Quality Of Life At End Of Life: Spirituality And Coping Mechanisms In Terminally Ill Patients

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Citation

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” (B), “Believers but Non-practising Church Members” (NPB) and “Non-Believers” (NB) 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 B & NPB in Hospice A attained higher score levels than NB patients, all 5 hypotheses were statistically non-significant. For Hospice B however, 4 of the 5 hypotheses achieved statistically significant results (p = 0.01). Findings implied that QOL assessments for B & NPB 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.

INTRODUCTION
When diagnosed with life-threatening illness, patients often appraise the prognosis with an unfavourable resolution and have to cope not only with deteriorating physical symptoms of the condition but also with the psychological consequences of relinquishing control over areas of their life previously regarded as personal or intimate. [1] Within a hospice environment, loss of control regarding everyday needs and schedules together with the adjustment to hospice policy and medical routine can compound stress concerning the implications of the illness resulting in an overall dynamic of anxiety. [2] During the disease trajectory, patients may come to realise that recovery may not be an option and may begin to compare their level of coping to others within the hospice environment, resulting in a positive or negative self-imaging. [3] Inevitably this combination of self-appraisal, anxiety and emotional distress necessitates the adoption of a coping strategy which may in turn help restore a degree of empowerment and self-esteem. [4] Adopting the most appropriate coping strategy is important to hospice patients who are not only struggling to come to terms with the possibility of death but who may also be searching for a meaning and purpose to their life-threatening illness. [5] Often incorporating existential, spirituality or religiosity factors, coping choice can play a major role in determining whether the patient views their current health state with fatalistic pessimism or with the type of optimism found in the view that dying is part of a greater plan for the universe. [6] It may even aid the patient to recover a little control and self-direction within an otherwise alien environment and in some circumstances, reduce physical pain and discomfort. [7] Failure to cope adequately may lead to psychological and physical degeneration.

Developing measurements to assess the quality of life (QOL) of end-of-life patients has been undertaken throughout the last decade in particular [7,10] in order to fulfil the criteria promoted by the World Health Organisation that “palliative care aims to achieve the best possible quality of life for patients whose disease is not
responsive to curative treatment”. [36]

Although QOL assessment is recognised within palliative care as a desirable tool in understanding the multidimensional impact of disease upon the patient [11] there still remains a hesitancy within the medical profession to undertake interviews or questionnaire testing with advanced terminally ill patients. The view that patients close to death would be too emotionally upset or unwilling to participate in assessment tests and that it may be expedient to allow them to die in peace still prevails among some medical practitioners. [12,13] But research has shown that 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”. [14] Consequently, researchers have persevered in their quest to find the most appropriate and least invasive QOL measuring tool which will present the physically frail and often mentally exhausted end-of-life patient with the least amount of participation difficulty. [15,16,17]

By their very nature, specialised care hospice policies strive to cater for the physical and emotional needs of their patients. [18–20] Spirituality, however, has yet to be included as a top priority [2] even although this aspect of a patient’s life may be crucial to their quality of life self-assessments. [3] Recent research has illustrated the need for spirituality / religiosity to be included within palliative care policies. [16,17,21] It is therefore vital that research studies continue to explore these variables within the context of a QOL agenda. By so doing, spirituality / religiosity orientation may be recognised as factors to be included within QOL considerations in order that a more holistic evaluation of patient’s physical, mental and spiritual needs can be brought to the attention of medical decision-makers. Patient’s evaluation of the quality of palliative care services offered within the hospice in which they receive their treatment often depends on their affiliation with the ethos of the hospice and their appraisal of hospice policies which impact upon their physical, emotional and spiritual well-being.

This research study evaluated the self-reported QOL assessments of spirituality and non-spirituality orientated end-of-life patients within 2 hospices in the west of Scotland.

METHODS

Over a six-month period (2003), the QOL scores of 120 advanced terminally ill patients within 2 specialized care hospices were evaluated using an adapted version of the McGill Quality of Life Questionnaire (MQOL). [22] The latter is an appropriate measuring tool as it was designed specifically for use with advanced palliative care patients and is one of the few instruments to include an existential domain. [23] The adapted version, the McGill Quality of Life Questionnaire – Scottish Version (MQOL-SV), retained all 4 domains – “Physical”, “Psychological”, “Existential” and “Support” since all four scales provide a good measure of Quality of Life (QOL) at all stages of the disease trajectory. Due to the fragile disease status of volunteer patient’s illnesses, it was decided (by permission of the original authors) to eliminate those questions that were considered repetitious, culturally difficult to understand or not vital to the main objectives of this study. Thus, the first 3 questions, labeled A, B and C. which concentrated on specific physical symptoms relating to each individual patient were deleted and replaced with the following.

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

From the remainder of the original 14 MQOL questions, number 8 -

“My life to this point has been completely worthless 1 2 3 4 5 6 7 Very worthwhile” was eliminated as it was thought very similar in context to number 6 –

My personal existence is, utterly meaningless & without purpose 1 2 3 4 5 6 7 Very purposeful & meaningful

Number 13 in the MQOL original version,

“The world is an impersonal unfeeling place 1 2 3 4 5 6 7 Caring and responsive to my needs” was eliminated in the interests of keeping the questionnaire as short as possible. Lastly a question about prayer, “Would you be willing to have prayers said for you?” - Yes, No, Not Appropriate - was included, 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 elimination of 2 MQOL questions was not considered a threat to the validity or reliability of the abridged MQOL-SV instrument. The changes were advised and sanctioned by hospice staff as it was felt the deleted questions were too
long and too confusing for patients with non-curable illnesses within the west of Scotland. The patients were considered too weak to read and answer MQOL-SV questionnaire by themselves. Consequently, in order to prevent the study becoming too taxing for their mental and physical welfare, the researcher personally interviewed all 120 volunteer patients. In every instance, information detailing the nature and aims of the study was discussed and ample time given for queries and explanations. All participating patients within both hospices were asked identical questions. Their self-rated evaluations were then recorded onto a questionnaire form. The original score ratings of 1-7 were reduced to 1-5. Evaluation ratings were assessed on a Likert-type scale - incorporating score ranges of between 1-60. An example of the Likert-type scale is illustrated by question 2:

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.

This design produced the subsequent advantage of eliminating unfinished questionnaires – a common feature within most palliative-care research.

The four MQOL-SV sub-scales remained identical to those of the MQOL.

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

The principal aim of the research was to establish whether patients with high / low “Quality of Life” scores were associated with one of the 3 groups within both hospices.

1. B (Believers and practising church-members).
2. NPB (Believers but non practising church members).
3. NB (Non-believers / non-practising)

All volunteer participating patients gave permission for confidential information to be extracted from their files. This information included the patient’s nominal religion and whether the patient practised his or her religious / spiritual beliefs. This information had been compiled when patients first became resident within Hospices A and B. Each individual patient was asked to base their religious / spiritual orientation on whether they believed in God or a spiritual creator; whether they regularly attended church or place of worship; whether they had religious or spiritual beliefs but did not practise rituals connected to their beliefs; or whether they had no spiritual or religious beliefs or affiliations.

Although specific religious groupings were identified – e.g. Catholic, Methodist, Church of Scotland etc., this research study was interested only in the coping mechanisms of patients within the 3 groupings above (B, NPB & NB).

Information concerning the patient’s illness and stage of disease was also supplied. Information was not accessed however until completion of all interviews in order to minimise criticism of researcher bias. The medical criteria for patient inclusion was 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.

Patients assessed by consultants in palliative medicine as meeting the necessary criteria were issued with Information Sheets which helped them to decide whether or not to participate in the research. The Information Sheets explained the rational 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 who had granted approval of the research study and all volunteers were assured that any personal information given in the study would be treated in the strictest confidence. Pilot tests were conducted with 2 patients from each hospice (not included in the final results) in order to acquire confidence in empathetic communication techniques with end-of-life patients and also to gain practise in data collection. The amount of time expended in the pilot tests had indicated “face to face interviewing” as a time-consuming procedure. Once empirical research began however, it became apparent that only 4 - 6 interviews on average were being achieved per
week. As a total of 6 months (3 months for each hospice) had been allocated for “Patient Research” the amount of time devoted to each interview ultimately determined the population sample. During 3 months of individual interviewing within the first participating hospice (Hospice A) the study attained 60 completed questionnaires. The same number of responses were subsequently 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.

During the 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.

RESULTS

MQOL-SV score totals for sub-scales Physical, Psychological, Meaningful Existence, Outlook / Support (Questions 1 – 12) were analysed using “Two Way Between Groups factorial ANOVA” (utilising a 3 x 2 factorial design). A Bonferroni adjustment was applied to all test results with p level of 0.01 set as determining statistical significance. As data from Questions A, B, & C was nominal / categorical in design, a non-parametric “crosstabulation procedure” - (3 x 3 contingency table, p = 0.05) specifically chi-square was used 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. Question 13 was concerned with whether patients were willing or not willing to have prayers said for them. One-way Analysis of Variance (ANOVA) was utilised (p = 0.05)

Since “Patient Research” took place within 2 separate hospices, Descriptive Statistics results are initially displayed in order to illustrate resulting differences (Table 1).
### Figure 2

<table>
<thead>
<tr>
<th>Stage of Disease</th>
<th>Total</th>
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<tbody>
<tr>
<td>Rehabilitation</td>
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<td>Cancer 58 (96.7%)</td>
</tr>
<tr>
<td>Symptom Control</td>
<td>29 (48.4%)</td>
<td>Cancer 58 (96.7%)</td>
</tr>
<tr>
<td>End of Life</td>
<td>17 (28.3%)</td>
<td>Other 53 (93.3%)</td>
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<tr>
<td>Total</td>
<td>60 - 100%</td>
<td>Total 60 - 100%</td>
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### Figure 3

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<td>Physical Sub-Scale</td>
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<table>
<thead>
<tr>
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<th>Very Poor Physically</th>
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<tr>
<td>Poor Psychological Health</td>
<td>16 (26.7%)</td>
<td>29 (48.3%)</td>
<td>11 (18.3%)</td>
</tr>
<tr>
<td>Fairly Poor Psychological Health</td>
<td>27 (45.8%)</td>
<td>17 (28.3%)</td>
<td>11 (18.3%)</td>
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<tr>
<td>Good Psychological Health</td>
<td>12 (20.1%)</td>
<td>12 (20.1%)</td>
<td>23 (38.5%)</td>
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<td>Total</td>
<td>60 - 100%</td>
<td>Total 60 - 100%</td>
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### Figure 4

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<th>Fairly Meaningless Existence (17/28.3%)</th>
<th>Very willing (42/70.0%)</th>
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<td>Total (60/100%)</td>
</tr>
<tr>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
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</table>

#### Outlook In Life Sub-Scale (Support)

<table>
<thead>
<tr>
<th>Poor Outlook (6/10.7%)</th>
<th>Poor Outlook (6/10.7%)</th>
<th>Religious belief / Spirituality (22/36.7%)</th>
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</thead>
<tbody>
<tr>
<td>Fair Outlook (14/23.3%)</td>
<td>Fair Outlook (14/23.3%)</td>
<td>Family / Self (26/43.3%)</td>
</tr>
<tr>
<td>Good Outlook (26/43.0%)</td>
<td>Good Outlook (26/43.0%)</td>
<td>Other Answer (12/20.0%)</td>
</tr>
<tr>
<td>Very Good Outlook (16/27.0%)</td>
<td>Very Good Outlook (16/27.0%)</td>
<td>Total (60/100%)</td>
</tr>
<tr>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
</tr>
</tbody>
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#### Willing to have Prayers said for you (Qu.13)

<table>
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<th>Very unwilling (6/10.0%)</th>
<th>Very unwilling (6/10.0%)</th>
</tr>
</thead>
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<tr>
<td>Fairly unwilling (6/10.0%)</td>
<td>Fairly unwilling (6/10.0%)</td>
<td>Fairly unwilling (6/10.0%)</td>
</tr>
<tr>
<td>Neutral (6/10.0%)</td>
<td>Neutral (6/10.0%)</td>
<td>Neutral (6/10.0%)</td>
</tr>
<tr>
<td>Fairly willing (6/10.0%)</td>
<td>Fairly willing (6/10.0%)</td>
<td>Fairly willing (6/10.0%)</td>
</tr>
</tbody>
</table>

### Figure 5

#### What Has Sustained During Crisis (Qu.A)

<table>
<thead>
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<th>Religious belief / Spirituality (22/36.7%)</th>
<th>Religious belief / Spirituality (22/36.7%)</th>
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<tbody>
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<td>Family / Self (26/43.3%)</td>
<td>Family / Self (26/43.3%)</td>
</tr>
<tr>
<td>Other Answer (12/20.0%)</td>
<td>Other Answer (12/20.0%)</td>
<td>Other Answer (12/20.0%)</td>
</tr>
<tr>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
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#### What Has Been On Mind (Qu.B)

<table>
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<th>Religious belief / Spirituality (6/10.0%)</th>
<th>Religious belief / Spirituality (6/10.0%)</th>
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</thead>
<tbody>
<tr>
<td>Family / Self (30/50.0%)</td>
<td>Family / Self (30/50.0%)</td>
<td>Family / Self (30/50.0%)</td>
</tr>
<tr>
<td>Other Answer (24/40.0%)</td>
<td>Other Answer (24/40.0%)</td>
<td>Other Answer (24/40.0%)</td>
</tr>
<tr>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
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</table>

#### What Gives Meaning to Life (Qu.C)

<table>
<thead>
<tr>
<th>Religious / Spirituality Concerns (24/40.0%)</th>
<th>Religious / Spirituality Concerns (24/40.0%)</th>
<th>Religious / Spirituality Concerns (24/40.0%)</th>
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<td>Religious / Spirituality Concerns (24/40.0%)</td>
<td>Religious / Spirituality Concerns (24/40.0%)</td>
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### Figure 6

#### Issues Concerning Family / Self

<table>
<thead>
<tr>
<th>Issues Concerning Family / Self (16/26.7%)</th>
<th>Issues Concerning Family / Self (16/26.7%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other Answer (22/38.7%)</td>
<td>Other Answer (22/38.7%)</td>
</tr>
<tr>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
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#### Time Between Interview & Death

<table>
<thead>
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<th>Time Between Interview &amp; Death (Less than 1 week (20.0%))</th>
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<tr>
<td>Less than 1 week (20.0%)</td>
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</tr>
<tr>
<td>Between 1 – 4 weeks (31.7%)</td>
<td>Between 1 – 4 weeks (31.7%)</td>
</tr>
<tr>
<td>Between 1 – 3 months (16.6%)</td>
<td>Between 1 – 3 months (16.6%)</td>
</tr>
<tr>
<td>Between 4 – 6 months (33.3%)</td>
<td>Between 4 – 6 months (33.3%)</td>
</tr>
<tr>
<td>Still alive after 8 months (30.5%)</td>
<td>Still alive after 8 months (30.5%)</td>
</tr>
<tr>
<td>Total (60/100%)</td>
<td>Total (60/100%)</td>
</tr>
</tbody>
</table>
TWO WAY BETWEEN GROUPS FACTORIAL ANOVA (PROFILE PLOTS 1 – 4)

Figure 7
Profile Plots 1: Estimated Marginal Means of Physical Status Sub Scale

Result differences between patients in hospices A & B could initially be detected in the Descriptive Statistics Tables (Table 1) Inferential statistics consisting of a 3 (Religious Orientation: B vs. NPB vs. NB) x 2 (Hospice: A vs. B) between groups factorial ANOVA explored the impact of “Hospice” and “Religious orientation” on levels of “Physical Status” as measured by the MQOL-SV. Tests of Between Subjects Effects showed that the main effect of “Hospice” was significant (F, 19.55, p = .000). The effect size was large (eta squared = .14). Religious Orientation was not significant (F, 1.78, p = .172) “Tests of Between Subjects Effects” showed the main effect to be qualified by a significant interaction effect (F, 5.20, p =.007) . 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 between mean scores of B, NPB when compared with NB patient's scores within Hospice B, - (F, 8.293, p = .001). No significant scores were recorded between the same groups in Hospice A – (F, .477, p = .634). (Profile 1)

Figure 8
Profile Plot 2: Estimated Marginal Means of Psychological Sub-Scale

Descriptive Statistics (Table 1) recorded result differences between patients in hospices A & B as not as pronounced as they were for the Physical Sub-Scale. Inferential tests of Between Subjects Effects showed that “Hospice” was non-significant (F, 2.14, p = .146). The main effect - “Religious Orientation” was significant (F, 4.57, p = .012) 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 (F, .334, p = .717). The most striking feature illustrated in Profile 2 was that both hospice populations were represented in an arrow formation in which the NPB constituted the apex of the arrow. Thus for Hospices A & B, the NPB assessed themselves to have the highest scores in the “Psychological Sub-scale”. In other words, the NPB felt less depressed, less anxious, less worried and less fearful of the future than the B & NB patients within their respective hospices. Subsequent one-way ANOVA identified no significant results between mean scores of B, NPB when compared with NB patients within Hospice B, (F, 2.591, p = .084). No significant scores were recorded between the same groups in Hospice A – (F, 2.456, p = .095). (Profile 2).
Result differences between patients in hospices A & B could initially be detected in the descriptive statistics (Table 1). Inferential Tests of Between Subjects Effects showed that the main effect of “Religious Orientation” (F, 5.98, p = .003) was significant with a moderate effect size (eta squared = .09). “Hospice” was not significant (F, .337, p = .563). Reference to the “Tests of Between Subjects Effects” also showed that the main effect was qualified by a significant interaction effect (F, 11.19, p = .000). 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. One-way ANOVA confirmed significant results for B & NPB when compared with NB patient's scores within Hospice B (F, 16.714, p = .000). No significant scores were recorded between the same groups in Hospice A (F, .960, p = .389). (Profile 3).

Descriptive Statistics (Table 1) record little difference in Support Sub-scale results between both hospices. Inferential tests of Between Subjects Effects showed that the main effect of “Religious Orientation” was significant (F, 13.77, p = .000) with a large effect size (eta squared = .19). The main effect for “Hospice” and the interaction effect did not reach statistical significance (F, .828, p = .439). One-way ANOVA confirmed significant results for B & NPB when compared with NB patient's scores within Hospice B (F, 11.067, p = .000). No significant scores were recorded between the same groups in Hospice A (F, 4.547, p = .015 - Bonferroni adjustment).

Total Scores

“One-Way ANOVA” tests produced non-significant results for Hospice A, but significant results for Hospice B. Investigation of the Post Hoc Tests (Multiple Comparisons) and (“Homogeneous Subsets”) illustrated that there were significant differences in mean score totals between all 3 groups in Hospice B (B, NPB & NB patients). Whereas for Hospice A, results indicated that there was no significant difference in quality of life Total Scores for B, NPB or NB patients.

MQOL-SV - Questions A, B & C.

Table 2: Question A – “What has sustained you during times of crisis?”
Table 3 displays a Chi-Square value of 13.773, p = .008.

**Chi-Square Tests - Table 3**

Table 4 Question B – “What has been on your mind recently?”

**Figure 13**

Table 5 displays a Chi-Square value of 3.990, p = .407.

**Chi-Square Tests - Table 5**

Table 6 Question C – “What do you think gives meaning to life?”

**Figure 14**

Table 7 displays a Chi-Square value of 38.107, p = .000.

**Chi-Square Tests - Table 7**

Table 8 – Hospice A Patients:

**Figure 15**

Analysis-of-Variance Table 3: Intercessory Prayer Response by Religious Orientation Status

**Figure 16**

Distribution of F (p = 0.05)

Table 8 displays an F value of .498, p = .610.
**DISCUSSION**

With reference to the Physical Sub-Scale (Profile plot 1), B & NPB in Hospice B, attained statistically significant score totals for physical status whereas NB patients attained the lowest overall scores among the 6 groups. For Hospice A, although NB patients attained marginally higher scores than B & NPB, inferential statistics revealed that these results were not statistically significant. Consequently, patients in all 3 categories of religious orientation in Hospice A, together with the NB patients in Hospice B assessed their physical health to be at a similar level. The homogeneous subsets demonstrated that B & NPB in Hospice B attained significantly higher physical status scores than the other 4 groups. A clue to a possible explanation for these results may be found in the design of this study which had afforded the researcher personal access to both patients and hospice policy for several months both during and prior to the operation of the study.

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 resulted in a notably attentive nursing staff whose care for their patients extended beyond solely medical and physical needs. Whenever possible, (i.e. when awake and without visitors) nursing staff engaged in communication with their patients [29] Nursing practice promoted a sense of community and self-esteem. Without being consciously aware of it, B & NPB may have been bolstered by the ethos of the hospice to the extent that they assessed 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 (Chart A). 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 NB, 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 perhaps have unintentionally promoted a sense of disorientation in their NB patients, making them feel “outsiders” in a comfortable yet unfamiliar environment. One additional explanation of why B & NPB 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 was that NB scores for “Physical status” in Hospice B were the same (statistically) as those within all 3 categories of Hospice A – (B, NPB & NB). It is possible that these groups were more representative of a terminally ill hospice population. However, this does not explain why the B & NPB populations in Hospice A seemed to feel slightly worse (physically) than the NB 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 B & NPB 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 chaplains. Certainly, descriptive statistics 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 NB patients it followed therefore, that B & NPB (who constituted 44% of the hospice population), assessed themselves as having lower physical health scores than those of the NB patients. (This follows a similar type of pattern to Hospice B). Even although they assessed their quality of life to be high, B & NPB in Hospice A nonetheless felt less physically well than the NB patients. Crucially their scores were also much lower than the scores of those within the same categories (B & NPB) in Hospice B.

In summary, all 3 categories of religious orientation (B, NPB & NB) within Hospice A, together with the NB 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. These research study results indicate that the significant results in Hospice B may have occurred due to a “bolstering influence” created by the spirituality ethos prevailing in Hospice B, which had the effect of helping their B & NPB feel physically better than they in fact actually were. It is important to point out that all patients taking part in this study were, in fact, physically very seriously ill. Recorded times between interviews and death 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. (Table 1)

Criticism that Hospice A patients must have been more physically ill than patients in Hospice B would be discredited 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). Consequently, severity of illness levels between volunteer patients within Hospices A & B were subject to identical criteria.

PSYCHOLOGICAL SUB-SCALE (PROFILE PLOT 2).

An explanation of why the NPB felt less depressed, less anxious, less worried and less fearful of the future than the B & NB patients within their respective hospices may lie in the fact that most patients answered the “Psychological Sub-scale” questions in one of 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. 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 classify. 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. For both hospices, NPB attained higher mean scores than those of the B
patients.

It is possible that the B patients 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 B patients were almost identical to the means of the NB patients. This factor leads to two possible conclusions. The latter scores represented a more truthful assessment of psychological status and that the B & NB patients may have accepted the reality of their terminal status better than the NPB who may have been exhibiting signs of denial. 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.

The NPB 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 interviews 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 NPB hope of accomplishing changes in the near 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 B & NB sample populations.

The Meaningful Existence Sub-Scale (Profile plot 3).

An interesting factor within the results for this sub-scale was that the NB populations (within both hospices) appeared to have attained similar means although there are differences in comparison with other groups. It was therefore necessary to consider two questions.

1. Why did NB patients in Hospice B produce lower scores than the NB & BNP patients in Hospice A as well as the lowest overall scores?

2. Why did NB patients in Hospice A self-assess similar scores to those of the BNP patients in Hospice B?

Beginning with MQOL-SV question 1, the low “Meaningful Existence” score of NB 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 B & BNP 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 NB patients due to a sense of isolation from the more overtly ritualistic practises experienced by the B 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 NB 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, NB patients. Interestingly, while there may be justification in proposing that B & BNP patients in Hospice A may also have experienced a similar state of mind to NB 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, 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 purpose for their claimed existence, even although family or occupation may also be important to them. 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 were to them.

With regard to question 2, the reasons why NB patients (Hospice A) attained similar scores to those of NPB patients in Hospice B will now be considered. Unlike the same grouping in Hospice B, NB patients in Hospice A, while also not possessing a belief system, were uninfluenced by spirituality policies such as staff / patient communication of spirituality issues (these were not policy within this hospice). Thus their assessment of “Meaningful Existence” would have no religious / spirituality connotation and would be based mainly on family, work or other concerns. These factors seemed to raise their assessments slightly higher than those of the B & NPB (Hospice A) although results for Hospice A groups were non-significant. The fact that NB patients in Hospice A achieved the same score as NPB in Hospice B was most probably coincidence. As previously mentioned, the latter attained lower scores than Hospice B patients within the B category because some experienced symptoms of denial or depression.

In conclusion, B & NPB (Hospice B) attained the highest mean scores in this existential sub-scale because these patients related meaningful existence to their religious / spirituality beliefs. 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 proposes that the mean scores for B, & NPB (Hospice A) & NB (Hospice B) were the result of a lowering of self-esteem and self-confidence due to the different policies operating within each hospice. NB (Hospice A) patients were the only group whose self assessed “Meaningful Existence” scores were uninfluenced by either “Religious Orientation” or hospice policy.

SUPPORT SUB-SCALE (PROFILE PLOT 4).

The main question to arise within this sub-scale was why NB patient scores in both hospices were so much lower than the scores of the B & NPB. During researcher / patient interviews, a frequent assessment recorded by some of the 120 patients was that their level of care within their respective hospice was comparable 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. Successful coping often depends on the individual's personality, background, experiences and beliefs and theories illustrating the “Connectedness” of hospice aid “triggering” deeper reflections of the consequences of illness were undoubtedly important to these results. “Religious orientation” was found to be of prime importance to the Support Sub-scale reinforcing previous research findings whereby serious illness often resulted in solitude and loneliness for patients unable to undergo a “spiritual journey”.

NB patients in both hospices (A & B) may have experienced less self-esteem and assessed life more burdensome (than the B & NPB) 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 would have been absent in NB patients. Conversely, hope may have provided the B & NPB populations with an active cognitive framework with which to face their future. 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”. The NB populations may have been subject to “spiritual distress” which is 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”. 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 NB patients during interviews, led 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 have caused some patients within the NB populations to feel less supported than their overtly religious / spiritual fellow patients. The intimate revelations confided to the researcher during the interviews nevertheless seemed to be insufficiently impacted upon the belief system of those involved to impinge upon their assessments of
questions within this “Support Sub-Scale”.

MQOL-SV - Questions A, B & C.

Question A - “During your lifetime, what has sustained you in times of crisis?”

Chi-Square Tests (Table 3) revealed a significant result and indicated that the responses of B & NPB within both hospices were more spiritually and religiously orientated than the responses given by “non-believing patients”.

Reference to Table 2 reveals that 24 B patients and 13 NPB reported turning to their faith / belief system as a coping aid during stressful circumstances. This supports the 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. [32] A small number (12) of NB patients purported turning to “spirituality” during times of stress. During the interviews, NB 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. 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 Question A (Table 2), “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 (Table 5) revealed a non-significant result. Reference to Table 4 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 B & NPB 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 are supported within other studies. [44, 45] 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. [16]

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 significant results within Chi-Square Tests. (Table 7) Responses of B & NPB within both hospices were more spiritually and religiously orientated than the responses given by “non-believing patients”.

Descriptive Statistics (Table 1) 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-SV results had indicated that B & NPB in Hospice A may have been disappointed and somewhat depressed at the exclusion of their spirituality / religious beliefs in conversations with staff.
Reference to Table 6 reveals that 17 “believing” and 13 “non-believing” patients chose category “Family / Self” as denoting “meaning to life”. Reference to Table 1 reveals 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”.

MQOL-SV Question 13, concerning prayer will now be discussed.

Descriptive results were fairly similar but not identical (Table 1). One-way ANOVA results demonstrated that within both hospices, NB patients were as willing as B & NPB patients to have prayers said for them. This result supports previous research findings. [46, 47, 48]

One of the qualities of greatest significance to the coping process regarding the relationship of B & NPB 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”. [36] 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. 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 NB patients) may be in their attitude towards spirituality / religious belief. Consequently, for some NB 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. [36] 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.

CONCLUSIONS

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.

Overall, the design of the MQOL-SV succeeded in its original intention of producing a comparison of QOL scores for the groups of B, NPB & NB 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”.

Results of the MQOL-SV also indicated that there seemed to be both conscious & unconscious coping strategy choice. 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 NB 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” (B & NP), coping strategy choices depended principally on personal “faith / spirituality beliefs” but the most surprising MQOL-SV finding was that for these patients QOL self-assessed scores seemed to be either “bolstered” or undermined by the policies operating within their respective hospice. Thus, it was “spirituality orientated” patients in Hospice B that recorded the significantly higher QOL scores (bolstered by the holistic
hospice policies within that hospice). “Spirituality orientated” Hospice A patients, while recording higher scores than NB patients within that hospice nonetheless failed to achieve significant scores which this study proposes may have been due to a lack of spirituality / holistic policies operating within Hospice A.

RECOMMENDATIONS

Routine inquiry relating to patient's spirituality / religiosity orientation should be included in initial interviews conducted with patients entering hospice care. Such information has clinical relevance since it establishes the patient as a unique individual and not merely an individual with a symptom.

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.

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.

Pain management should include psychological as well as physical assessments since pain may result from existential / spiritual distress as well as physical degeneration.

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 spirituality and non-spirituality orientated dying patient.

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