feel comfortable if a patient asked you to pray with them?  
Yes ( ) No ( ) Unsure ( ) .

9. (a) Do you consider spiritual issues worthy of inclusion within the category of “coping strategies in terminal illness”? Yes ( ) No ( ) Unsure ( ).

(b) Do you consider religious issues worthy of inclusion within the category of “coping strategies in terminal illness”? Yes ( ) No ( ) Unsure ( )

10. Do you ever get depressed due to the duties connected to your occupation? Yes ( ) No ( ) Occasionally ( ).

11. If you do get depressed, what helps you cope each day?  
.....

12. What do you think gives meaning to life? .....

13. Do you feel that you can cope with your job/profession? Yes ( ) No ( ) Unsure ( ).

14. Have you developed coping strategies to help you in your work? Yes ( ) No ( )  
Not appropriate ( ).

15. If you do employ coping strategies please state what they are.  
.....

16. How would you describe your quality of life in the past two days? Good ( ) Fair ( )  
Poor ( ).

17. Have you ever been a member of a church / Faith Group? Yes ( ) No ( )

If yes, which denomination / faith ? .....

18. Are you still a church / Faith Group member? Yes ( ) No ( )

If yes, which one is it? .....

19. How often would you normally worship? Please tick only **one** of the following.

Daily [ ]                      Weekly [ ]                      Monthly [ ]                      Never [ ]

20. How often do you pray? Please tick only **one** of the following boxes. –

Daily [ ]                      Weekly [ ]                      Monthly [ ]                      Never [ ]

**21. TO BE ANSWERED BY MEDICAL PRACTITIONERS ONLY:**

A. Do you assess your patient's anxiety or stress levels? Yes ( ) No ( ).  
If you do, please state which measures you apply.....

.....

B. Do you assess your patient's levels of coping with their illness? Yes ( ) No ( ).  
If you do, please state which measures you apply.....

.....

C. In your experience, is it the male patient or the female patient who most often appears to have better levels of coping abilities / strategies during times of serious illness? – males ( ) females ( ) about the same ( ) can't answer ( ).

D. Do you inform your patients that they are close to death? Always ( ) Only if they themselves ask ( ) Sometimes if considered appropriate ( ) Never ( )

**22. TO BE ANSWERED BY THE HOSPITAL CHAPLAIN / SPIRITUAL DIRECTOR**

Could you please write a few words outlining the benefits to the patients of including spiritual well-being and aspects of pastoral care within palliative medicine.

.....

.....

.....

**THANK YOU VERY MUCH FOR COMPLETING THIS STAFF QUESTIONNAIRE**



## Between-Subjects Factors

		Value Label	
VAR03 Religious Status	1.00	Believing and practising church member	38
	2.00	Believer but non-practising church member	35
	3.00	Non-believing/ non-practising	47
VAR34 Hospice	1.00	Hospice A	60
	2.00	Hospice B	60

## Descriptive Statistics

Dependent Variable: VAR06 Physical Sub-Scale

VAR03 Religious Status	VAR34 Hospice	Mean	Std. Deviation	N
1.00 Believing and practising church member	1.00 Hospice A	1.6667	.9701	18
	2.00 Hospice B	2.9000	.4472	20
	Total	2.3158	.9691	38
2.00 Believing but non- practising church member	1.00 Hospice A	1.7500	1.0000	16
	2.00 Hospice B	2.6842	.7493	19
	Total	2.2571	.9805	35
3.00 Non-believing / non-practising	1.00 Hospice A	1.9231	1.0168	26
	2.00 Hospice B	1.9524	1.0235	21
	Total	1.9362	1.0087	47
Total	1.00 Hospice A	1.8000	.9881	60
	2.00 Hospice B	2.5000	.8733	60
	Total	2.1500	.9928	120

## Levene's Test of Equality of Error Variances

Dependent Variable: VAR06 Physical Sub-Scale

F	df1	df2	Sig.
23.172	5	114	.000

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR03+VAR34+VAR03\*VAR34

### Tests of Between-Subjects Effects

Dependent Variable: VAR06 Physical Sub-Scale

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Eta Squared
Corrected Model	25.596 <sup>b</sup>	5	5.119	6.364	.000	.218
Intercept	540.474	1	540.474	671.881	.000	.855
VAR03	2.872	2	1.436	1.785	.172	.030
VAR34	15.732	1	15.732	19.557	.000	.146
VAR03 * VAR34	8.380	2	4.190	5.209	.007	.084
Error	91.704	114	.804			
Total	672.000	120				
Corrected Total	117.300	119				

### Tests of Between-Subjects Effects

Dependent Variable: VAR06 Physical Sub-Scale

Source	Noncent. Parameter	Observed Power <sup>a</sup>
Corrected Model	31.819	.996
Intercept	671.881	1.000
VAR03	3.571	.367
VAR34	19.557	.992
VAR03 * VAR34	10.418	.821
Error		
Total		
Corrected Total		

a. Computed using alpha = .05

b. R Squared = .218 (Adjusted R Squared = .184)

## Estimated Marginal Means

### 1. Religious Status

Dependent Variable: VAR06 Physical Sub-Scale

Religious Status	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Believing and practising church member	2.283	.146	1.995	2.572
2.00 Believer but non-practising church member	2.217	.152	1.916	2.519
3.00 Non-believing / non-practising church member	1.938	.132	1.677	2.198

### 2. Hospice

Dependent Variable: VAR06 Physical Sub-Scale

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	1.780	.118	1.546	2.014
2.00 Hospice B	2.512	.116	2.283	2.742



### 3. Religious \* Hospice

Dependent Variable: VAR 06 Physical Sub-Scale

Religious Status	Hospice	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
1.00 Believing and practising church member	1.00 Hospice A	1.6667	.211	1.248	2.085
	2.00 Hospice B	2.9000	.201	2.503	3.297
2.00 Believing but non-practising church member	1.00 Hospice A	1.7500	.224	1.306	2.194
	2.00 Hospice B	2.6842	.206	2.277	3.092
3.00 Non-believing / non-practising	1.00 Hospice A	1.9231	.176	1.575	2.272
	2.00 Hospice B	1.9254	.196	1.565	2.340

#### Post Hoc Tests

#### Religious Status

#### Multiple Comparisons

Dependent Variable: VAR 06 Physical Sub-Scale  
Tukey HSD

Religious Status	Religious Status	Mean	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1.00 Believing and practising church member	2.00 Believing but non-practising church member	5.865E-02	.2101	.958	-.4403	.5576
	3.00 Non-believing / non-practising patient	.3796	.1957	.132	-8.5028E-02	.8443
2.00 Believing but non-practising church member	1.00 Believing and practising church member	-5.8647E02	.2101	.958	-.5576	.4403
	3.00 Non-believing / non-practising patient	.3210	.2002	.249	-.1546	.7965
3.00 Non-believing / non-practising patient	1.00 Believing and practising church member	-.3796	.1957	.132	-.8443	8.503E-02
	2.00 Believing but non-practising patient	-.3210	.2002	.2002	-.7965	.1546

Based on observer means

#### Homogeneous Subsets

**VAR06 Physical Status Sub Scale**

Tukey HSD <sup>a,b,c</sup>

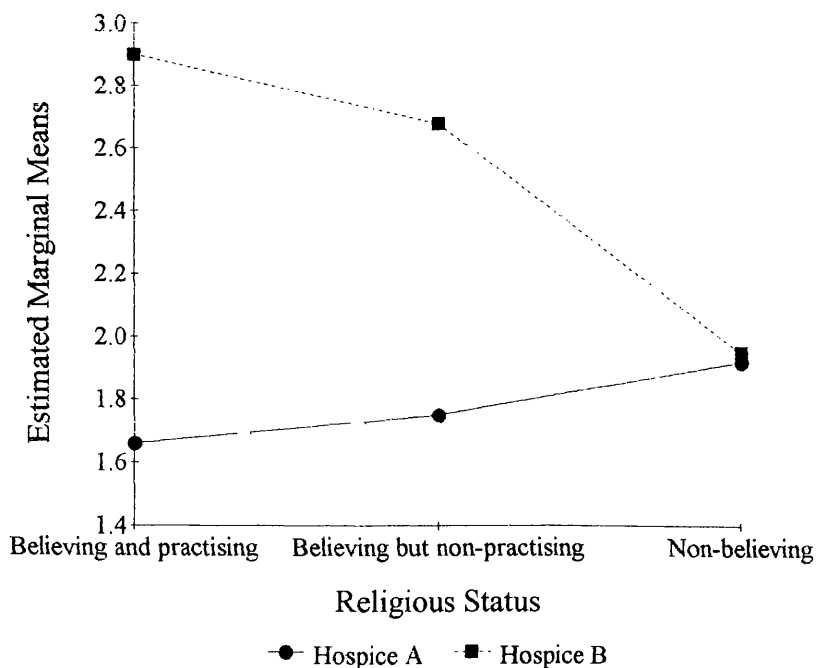
Religious Status	N	Subset
		1
1.00 Believer and practising church member	38	2.3158
2.00 Believing but non-practising church member	35	2.2571
3.00 Non-believing	47	1.9362

Means for groups in homogeneous subsets are displayed.  
Based on Type III Sum of Squares  
The error term is Mean Square (Error) = .804

- a. Uses Harmonic Mean Sample Size = 39.389
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.
- c. Alpha = .05

**Profile Plots**

Estimated Marginal Means of Physical Status Sub Scale



ANOVA

Physical Sub-Scale

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	25.596	5	5.119	6.364	.000
Within Groups	91.704	114	.804		
Total	117.300	119			

Post Hoc Tests

Multiple Comparisons

Dependent Variable: Physical Sub-Scale

dukey\_HSD

(I) CELLCODE	(J) CELLCODE	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1.00	2.00	-1.2333*	.2914	.001	-2.0780	-.3886
	3.00	-8.3333E-02	.3082	1.000	-.9766	.8100
	4.00	-1.0175*	.2950	.010	-1.8727	-.1624
	5.00	-.2564	.2750	.937	-1.0536	.5408
	6.00	-.2857	.2881	.920	-1.1208	.5494
2.00	1.00	1.2333*	.2914	.001	.3886	2.0780
	3.00	1.1500*	.3008	.003	.2780	2.0220
	4.00	.2158	.2873	.975	-.6171	1.0487
	5.00	.9769*	.2668	.005	.2036	1.7502
	6.00	.9476*	.2802	.012	.1353	1.7599
3.00	1.00	8.3333E-02	.3082	1.000	-.8100	.9766
	2.00	-1.1500*	.3008	.003	-2.0220	-.2780
	4.00	-.9342*	.3043	.031	-1.8164	-5.2038E-02
	5.00	-.1731	.2850	.990	-.9992	.6530
	6.00	-.2024	.2976	.984	-1.0651	.6604
4.00	1.00	1.0175*	.2950	.010	.1624	1.8727
	2.00	-.2158	.2873	.975	-1.0487	.6171
	3.00	.9342*	.3043	.031	5.204E-02	1.8164
	5.00	.7611	.2707	.063	-2.3558E-02	1.5458
	6.00	.7318	.2840	.111	-9.1360E-02	1.5550
5.00	1.00	.2564	.2750	.937	-.5408	1.0536
	2.00	-.9769*	.2668	.005	-1.7502	-.2036
	3.00	.1731	.2850	.990	-.6530	.9992
	4.00	-.7611	.2707	.063	-1.5458	2.356E-02
	6.00	-2.9304E-02	.2631	1.000	-.7921	.7335
6.00	1.00	.2857	.2881	.920	-.5494	1.1208
	2.00	-.9476*	.2802	.012	-1.7599	-.1353
	3.00	.2024	.2976	.984	-.6604	1.0651
	4.00	-.7318	.2840	.111	-1.5550	9.136E-02
	5.00	2.930E-02	.2631	1.000	-.7335	.7921

\*. The mean difference is significant at the .05 level.

Homogeneous Subsets

### Physical Sub-Scale

Tukey HSD<sup>a,b</sup>

CELLCODE	N	Subset for alpha = .05		
		1	2	3
1.00	18	1.6667		
3.00	16	1.7500		
5.00	26	1.9231	1.9231	
6.00	21	1.9524	1.9524	
4.00	19		2.6842	2.6842
2.00	20			2.9000
Sig.		.918	.093	.975

Means for groups in homogeneous subsets are displayed.

- a. Uses Harmonic Mean Sample Size = 19.559.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

## Between-Subjects Factors

		Value Label	
VAR03	1.00	Believing and practising church member	38
Religious Status	2.00	Believer but non-practising church member	35
	3.00	Non-believing/non-practising	47
VAR34	1.00	Hospice A	60
Hospice	2.00	Hospice B	60

## Descriptive Statistics

Dependent Variable: VAR07 Psychological Sub-Scale

VAR03 Religious Status	VAR34 Hospice	Mean	Std. Deviation	N
1.00 Believing and practising church member	1.00 Hospice A	2.3333	.7670	18
	2.00 Hospice B	1.9500	.8870	20
	Total	2.1316	.8438	38
2.00 Believing but non-practising church member	1.00 Hospice A	2.6875	.6021	16
	2.00 Hospice B	2.5263	.7723	19
	Total	2.6000	.6945	35
3.00 Non-believing / non-practising.	1.00 Hospice A	2.1538	.8339	26
	2.00 Hospice B	2.0476	.8646	21
	Total	2.1064	.8401	47
Total	1.00 Hospice A	2.3500	.7773	60
	2.00 Hospice B	2.1667	.8668	60
	Total	2.2583	.8250	120

## Levene's Test of Equality of Error Variances

Dependent Variable: VAR07 Psychological Sub-Scale

F	df1	df2	Sig.
1.186	5	114	.321

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR03+VAR34+VAR03\*VAR34

### Tests of Between-Subjects Effects

Dependent Variable: Psychological Sub-Scale

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Eta Squared
Corrected Model	7.530 <sup>b</sup>	5	1.506	2.337	.046	.093
Intercept	611.707	1	611.707	949.270	.000	.893
VAR03	5.890	2	2.945	4.570	.012	.074
VAR34	1.380	1	1.380	2.142	.146	.018
VAR03 * VAR34	.430	2	.215	.334	.717	.006
Error	73.461	114	.644			
Total	693.000	120				
Corrected Total	80.992	119				

### Tests of Between-Subjects Effects

Dependent Variable: Psychological Sub-Scale

Source	Noncent. Parameter	Observed Power <sup>a</sup>
Corrected Model	11.686	.732
Intercept	949.270	1.000
VAR03	9.141	.766
VAR34	2.142	.306
VAR03 * VAR34	.668	.102
Error		
Total		
Corrected Total		

a. Computed using alpha = .05

b. R Squared = .093 (Adjusted R Squared = .053)

## Estimated Marginal Means

### 1. Religious Status

Dependent Variable: Psychological Sub-Scale

Religious Status	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
Believing and practising church member	2.142	.130	1.883	2.400
Believer but non-practising church member	2.607	.136	2.337	2.877
Non-believing / non-practising church member	2.101	.118	1.867	2.334

### 2. Hospice

Dependent Variable: Psychological Sub-Scale

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	2.392	.106	2.182	2.601
2.00 Hospice B	2.175	.104	1.969	2.380

### 3. Religious \* Hospice

Dependent Variable: VAR07 Psychological Sub-Scale

Religious Status	Hospice	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
1.00 Believing and practising church member	1.00 Hospice A	2.3333	.189	1.959	2.708
	2.00 Hospice B	1.9500	.179	1.594	2.306
2.00 Believing but non- practising church member	1.00 Hospice A	2.6875	.201	2.290	3.085
	2.00 Hospice B	2.5263	.184	2.161	2.891
3.00 Non-believing / non-practising .	1.00 Hospice A	2.1538	.157	1.842	2.466
	2.00 Hospice B	2.0476	.175	1.701	2.395

#### Post Hoc Tests

#### Religious Status

#### Multiple Comparisons

Dependent Variable: VAR07 Psychological Sub-Scale  
Tukey HSD

(I) Religious Status	(J) Religious Status	Mean Difference (I-J)	Std. Error	Sig.
1.00 Believing and practising church member	2.00 Believing but non- practising church member	-.4684*	.1881	.037
	3.00 Non-believing / non-practising patient	2.520E-02	.1751	.989
2.00 Believing but non- practising church member	1.00 Believing and practising church member	-.4684*	.1881	.037
	3.00 Non-believing / non-practising patient	.4936*	.1792	.019
3.00 Non-believing / non-practising patient	1.00 Believing and practising church member	2.5196E-02	.1751	.989
	2.00 Believing but non- practising patient	-.4936	.1792	.019

Based on observer means

#### Homogeneous Subsets

### Multiple Comparisons

Dependent Variable: Psychological Sub-Scale

Tukey HSD

(I) Religious Status	(J) Religious Status	95% Confidence Interval	
		Lower Bound	Upper Bound
Believing and practising church member	Believer but non-practising church member	-.9150	-2.1814E-02
	Non-believing / non-practising church member	-.3907	.4411
Believer but non-practising church member	Believing and practising church member	2.181E-02	.9150
	Non-believing / non-practising church member	6.800E-02	.9192
Non-believing / non-practising church member	Believing and practising church member	-.4411	.3907
	Believer but non-practising church member	-.9192	-6.8005E-02

Based on observed means.

\*. The mean difference is significant at the .05 level.

### Homogeneous Subsets

Psychological Sub-Scale

Tukey HSD<sup>a,b,c</sup>

Religious Status	N	Subset	
		1	2
Non-believing / non-practising church member	47	2.1064	
Believing and practising church member	38	2.1316	
Believer but non-practising church member	35		2.6000
Sig.		.989	1.000

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = .644.

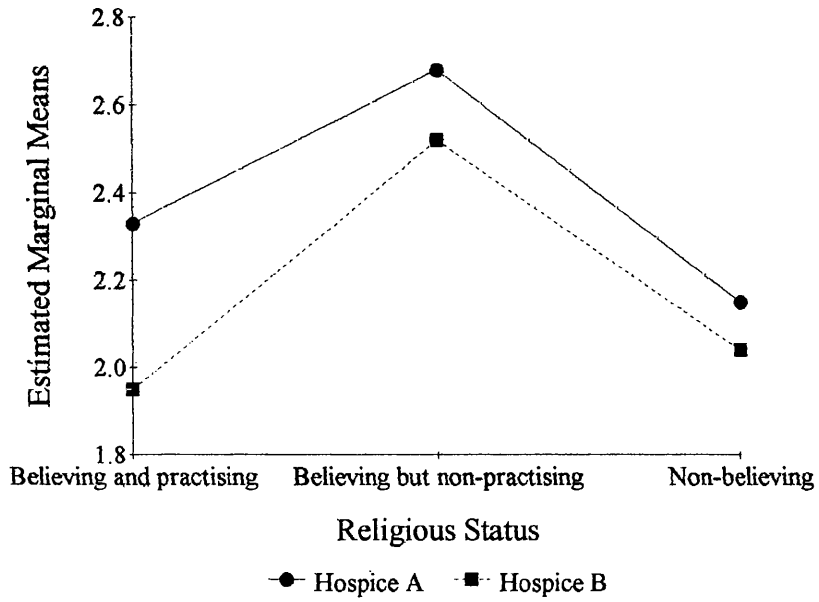
- Uses Harmonic Mean Sample Size = 39.389.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- Alpha = .05.

### Profile Plots



## Profile Plots

Estimated Marginal Means of Psychological Sub-Scale



**Appendices 2.3: - Univariate Analysis of Variance: (MQOL: Patient Research) Pages 1 of 6**
**Between-Subjects Factors**

		Value Label	
VAR03	1.00	Believing and-practising church member	38
Religious Status	2.00	Believer but non-practising church member	35
	3.00	Non-believing/non-practising	47
VAR34	1.00	Hospice A	60
Hospice	2.00	Hospice B	60

**Descriptive Statistics**

Dependent Variable: VAR08 Meaningful Existence Sub-Scale

VAR03 Religious Status	VAR34 Hospice	Mean	Std. Deviation	N
1.00 Believing and practising church member	1.00 Hospice A	2.1667	.7071	18
	2.00 Hospice B	2.7500	.4443	20
	Total	2.4737	.6467	38
2.00 Believing but non-practising church member	1.00 Hospice A	2.0000	.7303	16
	2.00 Hospice B	2.3158	.8201	19
	Total	2.1714	.7854	35
3.00 Non-believing / non-practising	1.00 Hospice A	2.3077	.6177	26
	2.00 Hospice B	1.6190	.5896	21
	Total	2.0000	.6916	47
Total	1.00 Hospice A	2.1833	.6763	60
	2.00 Hospice B	2.2167	.7831	60
	Total	2.2000	.7288	120

**Levene's Test of Equality of Error Variances**

Dependent Variable: VAR08 Meaningful Existence Sub-Scale

F	df1	df2	Sig.
2.037	5	114	.079

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR03+VAR34+VAR03\*VAR34

**Tests of Between-Subjects Effects**

Dependent Variable: Meaningful Existence Sub-Scale

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Eta Squared
Corrected Model	14.354 <sup>b</sup>	5	2.871	6.700	.000	.227
Intercept	564.481	1	564.481	1317.419	.000	.920
VAR03	5.133	2	2.566	5.989	.003	.095
VAR34	.144	1	.144	.337	.563	.003
VAR03 * VAR34	9.597	2	4.798	11.199	.000	.164
Error	48.846	114	.428			
Total	644.000	120				
Corrected Total	63.200	119				

**Tests of Between-Subjects Effects**

Dependent Variable: Meaningful Existence Sub-Scale

Source	Noncent. Parameter	Observed Power <sup>a</sup>
Corrected Model	33.500	.997
Intercept	1317.419	1.000
VAR03	11.979	.874
VAR34	.337	.089
VAR03 * VAR34	22.397	.991
Error		
Total		
Corrected Total		

a. Computed using alpha = .05

b. R Squared = .227 (Adjusted R Squared = .193)

**Estimated Marginal Means**

**1. Religious Status**

Dependent Variable: Meaningful Existence Sub-Scale

Religious Status	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
Believing and practising church member	2.458	.106	2.248	2.669
Believer but non-practising church member	2.158	.111	1.938	2.378
Non-believing / non-practising	1.963	.096	1.773	2.154

**2. Hospice**

Dependent Variable: Meaningful Existence Sub-Scale

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	2.158	.086	1.987	2.329
2.00 Hospice B	2.228	.085	2.061	2.396

### 3. Religious \* Hospice

Dependent Variable: VAR08 Meaningful Existence Sub-Scale

Religious Status	Hospice	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
1.00 Believing and practising church member	1.00 Hospice A	2.1667	.154	1.861	2.472
	2.00 Hospice B	2.7500	.146	2.460	3.040
2.00 Believing but non-practising church member	1.00 Hospice A	2.0000	.164	1.676	2.324
	2.00 Hospice B	2.358	.150	2.018	2.613
3.00 Non-believing / non-practising	1.00 Hospice A	2.3077	.128	2.053	2.562
	2.00 Hospice B	1.6190	.143	1.336	1.902

#### Post Hoc Tests

#### Religious Status

#### Multiple Comparisons

Dependent Variable: VAR08 Meaningful Existence Sub-Scale  
Tukey HSD

(I) Religious Status	(J) Religious Status	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1.00 Believing and practising church member	2.00 Believing but non-practising church member	.3023	.1534	.124	-.2844	.7581
	3.00 Non-believing / non-practising patient	.4737*	.1428	.003	-.1209	.8499
2.00 Believing but non-practising church member	1.00 Believing and practising church member	-.3023	.1534	.124	-.7581	.2844
	3.00 Non-believing / non-practising patient	.1714	.1461	.472	-.3691	.6244
3.00 Non-believing / non-practising patient	1.00 Believing and practising church member	-.4737*	.1428	.003	-.8499	.1209
	2.00 Believing but non-practising patient	-.1714	.1461	.472	-.6244	.3691

Based on observer means

#### Homogeneous Subsets

**VAR08 Meaningful Existence Sub-Scales**

Tukey HSD <sup>a,b,c</sup>

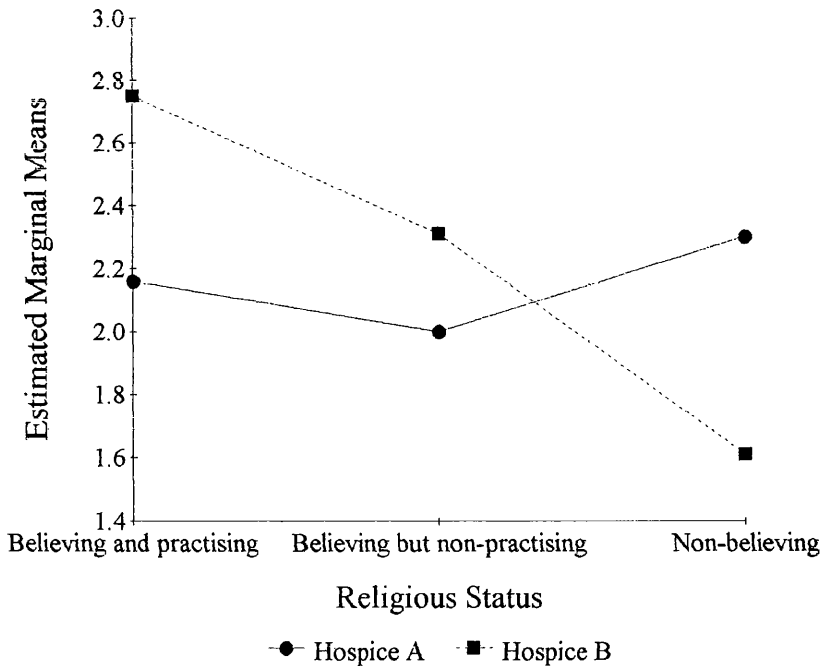
Religious Status	N	Subset 1
1.00 Believer and practising church member	38	2.4737
2.00 Believing but non-practising church member	35	2.1714
3.00 Non-believing	47	2.0000

Means for groups in homogeneous subsets are displayed.  
Based on Type III Sum of Squares  
The error term is Mean Square (Error) = .804

- a. Uses Harmonic Mean Sample Size = 39.389
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.
- c. Alpha = .05

**Profile Plots**

Estimated Marginal Means of Meaningful Existence



# Oneway |

## ANOVA

Meaningful Existence Sub-Scale

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	14.354	5	2.871	6.700	.000
Within Groups	48.846	114	.428		
Total	63.200	119			

## Post Hoc Tests

### Multiple Comparisons

Dependent Variable: Meaningful Existence Sub-Scale

Tukey HSD

(I) CELLCODE	(J) CELLCODE	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1.00	2.00	-.5833	.2127	.075	-1.1998	3.315E-02
	3.00	.1667	.2249	.976	-.4853	.8186
	4.00	-.1491	.2153	.982	-.7732	.4750
	5.00	-.1410	.2007	.981	-.7228	.4408
	6.00	.5476	.2103	.105	-6.1867E-02	1.1571
2.00	1.00	.5833	.2127	.075	-3.3145E-02	1.1998
	3.00	.7500*	.2196	.011	.1136	1.3864
	4.00	.4342	.2097	.310	-.1737	1.0421
	5.00	.4423	.1947	.214	-.1221	1.0067
	6.00	1.1310*	.2045	.000	.5381	1.7238
3.00	1.00	-.1667	.2249	.976	-.8186	.4853
	2.00	-.7500*	.2196	.011	-1.3864	-.1136
	4.00	-.3158	.2221	.714	-.9596	.3280
	5.00	-.3077	.2080	.678	-.9106	.2952
	6.00	.3810	.2172	.500	-.2487	1.0106
4.00	1.00	.1491	.2153	.982	-.4750	.7732
	2.00	-.4342	.2097	.310	-1.0421	.1737
	3.00	.3158	.2221	.714	-.3280	.9596
	5.00	8.097E-03	.1976	1.000	-.5646	.5808
	6.00	.6967*	.2073	.013	9.595E-02	1.2975
5.00	1.00	.1410	.2007	.981	-.4408	.7228
	2.00	-.4423	.1947	.214	-1.0067	.1221
	3.00	.3077	.2080	.678	-.2952	.9106
	4.00	-8.0972E-03	.1976	1.000	-.5808	.5646
	6.00	.6886*	.1921	.006	.1319	1.2454
6.00	1.00	-.5476	.2103	.105	-1.1571	6.187E-02
	2.00	-1.1310*	.2045	.000	-1.7238	-.5381
	3.00	-.3810	.2172	.500	-1.0106	.2487
	4.00	-.6967*	.2073	.013	-1.2975	-9.5954E-02
	5.00	-.6886*	.1921	.006	-1.2454	-.1319

\*. The mean difference is significant at the .05 level.

## Homogeneous Subsets

**Meaningful Existence Sub-Scale**

D<sup>a,b</sup>

DDE	N	Subset for alpha = .05		
		1	2	3
	21	1.6190		
	16	2.0000	2.0000	
	18	2.1667	2.1667	2.1667
	26		2.3077	2.3077
	19		2.3158	2.3158
	20			2.7500
		.102	.659	.067

r groups in homogeneous subsets are displayed.

s Harmonic Mean Sample Size = 19.559.

group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

## Appendix 2.4 - Univariate Analysis of Variance: (MQOL: Patient Research) Page 1 of 4

### Between-Subjects Factors

		Value Label	
VAR03	1.00	Believing and practising church member	38
	2.00	Believer but non-practising church member	35
	3.00	Non-believing/non-practising	47
VAR34	1.00	Hospice A	60
Hospice	2.00	Hospice B	60

### Descriptive Statistics

Dependent Variable: VAR 09 Outlook in Life / Support Sub-Scale

VAR03 Religious Status	VAR34 Hospice	Mean	Std. Deviation	N
1.00 Believing and practising church member	1.00 Hospice A	2.6111	.5016	18
	2.00 Hospice B	2.9500	.2236	20
	Total	2.7895	.4132	38
2.00 Believing but non-practising church member	1.00 Hospice A	2.6250	.6191	16
	2.00 Hospice B	2.6316	.5973	19
	Total	2.6286	.5983	35
3.00 Non-believing / non-practising	1.00 Hospice A	2.0385	.7200	26
	2.00 Hospice B	2.2857	.5606	21
	Total	2.1489	.6587	47
Total	1.00 Hospice A	2.3667	.6881	60
	2.00 Hospice B	2.6167	.5552	60
	Total	2.4917	.6351	120

a

### Levene's Test of Equality of Error Variances

Dependent Variable: VAR 09 Meaningful Existence Sub-Scale

F	df1	df2	Sig.
5.409	5	114	.000

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR03+VAR34+VAR03\*VAR34



**Tests of Between-Subjects Effects**

Dependent Variable: VAR09 Outlook on Life Sub-Scale

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Eta Squared
Corrected Model	11.346 <sup>b</sup>	5	2.269	7.059	.000	.236
Intercept	747.393	1	747.393	2325.019	.000	.953
VAR03	8.857	2	4.429	13.777	.000	.195
VAR34	1.145	1	1.145	3.563	.062	.030
VAR03 * VAR34	.532	2	.266	.828	.439	.014
Error	36.646	114	.321			
Total	793.000	120				
Corrected Total	47.992	119				

**Tests of Between-Subjects Effects**

Dependent Variable: VAR09 Outlook on Life Sub-Scale

Source	Noncent. Parameter	Observed Power <sup>a</sup>
Corrected Model	35.294	.998
Intercept	2325.019	1.000
VAR03	27.554	.998
VAR34	3.563	.465
VAR03 * VAR34	1.656	.189
Error		
Total		
Corrected Total		

a. Computed using alpha = .05

b. R Squared = .236 (Adjusted R Squared = .203)

**Estimated Marginal Means**

**1. Religious Status**

Dependent Variable: VAR09 Outlook on Life Sub-Scale

Religious Status	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Believing and practising church member	2.781	.092	2.598	2.963
2.00 Believer but non-practising church member	2.628	.096	2.438	2.819
3.00 Non-believing / non-practising	2.162	.083	1.997	2.327

**2. Hospice**

Dependent Variable: VAR09 Outlook on Life Sub-Scale

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	2.425	.075	2.277	2.573
2.00 Hospice B	2.622	.073	2.477	2.768

### 3. Religious \* Hospice

Dependent Variable: VAR08 Meaningful Existence Sub-Scale

Religious Status	Hospice	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
1.00 Believing and practising church member	1.00 Hospice A	2.1667	.154	1.861	2.472
	2.00 Hospice B	2.7500	.146	2.460	3.040
2.00 Believing but non-practising church member	1.00 Hospice A	2.0000	.164	1.676	2.324
	2.00 Hospice B	2.358	.150	2.018	2.613
3.00 Non-believing / non-practising	1.00 Hospice A	2.3077	.128	2.053	2.562
	2.00 Hospice B	1.6190	.143	1.336	1.902

### Post Hoc Tests

#### Religious Status

#### Multiple Comparisons

Dependent Variable: VAR08 Meaningful Existence Sub-Scale  
Tukey HSD

(I) Religious Status	(J) Religious Status	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1.00 Believing and practising church member	2.00 Believing but non-practising church member	.3023	.1534	.124	-.2844	.7581
	3.00 Non-believing / non-practising patient	.4737*	.1428	.003	-.1209	.8499
2.00 Believing but non-practising church member	1.00 Believing and practising church member	-.3023	.1534	.124	-.7581	.2844
	3.00 Non-believing / non-practising patient	.1714	.1461	.472	-.3691	.6244
3.00 Non-believing / non-practising patient	1.00 Believing and practising church member	-.4737*	.1428	.003	-.8499	.1209
	2.00 Believing but non-practising patient	-.1714	.1461	.472	-.6244	.3691

Based on observer means

### Homogeneous Subsets

**VAR09 Support/Outlook on Life**

Tukey HSD <sup>a,b,c</sup>

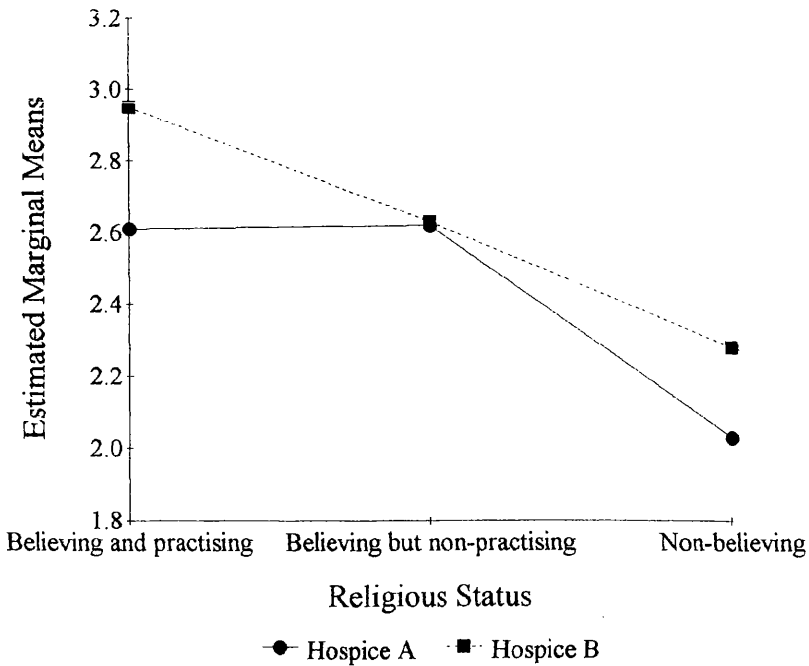
Religious Status	N	Subset	
		1	2
1.00 Believer and practising church member	38		2.7895
2.00 Believing but non-practising church member	35		2.6286
3.00 Non-believing	47	2.1489	
Sig.		1.000	.421

Means for groups in homogeneous subsets are displayed.  
 Based on Type III Sum of Squares  
 The error term is Mean Square (Error) = .321.

- a. Uses Harmonic Mean Sample Size = 39.389
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.
- c. Alpha = .05

**Profile Plots**

Estimated Marginal Means of Support/Outlook on Life



## Appendix 2.5 - Univariate Analysis of Variance (MQOL Patient Research) Pages 1 of 4

### Between-Subjects Factors

		Value Label	
VAR03	1.00	Believing and practising church member	38
Religious Status	2.00	Believer but non-practising church member	35
	3.00	Non-believing/non-practising	47
VAR34	1.00	Hospice A	60
Hospice	2.00	Hospice B	60

### Descriptive Statistics

Dependent Variable: VAR 10 Total Scores Sub-Scale

VAR03 Religious Status	VAR34 Hospice	Mean	Std. Deviation	N
1.00 Believing and practising church member	1.00 Hospice A	2.3333	.4851	18
	2.00 Hospice B	2.7500	.4443	20
	Total	2.5526	.5039	38
2.00 Believing but non-practising church member	1.00 Hospice A	2.1250	.5000	16
	2.00 Hospice B	2.3158	.4776	19
	Total	2.2286	.4902	35
3.00 Non-believing / non-practising.	1.00 Hospice A	2.0769	.5602	26
	2.00 Hospice B	2.1429	.4781	21
	Total	2.1064	.5206	47
Total	1.00 Hospice A	2.1667	.5262	60
	2.00 Hospice B	2.4000	.5276	60
	Total	2.2833	.5374	120

a

### Levene's Test of Equality of Error Variances

Dependent Variable: VAR 10 Total Scores Sub-Scale

F	df1	df2	Sig.
.511	5	114	.767

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR03+VAR34+VAR03\*VAR34

**Tests of Between-Subjects Effects**

Dependent Variable: VAR10 Total Scores

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Eta Squared
Corrected Model	6.344 <sup>b</sup>	5	1.269	5.161	.000	.185
Intercept	615.759	1	615.759	2504.973	.000	.956
VAR03	4.063	2	2.031	8.264	.000	.127
VAR34	1.478	1	1.478	6.013	.016	.050
VAR03 * VAR34	.648	2	.324	1.319	.271	.023
Error	28.023	114	.246			
Total	660.000	120				
Corrected Total	34.367	119				

**Tests of Between-Subjects Effects**

Dependent Variable: VAR10 Total Scores

Source	Noncent. Parameter	Observed Power <sup>a</sup>
Corrected Model	25.807	.983
Intercept	2504.973	1.000
VAR03	16.528	.958
VAR34	6.013	.681
VAR03 * VAR34	2.638	.280
Error		
Total		
Corrected Total		

a. Computed using alpha = .05

b. R Squared = .185 (Adjusted R Squared = .149)

**Post Hoc Tests**

**Religious Status**

### Multiple Comparisons

Dependent Variable: VAR10 Total Scores Sub-Scale

Tukey HSD

(I) Religious Status	(J) Religious Status	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
1.00 Believing and practising church member	2.00 Believing but non- practising church member	.3241*	.1162	.017	4.822E-02	.4763
	3.00 Non-believing / non-practising patient	.4462*	.1082	.000	.1894	.9343
2.00 Believing but non- practising church member	1.00 Believing and practising church member	-.3241*	.1162	.017	-.5999	.1545
	3.00 Non-believing / non-practising patient	.1222	.1107	.514	.1407	.7802
3.00 Non-believing / non-practising patient	1.00 Believing and practising church member	-.4462*	.1082	.000	-.7031	-.3468
	2.00 Believing but non- practising patient	-.1222	.1107	.514	-.3851	-.1790

Based on observer means

### Homogeneous Subsets

VAR 10 Total Scores

a,b,c

Tukey HSD

Religious Status	N	Subset	
		1	2
1.00 Believer and practising church member	38		2.5526
2.00 Believer but non-practising church member	35	2.2286	
3.00 Non-believing / non-practiser	47	2.1064	
Sig.		.520	1.000

Means for groups in homogeneous subsets are displayed.

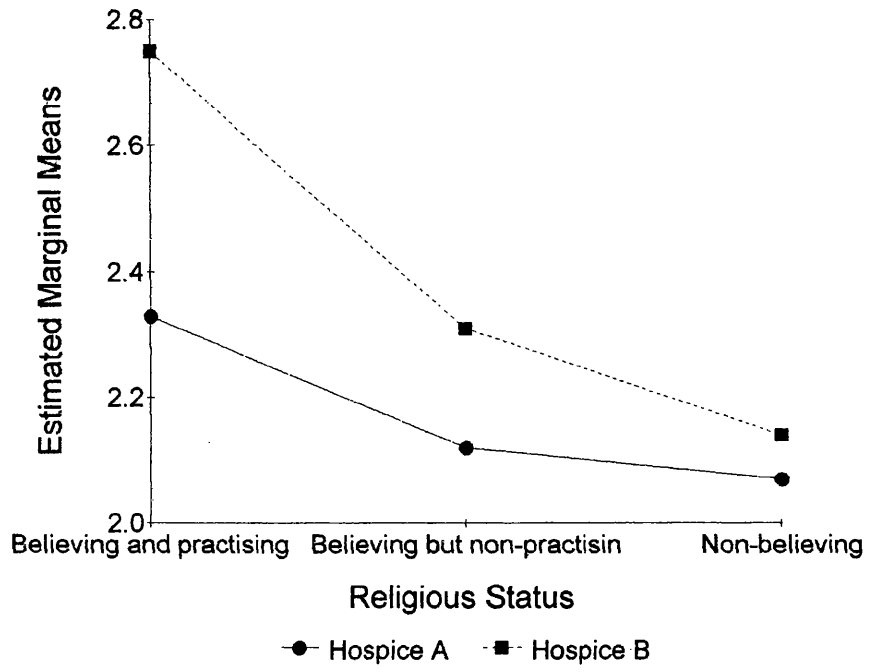
Based on Type III Sum of Squares

The error term is Mean Square (Error) = .246.

- a. Uses Harmonic Mean Sample Size = 39.389.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type 1 error levels are not guaranteed.
- c. Alpha = .05.

### Profile Plots

## Estimated Marginal Means of Total Scores Sub-Scale



## Appendix 3.1 - Non – Parametric Tau b Results for “Intercessory Prayer”. Pages 1 of 2

## Correlations

## Descriptive Statistics

	Mean	Std. Deviation	N
Religious Status Hospice A	2.1333	.8530	60
Intercessory Prayer	4.5167	1.1122	60

## Correlations

		Religious Status Hospice A	Intercessor y Prayer
Religious Status Hospice A	Pearson Correlation	1.000	-.181
	Sig. (1- tailed)	.	.083
	N	60	60
Intercessory Prayer	Pearson Correlation	-.181	1.000
	Sig. (1- tailed)	.083	.
	N	60	60

## Nonparametric Correlations

## Correlations

			Religious Status Hospice A	Intercessory Prayer
Kendall's tau_b	Religious Status Hospice A	Correlation Coefficient	1.000	-.174
		Sig. (1-tailed)	.	.071
		N	60	60
	Intercessory Prayer	Correlation Coefficient	-.174	1.000
		Sig. (1-tailed)	.071	.
		N	60	60



**Appendix 3.1 - Non – Parametric Tau b Results for “Intercessory Prayer”.**

**Correlations**

**Descriptive Statistics**

	Mean	Std. Deviation	N
Religious Status Hospice B	2.0167	.8334	60
Intercessory Prayer	4.5333	1.0808	60

**Correlations**

		Religious Status Hospice B	Intercessory Prayer
Religious Status Hospice B	Pearson Correlation	1.000	-.180
	Sig. (1- tailed)	.	.080
	N	60	60
Intercessory Prayer	Pearson Correlation	-.180	1.000
	Sig. (1- tailed)	.080	.
	N	60	60

**Nonparametric Correlations**

**Correlations**

			Religious Status Hospice B	Intercessory Prayer
Kendall's tau_b	Religious Status Hospice B	Correlation Coefficient	1.000	-.170
		Sig. (1-tailed)	.	.061
		N	60	60
	Intercessory Prayer	Correlation Coefficient	-.170	1.000
		Sig. (1-tailed)	.061	.
		N	60	60

**Appendix 3.2: Chi-Square Results. MQOL Questions A, B & C (Patient Research).Page 1 of 3****Crosstabs****Case Processing Summary**

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
VAR 23 Question A – Open Ended – What has sustained sustained during crisis? * VAR 03 Religious Status	120	100.0%	0	.0%	120	100.0%

**Table 7 (A) – VAR 23 – Open Ended -Question A – “What has sustained you during times of crisis?”****Religious Status Crosstabulation - (p = 0.05)**

Question A		Religious Status			Total
VAR 23 – Question A - “What has sustained you in times of crisis during your lifetime?”		Believing And Practising Church Member	Believing And Practising Non- Church Member	Non-believing/ non-practising patient	
Religious Belief / Spirituality	Count	24	13	12	49
	Expected Count	15.5	14.3	19.2	49
Family/ Self	Count	11	14	21	46
	Expected Count	14.6	13.4	18.0	46
Other Answer	Count	3	8	14	25
	Expected Count	7.9	7.3	9.8	25
Total	Count	38	35	47	120
	Expected Count	38	35	47	120

**Chi-Square Tests - Table 7 (B)**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	13.773	4	.008
Likelihood Ratio	14.323	4	.006
Linear-by-Linear Association	12.543	1	.000
N of Valid Cases	120		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.29

Table 7 (B) displays a Chi-Square value of 13.773,  $p = .008$ . This is above the Chi-Square Values for Significance Table, with  $df = (4)$ , where a value of at least 9.488 is required to reach  $p < 0.05$ . It can be concluded therefore that there is a significant association between the variables, Religious Status and Question A. Consequently, within this population sample, it may be acceptable to reject the null hypothesis ( $H_0$ ) in favour of the research hypothesis ( $H_1$ ).

**Crosstabs**

**Case Processing Summary**

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
VAR 24 Question B – Open Ended – What has been on your mind recently? * VAR 03 Religious Status	120	100.0%	0	.0%	120	100.0%

**Table 7 (C) Question B – “What has been on your mind recently?”–**

**Religious Status Crosstabulation - (p = 0.05)**

Question B		Religious Status			Total
“What has been on your mind recently?”–		Believing And Practising Church Member	Believing And Non- Practising Church Member	Non-believing/ non-practising patient	
Religious Belief / Spirituality	Count	8	3	4	15
	Expected Count	4.8	4.4	5.9	15
Family/ Self	Count	17	16	23	56
	Expected Count	17.7	16.3	21.9	56
Other Answer	Count	13	16	20	49
	Expected Count	15.5	14.3	19.2	49
Total	Count	38	35	47	120
	Expected Count	38	35	47	120

**Chi-Square Tests - Table 7 (D)**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.990	4	.407
Likelihood Ratio	3.753	4	.441
Linear-by-Linear Association	1.853	1	.173
N of Valid Cases	120		

a. 2 cells (22.2%) have expected count less than 5. The minimum expected count is 4.38

Table 7 (D) displays a Chi-Square value of 3.990,  $p = .407$ . This is below the Chi-Square Values for Significance Table, with  $df = (4)$ , where a value of at least 9.488 is required to reach  $p < 0.05$ . It can be concluded therefore that there is no significant association between the variables, Religious Status and Question B. Consequently, within this population sample, it is appropriate to reject the research hypothesis (H1) in favour of the null hypothesis (Ho).

**Crosstabs**

**Case Processing Summary**

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
VAR 23 Question C – Open Ended – What has do you think gives meaning to life? * VAR 03 Religious Status	120	100.0%	0	.0%	120	100.0%

**Table 7(E) Question C– “What do you think gives meaning to life?”**

**Religious Status Crosstabulation** - (p = 0.05)

Question B		Religious Status			Total
“What do you think gives meaning to life?”		Believing And Practising Church Member	Believing And Practising Church Member Non-	Non-believing/ non-practising patient	
Religious Belief / Spirituality	Count	30	11	8	49
	Expected Count	15.5	14.3	19.2	49
Family/ Self	Count	5	12	13	30
	Expected Count	9.5	8.8	11.8	30
Other Answer	Count	3	12	26	41
	Expected Count	13.0	12	16.1	41
Total	Count	38	35	47	120
	Expected Count	38	35	47	120

**Chi-Square Tests - Table 7(F)**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	38.107	4	.000
Likelihood Ratio	39.938	4	.000
Linear-by-Linear Association	32.799	1	.000
N of Valid Cases	120		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 8.75

Table 7(F) displays a Chi-Square value of 38.107,  $p = .000$ . This is above the Chi-Square Values for Significance Table, with  $df = (4)$ , where a value of at least 9.488 is required to reach  $p < 0.05$ . It can be concluded therefore that there is a significant association between the variables, Religious Status and Question C. Consequently, within this population sample, it may be acceptable to reject the null hypothesis ( $H_0$ ) in favour of the research hypothesis ( $H_1$ ).

**Dependent Variable: 02 Spirituality Issues Attitude****Between- Subjects Factors**

		Value Label	N
VAR 01 Spirituality	1.00	Scored 15-16 = High	24
	2.00	Scored 09-14 = Medium	37
	3.00	Scored 01- 8 = Low	39
VAR 06 Hospice	1.00	Hospice A	50
	2.00	Hospice B	50
VAR 07 Occupation of staff member	1.00	Nurse	59
	2.00	Doctor	12
	3.00	Other	
		Occupation	29

**Descriptive Statistics**

Dependent Variable: VAR02 Attitude to Spirituality Issues

VAR01 Spirituality	VAR06 Hospice	VAR07 Occupation of	Mean	Std. Deviation	N
1.00 Scored 15-16=High	1.00 Hospice A	1.00 Nurse	9.5000	.57735	4
		2.00 Doctor	7.5000	3.53553	2
		3.00 Other Occupation	9.0000	1.15470	4
		Total	8.9000	1.59513	10
	2.00 Hospice B	1.00 Nurse	7.9091	1.51357	11
		3.00 Other Occupation	8.3333	1.15470	3
		Total	8.0000	1.41421	14
	Total	1.00 Nurse	8.3333	1.49603	15
		2.00 Doctor	7.5000	3.53553	2
		3.00 Other Occupation	8.7143	1.11270	7
		Total	8.3750	1.52693	24
	2.00 Scored 9-14 = Medium	1.00 Hospice A	1.00 Nurse	8.8000	1.09545
2.00 Doctor			8.0000		1
3.00 Other Occupation			8.5556	1.81046	9
Total			8.6000	1.50238	15
2.00 Hospice B		1.00 Nurse	8.4118	1.41681	17
		2.00 Doctor	8.5000	.70711	2
		3.00 Other Occupation	10.0000	.00000	3
		Total	8.6364	1.36436	22
Total		1.00 Nurse	8.5000	1.33631	22
		2.00 Doctor	8.3333	.57735	3
		3.00 Other Occupation	8.9167	1.67649	12
		Total	8.6216	1.40141	37
3.00 Scored 1-8 = Low	1.00 Hospice A	1.00 Nurse	8.1667	2.20880	12
		2.00 Doctor	7.2000	1.30384	5
		3.00 Other Occupation	7.3750	2.55999	8
		Total	7.7200	2.15097	25
	2.00 Hospice B	1.00 Nurse	7.6000	3.30656	10
		2.00 Doctor	8.0000	2.82843	2
		3.00 Other Occupation	7.0000	1.41421	2
		Total	7.5714	2.90131	14
	Total	1.00 Nurse	7.9091	2.70641	22
		2.00 Doctor	7.4286	1.61835	7
		3.00 Other Occupation	7.3000	2.31181	10
		Total	7.6667	2.40978	39
Total	1.00 Hospice A	1.00 Nurse	8.5714	1.80476	21
		2.00 Doctor	7.3750	1.68502	8
		3.00 Other Occupation	8.1905	2.06444	21
		Total	8.2200	1.90905	50
	2.00 Hospice B	1.00 Nurse	8.0526	2.06577	38
		2.00 Doctor	8.2500	1.70783	4
		3.00 Other Occupation	8.6250	1.50594	8
		Total	8.1600	1.94160	50
	Total	1.00 Nurse	8.2373	1.97693	59
		2.00 Doctor	7.6667	1.66969	12
		3.00 Other Occupation	8.3103	1.91056	29
		Total	8.1900	1.91588	100

**Levene's Test of Equality of Error Variances<sup>a</sup>**

Dependent Variable: VAR02 Attitude to Spirituality Issues

F	df1	df2	Sig.
2.764	16	83	.001

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR01+VAR06+VAR07+VAR01 \* VAR06+VAR01 \* VAR07+VAR06 \* VAR07+VAR01 \* VAR06 \* VAR07

**Tests of Between-Subjects Effects**

Dependent Variable: VAR02 Attitude to Spirituality Issues

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	41.933 <sup>a</sup>	16	2.621	.677	.809	.115
Intercept	3487.968	1	3487.968	900.590	.000	.916
VAR01	14.296	2	7.148	1.846	.164	.043
VAR06	.205	1	.205	.053	.819	.001
VAR07	3.059	2	1.530	.395	.675	.009
VAR01 * VAR06	4.980	2	2.490	.643	.528	.015
VAR01 * VAR07	7.019	4	1.755	.453	.770	.021
VAR06 * VAR07	4.607	2	2.303	.595	.554	.014
VAR01 * VAR06 * VAR07	2.168	3	.723	.187	.905	.007
Error	321.457	83	3.873			
Total	7071.000	100				
Corrected Total	363.390	99				

a. R Squared = .115 (Adjusted R Squared = -.055)

**Estimated Marginal Means**

**1. Spirituality Measurement Score**

Dependent Variable: VAR02 Attitude to Spirituality Issues

Spirituality Measurement Score	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Scored 15-16=High	8.448 <sup>a</sup>	.470	7.514	9.383
2.00 Scored 9-14 = Medium	8.711	.487	7.743	9.680
3.00 Scored 1-8 = Low	7.557	.403	6.756	8.358

a. Based on modified population marginal mean.

**2. Hospice**

Dependent Variable: VAR02 Attitude to Spirituality Issues

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	8.233	.361	7.516	8.950
2.00 Hospice B	8.219 <sup>a</sup>	.382	7.459	8.980

a. Based on modified population marginal mean.

### 3. Occupation of Staff Member

Dependent Variable: VAR02 Attitude to Spirituality Issues

Occupation of Staff Member	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Nurse	8.398	.290	7.821	8.975
2.00 Doctor	7.840 <sup>a</sup>	.647	6.554	9.126
3.00 Other Occupation	8.377	.422	7.539	9.216

a. Based on modified population marginal mean.

### Post Hoc Tests

#### VAR01 Spirituality Measurement Score

##### Multiple Comparisons

Dependent Variable: VAR02 Attitude to Spirituality Issues

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	Mean Difference (I-J)	Std. Error	Sig.
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-.2466	.51580	.882
	3.00 Scored 1-8 = Low	.7083	.51057	.352
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	.2466	.51580	.882
	3.00 Scored 1-8 = Low	.9550	.45164	.093
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-.7083	.51057	.352
	2.00 Scored 9-14 = Medium	-.9550	.45164	.093

Based on observed means.



### Multiple Comparisons

Dependent Variable: VAR02 Attitude to Spirituality Issues

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-1.4776	.9843
	3.00 Scored 1-8 = Low	-.5101	1.9268
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	-.9843	1.4776
	3.00 Scored 1-8 = Low	-.1229	2.0328
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-1.9268	.5101
	2.00 Scored 9-14 = Medium	-2.0328	.1229

Based on observed means.

### Homogeneous Subsets

VAR02 Attitude to Spirituality issues

Tukey HSD<sup>a,b,c</sup>

Spirituality Measurement Score	N	Subset
		1
3.00 Scored 1-8 = Low	39	7.6667
1.00 Scored 15-16=High	24	8.3750
2.00 Scored 9-14 = Medium	37	8.6216
Sig.		.135

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = 3.873.

- a. Uses Harmonic Mean Sample Size = 31.802.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- c. Alpha = .05.

### VAR07 Occupation of Staff Member

### Multiple Comparisons

Dependent Variable: VAR02 Attitude to Spirituality Issues

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	Mean Difference (I-J)	Std. Error	Sig.
1.00 Nurse	2.00 Doctor	.5706	.62321	.632
	3.00 Other Occupation	-.0731	.44631	.985
2.00 Doctor	1.00 Nurse	-.5706	.62321	.632
	3.00 Other Occupation	-.6437	.67550	.609
3.00 Other Occupation	1.00 Nurse	.0731	.44631	.985
	2.00 Doctor	.6437	.67550	.609

Based on observed means.

### Multiple Comparisons

Dependent Variable: VAR02 Attitude to Spirituality Issues

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Nurse	2.00 Doctor	-.9167	2.0579
	3.00 Other Occupation	-1.1382	.9921
2.00 Doctor	1.00 Nurse	-2.0579	.9167
	3.00 Other Occupation	-2.2557	.9684
3.00 Other Occupation	1.00 Nurse	-.9921	1.1382
	2.00 Doctor	-.9684	2.2557

Based on observed means.

### Homogeneous Subsets

VAR02 Attitude to Spirituality Issues

Tukey HSD<sup>a,b,c</sup>

Occupation of Staff Member	N	Subset
		1
2.00 Doctor	12	7.6667
1.00 Nurse	59	8.2373
3.00 Other Occupation	29	8.3103
Sig.		.522

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = 3.873.

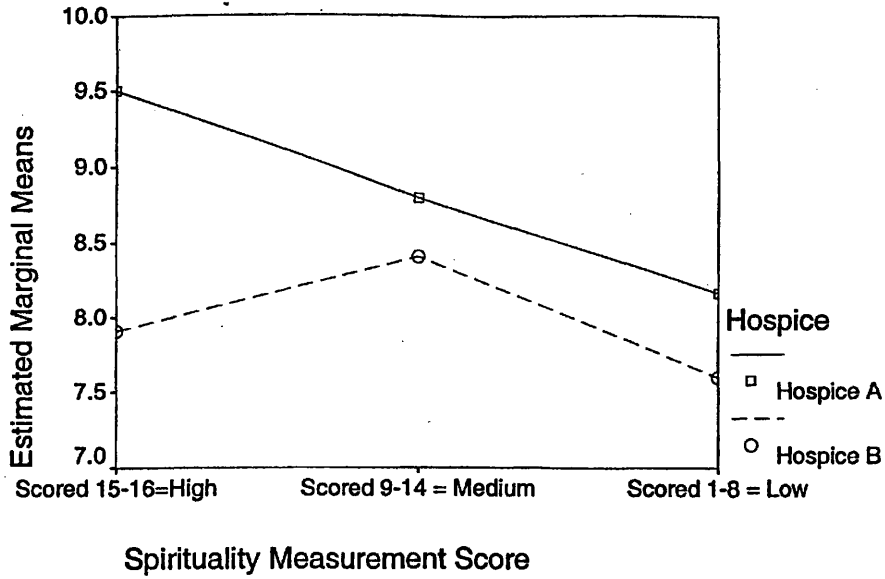
- a. Uses Harmonic Mean Sample Size = 22.261.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- c. Alpha = .05.

### Profile Plots

Spirituality Measurement Score \* Hospice \* Occupation of Staff Member

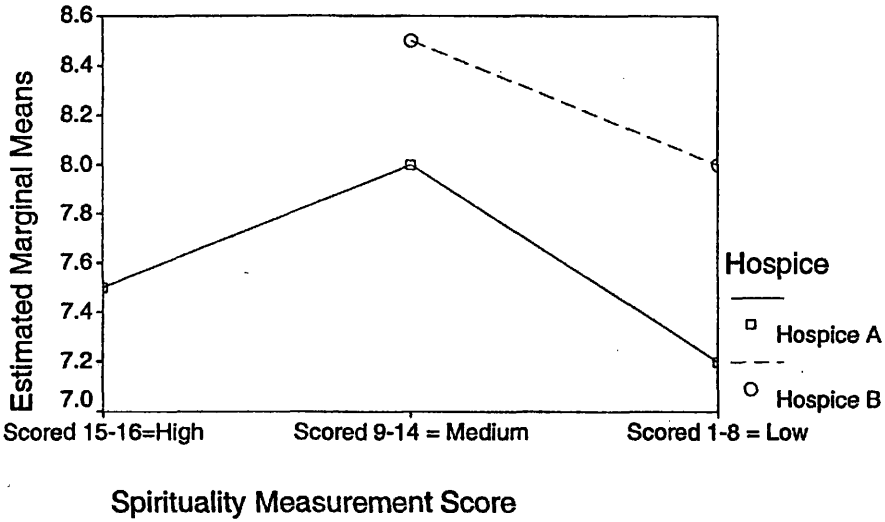
# Estimated Marginal Means of Attitude to Spirituality Issues

## At Occupation of Staff Member = Nurse



# Estimated Marginal Means of Attitude to Spirituality Issues

## At Occupation of Staff Member = Doctor



Non-estimable means are not plotted

## Dependent Variable: 03 Coping Category Inclusion

## Between- Subjects Factors

		Value Label	N
VAR 01 Spirituality	1.00	Scored 15-16 = High	24
	2.00	Scored 09-14 = Medium	37
	3.00	Scored 01- 8 = Low	39
VAR 06 Hospice	1.00	Hospice A	50
	2.00	Hospice B	50
VAR 07 Occupation of staff member	1.00	Nurse	59
	2.00	Doctor	12
	3.00	Other Occupation	29

**Descriptive Statistics**

Dependent Variable: VAR03 Category Inclusion

VAR01 Spirituality	VAR06 Hospice	VAR07 Occupation of	Mean	Std. Deviation	N		
1.00 Scored 15-16=High	1.00 Hospice A	1.00 Nurse	4.0000	.00000	4		
		2.00 Doctor	4.0000	.00000	2		
		3.00 Other Occupation	3.5000	1.00000	4		
		Total	3.8000	.63246	10		
	2.00 Hospice B	1.00 Nurse	3.8182	.60302	11		
		3.00 Other Occupation	3.0000	1.00000	3		
		Total	3.6429	.74495	14		
	Total	1.00 Nurse	3.8667	.51640	15		
		2.00 Doctor	4.0000	.00000	2		
		3.00 Other Occupation	3.2857	.95119	7		
Total		3.7083	.69025	24			
2.00 Scored 9-14 = Medium		1.00 Hospice A	1.00 Nurse	4.0000	.00000	5	
			2.00 Doctor	4.0000		1	
	3.00 Other Occupation		3.5556	.72648	9		
	Total		3.7333	.59362	15		
	2.00 Hospice B	1.00 Nurse	3.8235	.72761	17		
		2.00 Doctor	2.5000	2.12132	2		
		3.00 Other Occupation	4.0000	.00000	3		
		Total	3.7273	.88273	22		
	Total	1.00 Nurse	3.8636	.63960	22		
		2.00 Doctor	3.0000	1.73205	3		
3.00 Other Occupation		3.6667	.65134	12			
Total		3.7297	.76915	37			
3.00 Scored 1-8 = Low		1.00 Hospice A	1.00 Nurse	3.4167	.90034	12	
			2.00 Doctor	4.0000	.00000	5	
	3.00 Other Occupation		4.0000	.00000	8		
	Total		3.7200	.67823	25		
	2.00 Hospice B	1.00 Nurse	3.3000	.82327	10		
		2.00 Doctor	4.0000	.00000	2		
		3.00 Other Occupation	3.5000	.70711	2		
		Total	3.4286	.75593	14		
	Total	1.00 Nurse	3.3636	.84771	22		
		2.00 Doctor	4.0000	.00000	7		
		3.00 Other Occupation	3.9000	.31623	10		
		Total	3.6154	.71139	39		
		Total	1.00 Hospice A	1.00 Nurse	3.6667	.73030	21
				2.00 Doctor	4.0000	.00000	8
3.00 Other Occupation	3.7143			.64365	21		
Total	3.7400			.63278	50		
2.00 Hospice B	1.00 Nurse		3.6842	.73907	38		
	2.00 Doctor		3.2500	1.50000	4		
	3.00 Other Occupation		3.5000	.75593	8		
	Total		3.6200	.80534	50		
Total	1.00 Nurse		3.6780	.72968	59		
	2.00 Doctor		3.7500	.86603	12		
	3.00 Other Occupation	3.6552	.66953	29			
	Total	3.6800	.72307	100			

**Levene's Test of Equality of Error Variances<sup>a</sup>**

Dependent Variable: VAR03 Category Inclusion

F	df1	df2	Sig.
4.325	16	83	.000

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR01+VAR06+VAR07+VAR01 \* VAR06+VAR01 \* VAR07+VAR06 \* VAR07+VAR01 \* VAR06 \* VAR07

**Tests of Between-Subjects Effects**

Dependent Variable: VAR03 Category Inclusion

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	10.414 <sup>a</sup>	16	.651	1.307	.213	.201
Intercept	691.463	1	691.463	1388.082	.000	.944
VAR01	.173	2	.087	.174	.841	.004
VAR06	1.535	1	1.535	3.082	.083	.036
VAR07	.304	2	.152	.305	.738	.007
VAR01 * VAR06	.293	2	.147	.294	.746	.007
VAR01 * VAR07	4.971	4	1.243	2.495	.049	.107
VAR06 * VAR07	.706	2	.353	.709	.495	.017
VAR01 * VAR06 * VAR07	2.063	3	.688	1.380	.255	.048
Error	41.346	83	.498			
Total	1406.000	100				
Corrected Total	51.760	99				

a. R Squared = .201 (Adjusted R Squared = .047)

**Estimated Marginal Means**

**1. Spirituality Measurement Score**

Dependent Variable: VAR03 Category Inclusion

Spirituality Measurement Score	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Scored 15-16=High	3.664 <sup>a</sup>	.168	3.329	3.999
2.00 Scored 9-14 = Medium	3.647	.175	3.299	3.994
3.00 Scored 1-8 = Low	3.703	.144	3.415	3.990

a. Based on modified population marginal mean.

**2. Hospice**

Dependent Variable: VAR03 Category Inclusion

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	3.830	.129	3.573	4.087
2.00 Hospice B	3.493 <sup>a</sup>	.137	3.220	3.765

a. Based on modified population marginal mean.

### 3. Occupation of Staff Member

Dependent Variable: VAR03 Category Inclusion

Occupation of Staff Member	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Nurse	3.726	.104	3.519	3.933
2.00 Doctor	3.700 <sup>a</sup>	.232	3.239	4.161
3.00 Other Occupation	3.593	.151	3.292	3.893

a. Based on modified population marginal mean.

## Post Hoc Tests

### VAR01 Spirituality Measurement Score

#### Multiple Comparisons

Dependent Variable: VAR03 Category Inclusion

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	Mean Difference (I-J)	Std. Error	Sig.
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-.0214	.18498	.993
	3.00 Scored 1-8 = Low	.0929	.18311	.868
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	.0214	.18498	.993
	3.00 Scored 1-8 = Low	.1143	.16198	.761
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-.0929	.18311	.868
	2.00 Scored 9-14 = Medium	-.1143	.16198	.761

Based on observed means.



### Multiple Comparisons

Dependent Variable: VAR03 Category Inclusion  
Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-.4629	.4201
	3.00 Scored 1-8 = Low	-.3440	.5299
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	-.4201	.4629
	3.00 Scored 1-8 = Low	-.2722	.5009
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-.5299	.3440
	2.00 Scored 9-14 = Medium	-.5009	.2722

Based on observed means.

### Homogeneous Subsets

VAR03 Category Inclusion

Tukey HSD<sup>a,b,c</sup>

Spirituality Measurement Score	N	Subset
		1
3.00 Scored 1-8 = Low	39	3.6154
1.00 Scored 15-16=High	24	3.7083
2.00 Scored 9-14 = Medium	37	3.7297
Sig.		.795

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = .498.

- a. Uses Harmonic Mean Sample Size = 31.802.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- c. Alpha = .05.

### VAR07 Occupation of Staff Member

### Multiple Comparisons

Dependent Variable: VAR03 Category Inclusion

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	Mean Difference (I-J)	Std. Error	Sig.
1.00 Nurse	2.00 Doctor	-.0720	.22351	.944
	3.00 Other Occupation	.0228	.16006	.989
2.00 Doctor	1.00 Nurse	.0720	.22351	.944
	3.00 Other Occupation	.0948	.24226	.919
3.00 Other Occupation	1.00 Nurse	-.0228	.16006	.989
	2.00 Doctor	-.0948	.24226	.919

Based on observed means.

### Multiple Comparisons

Dependent Variable: VAR03 Category Inclusion

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Nurse	2.00 Doctor	-.6054	.4614
	3.00 Other Occupation	-.3592	.4048
2.00 Doctor	1.00 Nurse	-.4614	.6054
	3.00 Other Occupation	-.4833	.6730
3.00 Other Occupation	1.00 Nurse	-.4048	.3592
	2.00 Doctor	-.6730	.4833

Based on observed means.

### Homogeneous Subsets

VAR03 Category Inclusion

Tukey HSD<sup>a,b,c</sup>

Occupation of Staff Member	N	Subset
		1
3.00 Other Occupation	29	3.6552
1.00 Nurse	59	3.6780
2.00 Doctor	12	3.7500
Sig.		.895

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = .498.

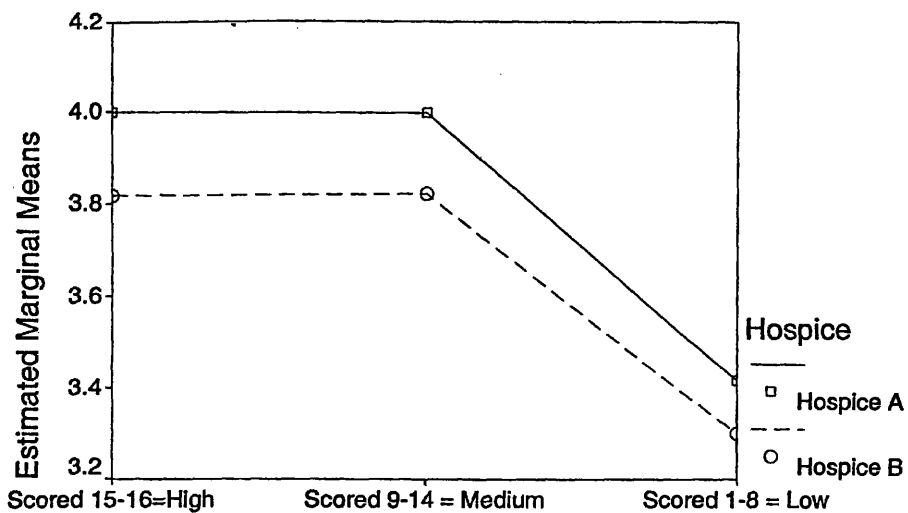
- Uses Harmonic Mean Sample Size = 22.261.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- Alpha = .05.

### Profile Plots

Spirituality Measurement Score \* Hospice \* Occupation of Staff Member

# Estimated Marginal Means of Category Inclusion

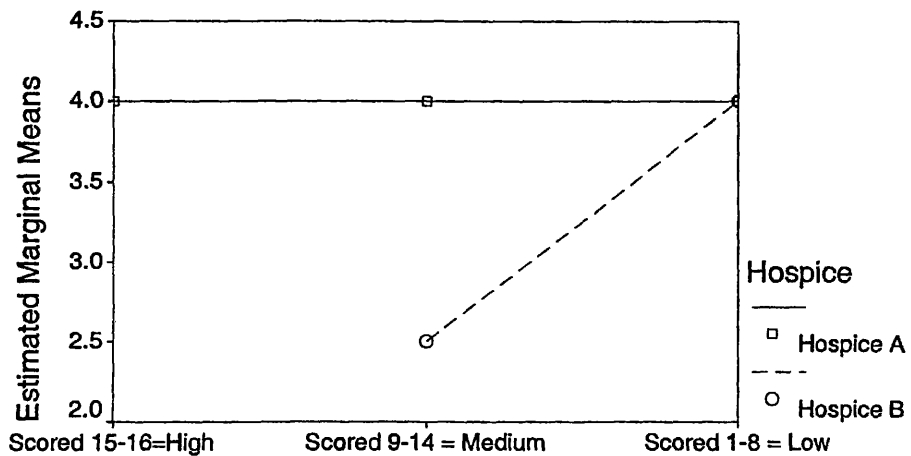
## At Occupation of Staff Member = Nurse



Spirituality Measurement Score

# Estimated Marginal Means of Category Inclusion

## At Occupation of Staff Member = Doctor



Spirituality Measurement Score

Non-estimable means are not plotted

**Dependent Variable: 04 Coping with Occupation****Between- Subjects Factors**

		Value Label	N
VAR 01 Spirituality	1.00	Scored 15-16 = High	24
	2.00	Scored 09-14 = Medium	37
	3.00	Scored 01- 8 = Low	39
VAR 06 Hospice	1.00	Hospice A	50
	2.00	Hospice B	50
VAR 07 Occupation of staff member	1.00	Nurse	59
	2.00	Doctor	12
	3.00	Other	
		Occupation	29

**Descriptive Statistics**

Dependent Variable: VAR04 Coping with Occupation

VAR01 Spirituality	VAR06 Hospice	VAR07 Occupation of	Mean	Std. Deviation	N
1.00 Scored 15-16=High	1.00 Hospice A	1.00 Nurse	2.7500	.95743	4
		2.00 Doctor	3.5000	.70711	2
		3.00 Other Occupation	2.2500	.50000	4
		Total	2.7000	.82327	10
	2.00 Hospice B	1.00 Nurse	2.3636	.67420	11
		3.00 Other Occupation	2.0000	1.00000	3
		Total	2.2857	.72627	14
	Total	1.00 Nurse	2.4667	.74322	15
		2.00 Doctor	3.5000	.70711	2
		3.00 Other Occupation	2.1429	.69007	7
Total		2.4583	.77903	24	
2.00 Scored 9-14 = Medium	1.00 Hospice A	1.00 Nurse	3.2000	.83666	5
		2.00 Doctor	4.0000	.	1
		3.00 Other Occupation	3.6667	.70711	9
		Total	3.5333	.74322	15
	2.00 Hospice B	1.00 Nurse	2.7647	.83137	17
		2.00 Doctor	3.0000	.00000	2
		3.00 Other Occupation	3.0000	1.00000	3
		Total	2.8182	.79501	22
	Total	1.00 Nurse	2.8636	.83355	22
		2.00 Doctor	3.3333	.57735	3
3.00 Other Occupation		3.5000	.79772	12	
Total		3.1081	.84274	37	
3.00 Scored 1-8 = Low	1.00 Hospice A	1.00 Nurse	2.7500	1.05529	12
		2.00 Doctor	3.2000	.44721	5
		3.00 Other Occupation	3.0000	1.19523	8
		Total	2.9200	.99666	25
	2.00 Hospice B	1.00 Nurse	2.5000	.70711	10
		2.00 Doctor	2.5000	.70711	2
		3.00 Other Occupation	3.5000	.70711	2
		Total	2.6429	.74495	14
	Total	1.00 Nurse	2.6364	.90214	22
		2.00 Doctor	3.0000	.57735	7
3.00 Other Occupation		3.1000	1.10050	10	
Total		2.8205	.91398	39	
Total	1.00 Hospice A	1.00 Nurse	2.8571	.96362	21
		2.00 Doctor	3.3750	.51755	8
		3.00 Other Occupation	3.1429	1.01419	21
		Total	3.0600	.93481	50
	2.00 Hospice B	1.00 Nurse	2.5789	.75808	38
		2.00 Doctor	2.7500	.50000	4
		3.00 Other Occupation	2.7500	1.03510	8
		Total	2.6200	.77959	50
	Total	1.00 Nurse	2.6780	.83955	59
		2.00 Doctor	3.1667	.57735	12
3.00 Other Occupation		3.0345	1.01710	29	
Total		2.8400	.88443	100	

### Levene's Test of Equality of Error Variances<sup>a</sup>

Dependent Variable: VAR04 Coping with Occupation

F	df1	df2	Sig.
1.246	16	83	.252

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR01+VAR06+VAR07+VAR01 \* VAR06+VAR01 \* VAR07+VAR06 \* VAR07+VAR01 \* VAR06 \* VAR07

### Tests of Between-Subjects Effects

Dependent Variable: VAR04 Coping with Occupation

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	18.486 <sup>a</sup>	16	1.155	1.627	.080	.239
Intercept	441.890	1	441.890	622.124	.000	.882
VAR01	3.902	2	1.951	2.747	.070	.062
VAR06	2.222	1	2.222	3.128	.081	.036
VAR07	1.315	2	.658	.926	.400	.022
VAR01 * VAR06	.762	2	.381	.536	.587	.013
VAR01 * VAR07	3.425	4	.856	1.205	.315	.055
VAR06 * VAR07	.734	2	.367	.517	.598	.012
VAR01 * VAR06 * VAR07	.655	3	.218	.307	.820	.011
Error	58.954	83	.710			
Total	884.000	100				
Corrected Total	77.440	99				

a. R Squared = .239 (Adjusted R Squared = .092)

## Estimated Marginal Means

### 1. Spirituality Measurement Score

Dependent Variable: VAR04 Coping with Occupation

Spirituality Measurement Score	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Scored 15-16=High	2.573 <sup>a</sup>	.201	2.173	2.973
2.00 Scored 9-14 = Medium	3.272	.208	2.857	3.687
3.00 Scored 1-8 = Low	2.908	.173	2.565	3.251

a. Based on modified population marginal mean.

### 2. Hospice

Dependent Variable: VAR04 Coping with Occupation

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	3.146	.154	2.839	3.453
2.00 Hospice B	2.704 <sup>a</sup>	.164	2.378	3.029

a. Based on modified population marginal mean.

### 3. Occupation of Staff Member

Dependent Variable: VAR04 Coping with Occupation

Occupation of Staff Member	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Nurse	2.721	.124	2.474	2.969
2.00 Doctor	3.240 <sup>a</sup>	.277	2.689	3.791
3.00 Other Occupation	2.903	.181	2.544	3.262

a. Based on modified population marginal mean.

## Post Hoc Tests

### VAR01 Spirituality Measurement Score

#### Multiple Comparisons

Dependent Variable: VAR04 Coping with Occupation

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	Mean Difference (I-J)	Std. Error	Sig.
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-.6498*	.22089	.012
	3.00 Scored 1-8 = Low	-.3622	.21865	.228
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	.6498*	.22089	.012
	3.00 Scored 1-8 = Low	.2876	.19342	.302
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	.3622	.21865	.228
	2.00 Scored 9-14 = Medium	-.2876	.19342	.302

Based on observed means.



### Multiple Comparisons

Dependent Variable: VAR04 Coping with Occupation

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-1.1769	-.1226
	3.00 Scored 1-8 = Low	-.8840	.1596
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	.1226	1.1769
	3.00 Scored 1-8 = Low	-.1740	-.7492
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-.1596	.8840
	2.00 Scored 9-14 = Medium	-.7492	.1740

Based on observed means.

\*. The mean difference is significant at the .05 level.

### Homogeneous Subsets

VAR04 Coping with Occupation

Tukey HSD<sup>a,b,c</sup>

Spirituality Measurement Score	N	Subset	
		1	2
1.00 Scored 15-16=High	24	2.4583	
3.00 Scored 1-8 = Low	39	2.8205	2.8205
2.00 Scored 9-14 = Medium	37		3.1081
Sig.		.206	.366

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = .710.

- Uses Harmonic Mean Sample Size = 31.802.
- The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- Alpha = .05.

### VAR07 Occupation of Staff Member

### Multiple Comparisons

Dependent Variable: VAR04 Coping with Occupation

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	Mean Difference (I-J)	Std. Error	Sig.
1.00 Nurse	2.00 Doctor	-.4887	.26689	.166
	3.00 Other Occupation	-.3565	.19113	.155
2.00 Doctor	1.00 Nurse	.4887	.26689	.166
	3.00 Other Occupation	.1322	.28928	.891
3.00 Other Occupation	1.00 Nurse	.3565	.19113	.155
	2.00 Doctor	-.1322	.28928	.891

Based on observed means.

### Multiple Comparisons

Dependent Variable: VAR04 Coping with Occupation

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Nurse	2.00 Doctor	-1.1256	.1482
	3.00 Other Occupation	-.8126	.0996
2.00 Doctor	1.00 Nurse	-.1482	1.1256
	3.00 Other Occupation	-.5582	.8225
3.00 Other Occupation	1.00 Nurse	-.0996	.8126
	2.00 Doctor	-.8225	.5582

Based on observed means.

### Homogeneous Subsets

VAR04 Coping with Occupation

Tukey HSD<sup>a,b,c</sup>

Occupation of Staff Member	N	Subset
		1
1.00 Nurse	59	2.6780
3.00 Other Occupation	29	3.0345
2.00 Doctor	12	3.1667
Sig.		.135

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = .710.

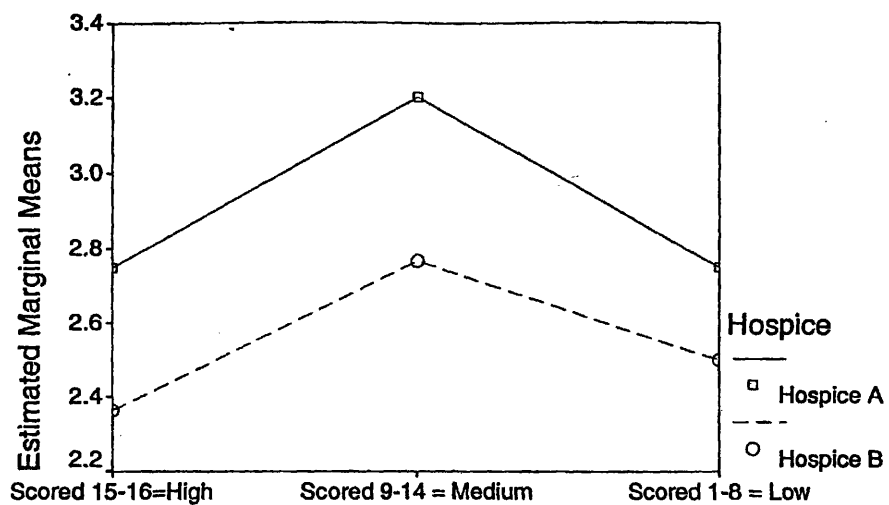
- a. Uses Harmonic Mean Sample Size = 22.261.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- c. Alpha = .05.

### Profile Plots

Spirituality Measurement Score \* Hospice \* Occupation of Staff Member

## Estimated Marginal Means of Coping with Occupation

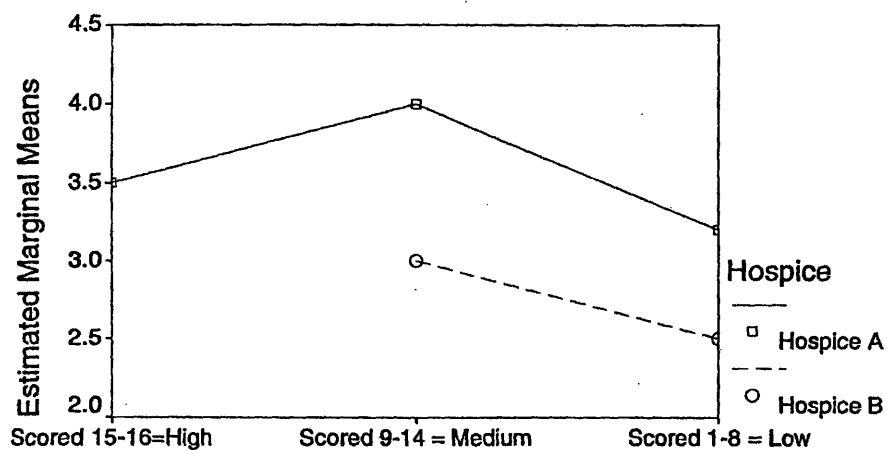
### At Occupation of Staff Member = Nurse



Spirituality Measurement Score

## Estimated Marginal Means of Coping with Occupation

### At Occupation of Staff Member = Doctor



Spirituality Measurement Score

Non-estimable means are not plotted

Dependent Variable: 05 Quality of Life

Between- Subjects Factors

		Value Label	N
VAR 01 Spirituality	1.00	Scored 15-16 = High	24
	2.00	Scored 09-14 = Medium	37
	3.00	Scored 01- 8 = Low	39
VAR 06 Hospice	1.00	Hospice A	50
	2.00	Hospice B	50
VAR 07 Occupation of staff member	1.00	Nurse	59
	2.00	Doctor	12
	3.00	Other Occupation	29

### Descriptive Statistics

Dependent Variable: VAR05 Quality of Life

VAR01 Spirituality	VAR06 Hospice	VAR07 Occupation of	Mean	Std. Deviation	N
1.00 Scored 15-16=High	1.00 Hospice A	1.00 Nurse	4.0000	.00000	4
		2.00 Doctor	3.5000	.70711	2
		3.00 Other Occupation	2.5000	1.00000	4
		Total	3.3000	.94868	10
	2.00 Hospice B	1.00 Nurse	3.1818	1.07872	11
		3.00 Other Occupation	2.3333	.57735	3
		Total	3.0000	1.03775	14
	Total	1.00 Nurse	3.4000	.98561	15
		2.00 Doctor	3.5000	.70711	2
		3.00 Other Occupation	2.4286	.78680	7
		Total	3.1250	.99181	24
	2.00 Scored 9-14 = Medium	1.00 Hospice A	1.00 Nurse	3.8000	.44721
2.00 Doctor			3.0000	.	1
3.00 Other Occupation			2.8889	1.36423	9
Total			3.2000	1.14642	15
2.00 Hospice B		1.00 Nurse	2.8824	1.11144	17
		2.00 Doctor	2.5000	.70711	2
		3.00 Other Occupation	3.0000	1.00000	3
		Total	2.8636	1.03719	22
Total		1.00 Nurse	3.0909	1.06499	22
		2.00 Doctor	2.6667	.57735	3
		3.00 Other Occupation	2.9167	1.24011	12
		Total	3.0000	1.08012	37
3.00 Scored 1-8 = Low	1.00 Hospice A	1.00 Nurse	2.6667	1.23091	12
		2.00 Doctor	3.0000	1.00000	5
		3.00 Other Occupation	2.7500	1.28174	8
		Total	2.7600	1.16476	25
	2.00 Hospice B	1.00 Nurse	2.8000	1.22927	10
		2.00 Doctor	4.0000	.00000	2
		3.00 Other Occupation	4.0000	.00000	2
		Total	3.1429	1.16732	14
	Total	1.00 Nurse	2.7273	1.20245	22
		2.00 Doctor	3.2857	.95119	7
		3.00 Other Occupation	3.0000	1.24722	10
		Total	2.8974	1.16517	39
Total	1.00 Hospice A	1.00 Nurse	3.1905	1.12335	21
		2.00 Doctor	3.1250	.83452	8
		3.00 Other Occupation	2.7619	1.22085	21
		Total	3.0000	1.12486	50
	2.00 Hospice B	1.00 Nurse	2.9474	1.11373	38
		2.00 Doctor	3.2500	.95743	4
		3.00 Other Occupation	3.0000	.92582	8
		Total	2.9800	1.05926	50
	Total	1.00 Nurse	3.0339	1.11365	59
		2.00 Doctor	3.1667	.83485	12
		3.00 Other Occupation	2.8276	1.13606	29
		Total	2.9900	1.08707	100

### Levene's Test of Equality of Error Variances<sup>a</sup>

Dependent Variable: VAR05 Quality of Life

F	df1	df2	Sig.
3.184	16	83	.000

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept+VAR01+VAR06+VAR07+VAR01 \* VAR06+VAR01 \* VAR07+VAR06 \* VAR07+VAR01 \* VAR06 \* VAR07

### Tests of Between-Subjects Effects

Dependent Variable: VAR05 Quality of Life

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	17.467 <sup>a</sup>	16	1.092	.910	.560	.149
Intercept	501.069	1	501.069	417.879	.000	.834
VAR01	.359	2	.179	.150	.861	.004
VAR06	.003	1	.003	.002	.963	.000
VAR07	1.428	2	.714	.596	.554	.014
VAR01 * VAR06	4.814	2	2.407	2.007	.141	.046
VAR01 * VAR07	9.707	4	2.427	2.024	.099	.089
VAR06 * VAR07	3.340	2	1.670	1.393	.254	.032
VAR01 * VAR06 * VAR07	.217	3	.072	.060	.980	.002
Error	99.523	83	1.199			
Total	1011.000	100				
Corrected Total	116.990	99				

a. R Squared = .149 (Adjusted R Squared = -.015)

## Estimated Marginal Means

### 1. Spirituality Measurement Score

Dependent Variable: VAR05 Quality of Life

Spirituality Measurement Score	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Scored 15-16=High	3.103 <sup>a</sup>	.261	2.583	3.623
2.00 Scored 9-14 = Medium	3.012	.271	2.473	3.551
3.00 Scored 1-8 = Low	3.203	.224	2.757	3.649

a. Based on modified population marginal mean.

### 2. Hospice

Dependent Variable: VAR05 Quality of Life

Hospice	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Hospice A	3.123	.201	2.724	3.522
2.00 Hospice B	3.087 <sup>a</sup>	.213	2.664	3.510

a. Based on modified population marginal mean.

### 3. Occupation of Staff Member

Dependent Variable: VAR05 Quality of Life

Occupation of Staff Member	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
1.00 Nurse	3.222	.161	2.901	3.543
2.00 Doctor	3.200 <sup>a</sup>	.360	2.484	3.916
3.00 Other Occupation	2.912	.235	2.445	3.379

a. Based on modified population marginal mean.

## Post Hoc Tests

### VAR01 Spirituality Measurement Score

#### Multiple Comparisons

Dependent Variable: VAR05 Quality of Life

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	Mean Difference (I-J)	Std. Error	Sig.
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	.1250	.28700	.901
	3.00 Scored 1-8 = Low	.2276	.28409	.703
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	-.1250	.28700	.901
	3.00 Scored 1-8 = Low	.1026	.25130	.912
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-.2276	.28409	.703
	2.00 Scored 9-14 = Medium	-.1026	.25130	.912

Based on observed means.



### Multiple Comparisons

Dependent Variable: VAR05 - Quality of Life

Tukey HSD

(I) Spirituality Measurement Score	(J) Spirituality Measurement Score	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Scored 15-16=High	2.00 Scored 9-14 = Medium	-.5599	.8099
	3.00 Scored 1-8 = Low	-.4504	.9055
2.00 Scored 9-14 = Medium	1.00 Scored 15-16=High	-.8099	.5599
	3.00 Scored 1-8 = Low	-.4972	.7023
3.00 Scored 1-8 = Low	1.00 Scored 15-16=High	-.9055	.4504
	2.00 Scored 9-14 = Medium	-.7023	.4972

Based on observed means.

## Homogeneous Subsets

VAR05 Quality of Life

Tukey HSD<sup>a,b,c</sup>

Spirituality Measurement Score	N	Subset
		1
3.00 Scored 1-8 = Low	39	2.8974
2.00 Scored 9-14 = Medium	37	3.0000
1.00 Scored 15-16=High	24	3.1250
Sig.		.686

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = 1.199.

- a. Uses Harmonic Mean Sample Size = 31.802.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- c. Alpha = .05.

## VAR07 Occupation of Staff Member

### Multiple Comparisons

Dependent Variable: VAR05 - Quality of Life

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	Mean Difference (I-J)	Std. Error	Sig.
1.00 Nurse	2.00 Doctor	-.1328	.34677	.922
	3.00 Other Occupation	.2063	.24834	.685
2.00 Doctor	1.00 Nurse	.1328	.34677	.922
	3.00 Other Occupation	.3391	.37586	.640
3.00 Other Occupation	1.00 Nurse	-.2063	.24834	.685
	2.00 Doctor	-.3391	.37586	.640

Based on observed means.

### Multiple Comparisons

Dependent Variable: VAR05 Quality of Life

Tukey HSD

(I) Occupation of Staff Member	(J) Occupation of Staff Member	95% Confidence Interval	
		Lower Bound	Upper Bound
1.00 Nurse	2.00 Doctor	-.9603	.6948
	3.00 Other Occupation	-.3863	.7990
2.00 Doctor	1.00 Nurse	-.6948	.9603
	3.00 Other Occupation	-.5579	1.2361
3.00 Other Occupation	1.00 Nurse	-.7990	.3863
	2.00 Doctor	-1.2361	.5579

Based on observed means.

### Homogeneous Subsets

VAR05 Quality of Life

Tukey HSD<sup>a,b,c</sup>

Occupation of Staff Member	N	Subset
		1
3.00 Other Occupation	29	2.8276
1.00 Nurse	59	3.0339
2.00 Doctor	12	3.1667
Sig.		.558

Means for groups in homogeneous subsets are displayed.

Based on Type III Sum of Squares

The error term is Mean Square(Error) = 1.199.

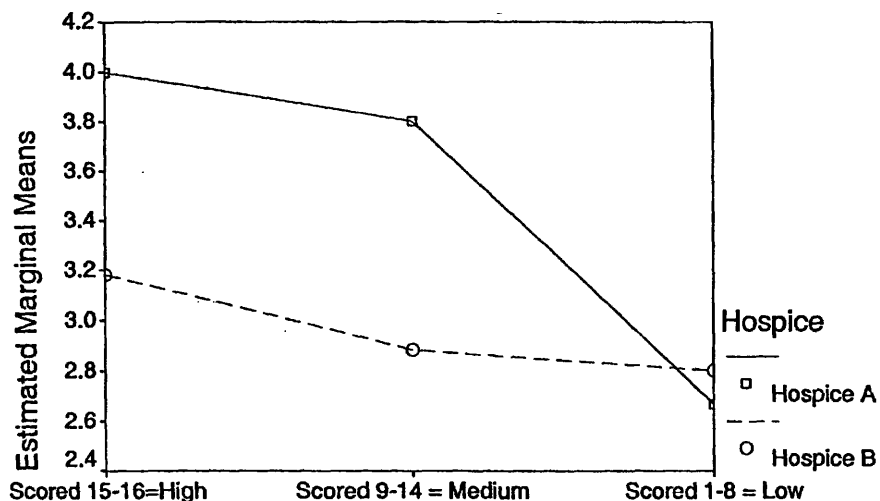
- a. Uses Harmonic Mean Sample Size = 22.261.
- b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.
- c. Alpha = .05.

### Profile Plots

Spirituality Measurement Score \* Hospice \* Occupation of Staff Member

# Estimated Marginal Means of Quality of Life

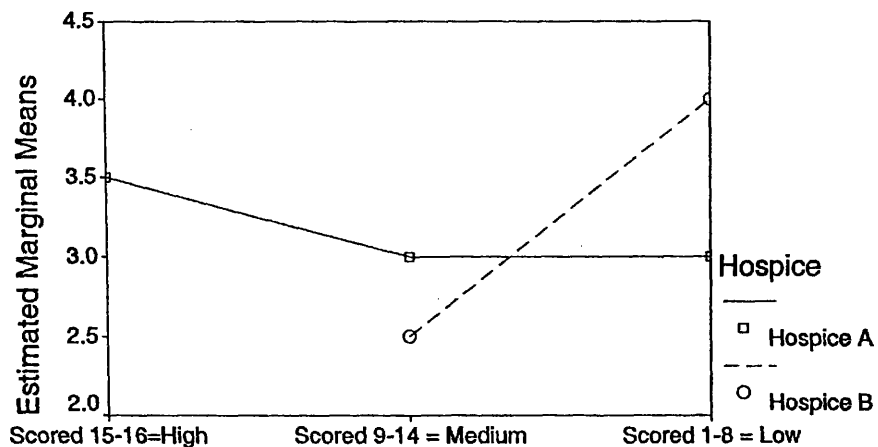
## At Occupation of Staff Member = Nurse



Spirituality Measurement Score

# Estimated Marginal Means of Quality of Life

## At Occupation of Staff Member = Doctor



Spirituality Measurement Score

Non-estimable means are not plotted

North Glasgow University Hospitals NHS Trust

Research Ethics Committee  
Glasgow Royal Infirmary  
4<sup>th</sup> floor, 10 Alexandra Parade  
GLASGOW G31 2ER  
Tel: 0141 211 4020  
Fax: 0141 553 2558



Date 16<sup>th</sup> August 2002

Mrs C Caddell  
44 Glasgow Road  
Uddingston  
G71 7BA

Enquiries to Mrs Sharon Macgregor  
Email: sharon.macgregor@northglasgow.scot.nhs.uk

Chairman: Dr Brian Neilly

Dear Mrs Caddell,

**Project Title: The Coping Strategies of Hospice Patients With Life-Threatening Illnesses.**  
**Project number: 02ON012 (Please quote on all correspondence)**

Further to your letter dated 31<sup>st</sup> July 2002, the Chair of the Committee has considered the amendments submitted in response to the Committee's earlier review of your application as set out in my letter dated 10<sup>th</sup> July 2002.

The Chair, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. He has therefore happy to grant favourable ethical opinion subject to the following conditions:

- The favourable opinion contained in this letter is valid for all sites that form part of the North Glasgow Trust. However, if this research is to be carried out at any other sites, the person responsible for the research on that site **must** write to their REC advising that they wish to initiate the study there and list names, titles and addresses of all collaborating researchers. A copy of this letter and the original application must be enclosed.
- You do not deviate from, or make changes to, the protocol without prior written approval of the REC, except when it is necessary to eliminate immediate hazards to subjects or when the change involves only logistical or administrative aspects of the research. In such cases the REC should be informed within seven days of the implementation of the change.
- You complete and return the standard progress report form to the REC that will be sent to you one year from the date on this letter and thereafter on an annual basis until study completion. When your research is completed, you should submit an end of study report to the REC within three months of completion.
- If you decide to terminate this research prematurely, you send a report to this REC within 15 days, indicating the reason for early termination.
- You resubmit the project if the study does not start within three years of the date on this letter.

Yours sincerely

**Sharon Macgregor**  
**LREC Administrator**