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# A pilot project to assess the impact of a psychosocial retreat intervention on the quality of life, distress, marital satisfaction and existential concerns in palliative cancer patients and their partners

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "A pilot project to assess the impact of a psychosocial retreat intervention on the quality of life, distress, marital satisfaction and existential concerns in palliative cancer patients and their partners" submitted by Sheila N. Garland in partial fulfillment of the requirements for the degree of Masters of Science.

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Abstract

The negative impact of a palliative cancer diagnosis on the quality of life of patients and their partners is well documented. Unfortunately, research on interventions to improve psychological and spiritual well-being of these couples has been considered impractical because of the deleterious influence of disease progression on participation. This study evaluated the feasibility of offering the Tapestry Retreat, an intensive psychosocial intervention, to 15 patients with palliative breast, prostate or colon cancer and their partners (n=30). Also included was a natural history group consisting of 20 patients and their partners (n=40). All couples completed questionnaires related to quality of life, distress, marital satisfaction and existential concerns at baseline, after the retreat or 1 month after baseline and then again at 3, 6, 9, and 12 months. Despite issues with recruitment and retention, retreat participation is suggestive of benefit for patient quality of life and existential well-being. Recommendations for future research are discussed.

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This thesis represents the combined work of a number of very important people. The Tapestry Retreat program is facilitated by a group of talented and compassionate individuals who help to positively impact the lives of all people who attend. I would like to thank Dr. Helen McRae and Dr. Maureen Angen for their dedication to continuing to provide this wonderful service to patients wanting a deeper meaning of their cancer experience.

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## Dedication

This work would not have been possible without the generosity of the couples who selflessly donated their time to increase our understanding of the issues important to health and life. It is recognized that their contribution was often provided without complaint despite barriers of ill health. Their gift is appreciated and will be used to improve outcomes for couples who may later face a similar challenge.

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*Introduction*

The distress elicited by a cancer diagnosis at any stage is well documented. The negative consequences of receiving a palliative cancer diagnosis can be even more severe. Cancer, especially when untreatable, is demonstrated to have a deleterious effect on patient quality of life (QL), psychological health, and marital satisfaction. In addition, patients are often confronted with end of life considerations and existential issues. The partners of these patients also report negative life effects, and worries of the future that can meet or exceed that of the patient. Despite the demonstrated difficulties experienced by these patients and their partners, there are few interventions designed to address their complex needs. This study evaluates the feasibility and acceptability of a psychosocial intervention designed to address the issues important to patients with palliative cancer and their partners.

*Quality of Life at the End of Life*

According to the World Health Organization (WHO), palliative care is defined as the active total care of patients whose disease is not responsive to curative treatment with the goal of improving quality of life (QL) (World Health Organization, 1990). Quality of life has been described as a multidimensional quantification of the overall physical, social, emotional and functional well-being of the patient and has recently began to include additional domains of spiritual well-being (Velikova, Stark, & Selby, 1999; Cella & Bonomi, 1995). The inclusion of the existential domain is particularly significant for

patients with palliative cancer (Cohen et al., 1997). Patient reported QL may differ depending on when it is measured in the disease trajectory, with most research suggesting a general downward trend and dramatic decreases in QL over the last 12 weeks of life (Axelsson & Sjoden, 1998; Hwang, Chang, Fairclough, Cogswell, & Kasimis, 2003). Hwang et al. (2003) also found differences in the deterioration rate of QL domains, with physical well-being and overall quality of life showing the fastest decrements and emotional well-being demonstrating slow, steady decline. In the last weeks of life, existential concerns and overall QL often take priority over other areas of functioning (Lo et al., 2002).

Quality of life measurement with palliative patients is complicated by progression of the disease as well as the effect of treatments, which can be associated with considerable morbidity. Reliable research on QL in palliative oncology is scarce; mainly due to problems with recruitment and patient attrition (Jordhoy et al., 1999). Recruitment is negatively influenced by the patient's complex symptomotology, physical and mental exhaustion and the health care team's tendency to be reluctant to add perceived burden to patients often considered fragile. Attrition in palliative QL studies is primarily caused by patient death or functional impairment due to progressing disease. Disease progression can also affect the patient's ability to complete self-assessments of QL, making the assessments impossible or inaccurate. Despite the challenges in this research, more studies are needed to identify ways to meet the goals of palliative care: that is to, maximize QL in patients at the end of life.

*Quality of Life of Partners*

Patients' preference to receive care on an outpatient basis or within the home often places extra demands on partners of terminally ill cancer patients in caregiving roles (Pitceathly & Maguire, 2003). Caregivers have been found to have poorer mental health, vitality and social functioning compared to others in their age group (Grov, Dahl, Moum, & Fossa, 2005). There is considerable research demonstrating that the QL of the partner is significantly correlated to the patient's QL (Kornblith et al., 2001; Axelsson & Sjoden, 1998; Blanchard, Albrecht, & Ruckdeschel, 1997; Chen, Chu, & Chen, 2004; Fleming et al., 2006; Carlson, Ottenbreit, St, & Bultz, 2001; Northouse et al., 2002). It has also been reported that the caregivers' emotional well-being is worse than the patients', and significantly worse than the normal population (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Grov et al., 2005; Northouse et al., 2002). Unfortunately, other research has demonstrated that caregivers are less likely to disclose their concerns and worries than patients and only half of those with serious problems will seek help, often because they neglect their own needs to focus on those of the patient (Pitceathly & Maguire, 2003).

The partner's QL can also be influenced by the stage of the patient's disease. Caregivers of palliative patients report significantly worse QL, and greater impairment in physical functioning, general health and vitality than do caregivers of patients in active or curative treatment (Weitzner, McMillan, & Jacobsen, 1999). Others report that the partners' domains of physical limitations, emotionality, and mental health suffer most before the death of the patient but rise consistently thereafter (Ringdal et al., 2004).

Despite the fact they are highly correlated with each other, the QL of partners has not received nearly as much attention as the QL of the patient.

*Negative Psychological Symptomotology*

*Distress*

It has been suggested that psychological distress be the 6th vital sign that is routinely screened for in comprehensive cancer care (Bultz & Carlson, 2005). This suggestion is based on a number of studies reporting significant cancer-related distress in approximately 1/3 of all patients across the disease trajectory (Carlson & Bultz, 2003; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001; Stefanek, Derogatis, & Shaw, 1987; Carlson et al., 2004). Distress in patients with palliative cancer has been demonstrated to exceed that of patients in other stages of the disease trajectory (Zabora et al., 1997). In partners, levels of distress are highly related to the interference of caregiving with one's lifestyle (Cameron, Franche, Cheung, & Stewart, 2002). In addition to caregivers reporting worse QL, some research has reported that the psychological distress of caregivers is often more severe than among patients (Northouse, Mood, Templin, Mellon, & George, 2000).

*Depression*

The reported prevalence rate of major depression in terminally ill cancer patients ranges from 38% (Fleming et al., 2006) to 49% (Kissane, Bloch, Burns, McKenzies, & Posterinos, 1994) when assessed with self report questionnaires. As with distress, the rates of depression in palliative cancer patients tend to be higher than the larger oncology population (Pitceathly & Maguire, 2003). Studies that have used standardized psychiatric interviews tend to find lower, but still significant, levels of depression in palliative cancer

patients (Lloyd-Williams, Dennis, & Taylor, 2004; Maguire, Walsh, Jeacock, & Kingston, 1999). According to Maguire et al. (1999) the prevalence rate of psychiatric morbidity in caregivers is 33%, similar to the prevalence rate of 35% reported by Kissane et al. (1994). These studies suggest that depressive symptoms are likely a concern in at least 1/3 of palliative cancer patients and their partners. Considering the negative impact that depression can have on QL and the limited survival of these patients, depression is an important area of focus for palliative research.

*Fatigue*

Fatigue is one of the most commonly reported symptoms causing distress in cancer patients. Much of the research to date has focused on fatigue in patients with a good prognosis to recover; less is known about the impact of fatigue on patients with palliative cancer and their partners (Krishnasamy, 2000). In a sample of palliative cancer patients, fatigue was reported in 57%, compared to only 20% of the control participants (Stone et al., 1999). High fatigue levels have been shown to contribute to negative psychological symptomotology, and improving fatigue can improve symptoms of anxiety and depression in cancer patients (Tchekmedyian, Kallich, McDermott, Fayers, & Erder, 2003). Fatigue in the partners and caregivers of cancer patients is also a significant problem. Jensen and Given (1991) report that over 50% of 248 caregivers of cancer patients reported moderate or severe levels of fatigue which positively correlated with their sense of burden. Unfortunately, no available research to date has investigated fatigue in the partners of individuals in palliative care.

*Marital Satisfaction*

The marital relationship can be a primary source of support for a person with a palliative cancer diagnosis. In fact, having a marital partner has been hypothesized to increase cancer patients' motivation to seek more aggressive treatment and practice better health habits, leading to an earlier diagnosis and/or improved survival (Goodwin, Hunt, Key, & Samet, 1987). Marital status itself is not a solitary predictor of better adjustment to a cancer diagnosis, but rather certain qualities of the relationship, such as emotional expression, predict better adjustment (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000). Furthermore, increases in distress reported by the patient has been linked to a reduction in spousal ratings of marital satisfaction (Fang, Manne, & Pape, 2001). Other research has demonstrated that open and active communication relating to death and dying in this terminal phase predicts more positive adjustment for the patients and lower mood disturbance in the partner following the patient's death (Hagedoorn et al., 2000; Northouse, 1984). Considering the important role that the partner plays in the quality of the patients end of life experience, more research needs to examine factors that contribute to a reduction in marital satisfaction and methods to improve these relationships.

*Existential Concerns*

*Spirituality*

Spiritual well-being is increasingly being recognized as an integral part of palliative care. Spirituality is a broad concept but has been described as the way individuals understand the ultimate meaning and value of their lives (Muldoon & King, 1995). Terminally ill cancer patients are often forced to confront issues they had

previously avoided, such as questions about their mortality, the meaning and purpose of life, and whether a greater power exists. Patients have often described the cancer experience as having deepened their existing faith/spirituality (Griffiths, Norton, Wagstaff, & Brunas-Wagstaff, 2002), and it has been suggested that the experience of living with cancer is an impetus to develop one's spiritual awareness (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Johnston Taylor, 2005). Research has demonstrated that spiritual meaning is not limited to the patient, but that partners experience similar needs (Johnston Taylor, 2003). Spirituality has been reported to have positive benefits for patients with cancer, such as being protective against negative psychological states and increasing tolerance of more physical symptoms (Brady et al., 1999; Nelson, Rosenfeld, Breitbart, & Galietta, 2002). Furthermore, spirituality has been demonstrated to account for a significant amount of the variance in hopelessness, desire for hastened death and suicidal ideation, even after controlling for depressive symptoms in terminally ill cancer patients (McClain, Rosenfeld, & Breitbart, 2003). Improving understanding of spiritual needs has the potential to improve the quality of remaining time for palliative patients and their partners (Chochinov & Cann, 2005).

*Attitudes to Death and Dying*

Discussions with terminally ill individuals about death and dying are often overlooked because of the perceived stress or harm that it may cause to the dying person, when in fact little is known about how terminally ill patients and their families actually feel about such discussions. Research is just beginning to provide some guidance in this area and suggests that very few patients and their caregivers find talking about death, dying and bereavement to be stressful and many find it helpful and therapeutic (Emanuel,

Fairclough, Wolfe, & Emanuel, 2004). Interventions that promote open communication about death and dying have the potential to help patients and their partners come to terms with end of life issues and promote understanding and acceptance which can ease the transition for the patient and adjustment in the bereaved. No research on the effects of psychosocial interventions on attitudes towards death and dying has been reported to date.

*Interventions for Palliative Patients and their Partners*

It is clear from the previous literature review that both patients and partners suffer from a number of varied concerns when dealing with cancer diagnosis; hence treatment should include both members of the dyad. In recognition of these needs, interventions to address the psychosocial needs of cancer patients and their families are increasingly being utilized. Despite the expansion of programs and services for cancer patients, their partners, and families in general, there has not been a corresponding growth of interventions during palliative care (Hudson, 2004). In fact, only 15% of 329 studies included in a systematic review of psychological therapies were designed for advanced stage cancer patients (Newell, Sanson-Fisher, & Savolainen, 2002). A recent review of interventions for couples facing end of life cancer revealed only 5 studies (McLean & Jones, 2007). They identified several gaps in the literature including the lack of theory in intervention development and recommend future research use longitudinal designs with validated outcome measures. The current research represents the first step in evaluating the feasibility of offering an intensive intervention to patients with palliative cancer and their partners and will be the foundation for future studies.

*Retreats as Interventions*

Retreats as interventions are becoming more popular as a means by which to offer psychosocial services because they offer a relatively intensive intervention in a shorter period of time. Unfortunately, many of the popular retreat interventions have not yet been systematically evaluated and as such, outcome literature is sparse. A possible reason for this is the atheoretical basis of many of the programs, including the Tapestry retreat. This limits understanding of participation outcome and hinders further development. Despite this, the research available to date suggests that retreat interventions may positively impact QL domains (Rutledge & Raymon, 2001). Preliminary research has been conducted to investigate outcomes of the Tapestry Retreat program (Angen, MacRae, Simpson, & Hundleby, 2002). After participation, participants reported improvements in individual levels of hope, tension and worry, stress, mental clarity, and isolation, results that were maintained at 3 month follow up. Qualitative examination revealed that participants experienced changes in attitude and behavior, an increase in perceived social support, and spiritual growth (Angen, Simpson, MacRae, & Hundleby, 2003). To date, no retreat interventions have addressed the specific needs of palliative cancer patients and their partners.

*Overview of the Tapestry Program*

The Tapestry retreat is based on the Commonweal Cancer Help Program (Remen, 1995) and has previously been described (Angen et al., 2002; Angen et al., 2003). A detailed day-by-day description is provided in Appendix B (p. 45). To date, the Tapestry retreat has been attended by over 350 cancer patients and more recently 20 couples. During the 5 days of the retreat, participants stay in an interdenominational Christian

Retreat Center located in the foothills of the Rocky Mountains. The program is attended by 8-12 people per retreat (4-6 couples), the retreats run 4-6 times per year and are facilitated by 3 psychologists and 1 psychiatrist. The program format consists of 5 major components and is non-religious in nature (that is, it has no formal connection to any specific religious faith tradition). First, the overall program is designed to create a safe and sacred space within the retreat center to encourage reflection, relaxation and respite. Secondly, the participants participate in a daily narrative group that encourages participants to share their experience with their own or their partner's cancer in a non-judgmental and supportive environment. Thirdly, throughout the program the participants take part in various creative activities, with an invitation to use this time to reflect and gain insight and wisdom. Fourthly, the participants are provided with opportunity upon waking and retiring for the evening to participate in gentle hatha yoga exercises, meditation, deep relaxation and visualization. Lastly, the facilitators offer educational/informational sessions in the areas of complementary and alternative medicine, pain control, and death and dying. Participants have included many different faiths including Christian, Muslim and Hindus as well as participants with no religious faith, although the vast majority acknowledges a personally meaningful spirituality grounded in humanist philosophies (personal communication).

## Objectives

This pilot study aims to assess the feasibility of a novel intensive psychosocial retreat program to enhance QL, reduce distress, improve marital relationships and address existential concerns in palliative cancer patients and their partners. This study has the following objectives:

1. Estimate feasibility of the recruitment strategy for the retreat program for use in subsequent research designs.

2. Collect pilot data on the acceptability of the research project and completion rates of a battery of outcome measures that have been selected to reflect the likely outcomes from an intensive psychosocial intervention for couples (with documentation of missed data due to death and drop-outs)

3. Determine which measures included in the questionnaire battery are sensitive to changes in the intervention group for use in future research design.

4. Examine changes over 12 months in general QL, distress, marital satisfaction and existential concerns for terminally ill cancer patients and their partners who choose or decline participation in the Tapestry retreat program.

## Methods

### *Participants*

Participants were identified as eligible if they had histopathologically confirmed metastatic cancer of the breast, prostate or colon, were legally married to a person of the opposite sex and resided within 1 hour of the Calgary region and attend the Tom Baker Cancer Center. After being identified as eligible, the patient charts were further reviewed by a research nurse, psychiatrist, palliative physician, and the attending oncologist. Exclusion criteria are extensive and described in Appendix C (p. 48).

### *Questionnaires*

#### *Patient Quality of Life*

Functional Assessment of Cancer Therapy-General (Cella et al., 1993): The Functional Assessment of Cancer Therapy- General form, version 4 (FACT-G) is part of

a measurement system called Functional Assessment of Chronic Illness Therapy (FACIT) intended for use in chronic diseases. The FACT-G is comprised of 27 items and includes an overall QL index and physical, social/family, emotional, and functional wellbeing subscales. Both the total score and the individual subscale scores have good internal consistency and have been well validated (Cronbach's alpha =0.89; $r$ = 0.82-0.88). Normative data is available for a large sample of 1075 adults in the general U.S. population and 2236 adult cancer patients (Brucker, Yost, Cashy, Webster, & Cella, 2005). Higher scores indicate better QL.

McGill Quality of Life Questionnaire (Cohen, Mount, Strobel, & Bui, 1995): The McGill Quality of Life Questionnaire (MQOL) was developed specifically for use in terminally ill populations. The MQOL is comprised of 17 items comprising five sub-measures relating to: physical symptoms, physical well being, psychological well being, existential well being, and social support as well as a total QL score. Higher scores indicate better quality of life. The questionnaire was validated in a multi-center study (Cohen et al., 1997) and was quantitatively able to capture the QL areas identified as being important to the palliative patients (Cohen & Mount, 2000). Feedback obtained from the retreat facilitator staff (Simpson, MacRae and Angen personal communication) also confirmed the MQOL questionnaire's applicability. The internal consistency of the item/total correlation ranges from 0.81 to 0.91 and the internal consistency for the subscales range from 0.65 for physical symptoms subscale to 0.87 for the psychological symptoms subscale. Test-retest reliability, as measured by an interclass correlation coefficient, was acceptable in the range of 0.69 to 0.78.

*Partner Quality of Life*

Quality of Life in Life-Threatening Illness – Family Caregiver Version (Cohen et al., 2001): The Quality of Life in Life-Threatening Illness – Family Caregiver Version (QOLLTI-F) is a 19 item self report instrument designed to measure the QL of family caregivers of palliative care patients. The items have a possible range from 0 to 10 with 0 indicating the worst situation and 10 the best situation (after transposition). The QOLLTI-F provides a total score as well as 7 subscales: Environment, patient state, own state, outlook, quality of care, relationships, and financial worries. The QOLLTI-F also includes an open-ended question asking the caregiver to list or describe the things which had their greatest effect on their QL in the past 2 weeks. The QOLLTI-F has been found to be acceptable to patients and psychometric validation is ongoing (Cohen et al., 2006)

*Negative Psychological Symptomotology*

Beck Depression Inventory-II (Beck, Steer, & Brown, 1996): The Beck Depression Inventory-II (BDI-II) is a 21 item self report measure of depressive symptomotology. It is widely accepted as a valid screening instrument for depression and has been used extensively in clinical and non clinical populations. The BDI-II possesses very good internal consistency (Cronbach's alpha = 0.92) and test-retest reliability (0.93), in addition to documented content and construct validity (Beck et al., 1996). Scores less than 13 on the BDI indicate minimal depressive symptoms, scores 14-19 indicate mild symptoms, scores 20-28 indicate moderate depression and scores greater than 29 signal severe depressive symptoms (Beck et al., 1996).

Brief Symptom Inventory-18 (Derogatis, 2001): The Brief Symptom Inventory (BSI-18) is a shortened version of the BSI (Derogatis & Lazarus, 1993) designed to

assess distress. It has been normed for use with cancer patients (Carlson et al., 2004; Zabora et al., 2001). It contains 3 subscales: Somatization, Depression and Anxiety and a global index of symptomotology, the Global Severity Index, where higher scores indicate a greater number of present symptoms. The BSI-18 has demonstrated good internal consistency (Cronbach's alpha=0.85-0.71) and test-retest reliability (r=0.91-0.68).

Functional Assessment of Cancer Therapy – Fatigue Module (Yellen, Cella, Webster, Blendowski, & Kaplan, 1997): The Functional Assessment of Cancer Therapy – Fatigue Module (FACT-F) has been designed to measure the extent of 13 symptoms of fatigue, utilizes a 5 point Likert Scale ranging from 0 (not at all) to 5 (very much). It has been shown to have good test-retest reliability ($r = 0.90$), very high internal consistency ($\alpha = 0.93$ and 0.95), a strong positive relationship with other fatigue measures and is able to differentiate patients by hemoglobin levels (Yellen et al., 1997). Items indicating higher fatigue are reversed scored and all items summed so that higher scores correspond with less fatigue. A recent study confirmed excellent statistical properties of the FACT-F and suggested a cutoff score of 34 for a diagnosis of fatigue (Van et al., 2005).

*Impact on Relationship*

Index of Marital Satisfaction (Cheung & Hudson, 1982): The Index of Marital Satisfaction (IMS) is designed to measure the magnitude of marital discord or dissatisfaction a partner has in a relationship. The scale consists of 25 items on a Likert Scale with responses ranging from 1 (none of the time) to 7 (all of the time). A selection of items is reverse scored so that higher scores indicate more dissatisfaction with the relationship. A score greater than 30 indicates a clinically significant problem in this

area. The IMS has a discriminant validity of 0.82; construct validity of 0.64 and alpha coefficients ranging from 0.94 to 0.96.

*Existential Concerns*

Attitude to Death and Dying: The Attitude to Death and Dying (ADAD) scale is a four item measure of attitudes toward mortality drawn from Bugen's larger Coping with Death Scale used with palliative professionals (Bugen, 1980). The Coping with Death Scale has an internal consistency of 0.89 and a test-retest reliability of 0.91 (Robbins, 1990). The items chosen from this measure were designed to assess the patient and partner's perspective on death and dying, the extent that they can talk about death with their partner, and their preparedness to face their own or their partner's death and dying process. The questions range on a scale from 7 (strongly agree) to 4 (neutral) to 1 (strongly disagree), with higher scores indicating more positive attitudes towards death and dying.

Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974): The Beck Hopelessness Scale (BHS) consists of 20 items and is based on a one dimensional perspective of hopelessness. The responses are in a true-false format and are scored either a 1 or a 0. Higher scores indicate a higher degree of hopelessness. The BHS has an internal consistency of 0.93 and is reported to have high concurrent and construct validity. The internal consistency of the BHS in a sample of palliative cancer patients was 0.90 (Benzein & Berg, 2005).

Functional Assessment of Chronic Illness and Treatment-Spirituality Subscale (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002): Functional Assessment of Chronic Illness and Treatment-Spirituality Subscale (FACIT-Sp) was designed to

measure spirituality in people with chronic and/or life-threatening illnesses. This scale is comprised of 12 questions and provides an overall measure of spirituality along with 2 subscales corresponding to one's sense of meaning and/or purpose in life (e.g. My life lacks meaning and purpose) and one's comfort and support from their personal faith (e.g. I receive support from my faith). The FACIT-Sp has been found to be valid and reliable in persons with cancer and HIV (Brady et al., 1999). Overall Cronbach's alpha was 0.87, 0.81 for the meaning/peace subscale, and 0.88 for the faith subscale.

*Procedure*

Patients were identified by file review of current outpatient breast, colon, and prostate cancer clinics and considered for eligibility. A research assistant flagged potentially eligible patients and attached a letter of introduction to the study to their file. The attending oncologist reviewed the patient eligibility and gave the letter of introduction to the patients if eligible. All eligible patients were contacted by the research assistant who explained the study in more detail and obtained informed consent. Patients were first offered the opportunity to attend the Tapestry retreat with their partners. There was no cost to the couple to attend the retreat. If they chose not to attend the retreat, they were asked if they would remain in the study as part of the natural history group. After obtaining consent for file review, a palliative physician and psychiatrist further reviewed the patient's eligibility to participate in the study. After eligibility was confirmed, a meeting was scheduled with the nurse researcher to complete the baseline questionnaires. Assessments were all performed by the same nurse researcher in the patient's home or another location of the patient's choice. Baseline assessment of couples attending the Tapestry retreat was completed approximately 1 week prior to

retreat attendance. Follow up assessments were then performed 1 month after baseline (or retreat), and at 3 month intervals up to time the patient refused contact due to worsening illness, the patient died or 1 year (which ever came first). Ethical approval for this study was obtained from the Conjoint Ethics Review Board of the University of Calgary/ Tom Baker Cancer Centre.

*Sample Size*

Sample size was determined based on considerations of the patient population concerned and the exploratory nature of the study. Originally three retreats were scheduled to accommodate study participants (18 couples). The natural history cohort was intended to recruit 30 couples, but the study was truncated after 18 months as the recruitment rate was lower than expected. Patients who expressed interest in the study were initially given the choice to attend the retreat or remain in the study as part of the natural history group. Recruitment continued until the potential participant resource had been exhausted and no new cases could be identified. A major limitation in the recruitment is that the retreat centre availability is a fixed and limited resource i.e. it must be booked a long time in advance and thus only couples recruited prior to these fixed dates could be offered the opportunity to attend the program. Detailed recruitment data (number screened, number eligible from chart review, number approached, number consented), and reasons for refusal or ineligibility, was compiled. The final sample consisted of 15 couples in the Tapestry group and 20 couples in the natural history group.

## Data Analysis

Data analysis was performed using the Statistical Package for Social Sciences, version 15. Due to the exploratory nature of this research, significance at or below the .10 probability level are reported. Since this research is primarily hypothesis generating, no corrections were made for multiple comparisons. Data analysis proceeded in accordance with the study objectives:

1. Feasibility of Recruitment - The feasibility of conducting a longitudinal study with palliative patients and their partners was assessed on 2 levels: 1. the number of patients eligible as identified in the clinics; and 2. the number who consent and complete the baseline assessment battery. Reasons for patient ineligibility and participation refusal are reported.

2. Suitability of Research Project - The couples who consented to the study and completed baseline assessments were included in the final sample. Completion rates were assessed by the proportion of couples who complete the questionnaire package at each time point. Reasons for missed assessments and study withdrawal were tabulated. Mortality during the 12 month follow up was determined and dates of patient death were confirmed by medical charts.

3. Measurement Utility – Paired sample T-tests were performed on the total scores of all questionnaires to determine whether they were able to detect changes in the Tapestry group only, for patients and partners separately. Further t-tests were performed on the subscales of the measures if the change represented in the total score was significant.

4. Patient Follow-up Assessment – Demographics of the couples in each group were reported and compared. Pearson's t-tests or chi square analyses were performed on the

demographic variables as appropriate to determine whether significant differences existed between the groups at baseline. Range of values (including mean and standard deviation) for all questionnaires were reported for the total scores at each time point. To investigate potential treatment impact between groups, a repeated measures 2 x 3 analysis of variance (ANOVA) was performed with 2 levels of treatment (Tapestry and natural history), and 3 data collection periods (baseline, 1 month or post retreat and 3 months) for both patients and partners for all measurements that were not found to be different when compared using t-tests. Those measurements with significant differences were analyzed with repeated measures 2 x 3 analysis of covariance (ANCOVA) with baseline scores as covariates. Data was also collected at 6, 9 and 12 months, but due to significant patient attrition, missing data, and the likelihood that the small subset of patients surviving to this point was significantly different from the remainder of patients, analyses did not include these assessments (Diehr & Johnson, 2005).

## Results

### *Objective 1: Feasibility of Recruitment*

The primary area of investigation in this pilot project was the extent to which a suitable sample of patients with advanced disease could be recruited for study participation. Patient screening began in the summer of 2005 and continued for 18 months until no new patients could be identified in clinic. These results are summarized in Appendix A, Figure 1 (p. 42). A total of 1178 patients visiting the breast (685), prostate (326) and colon (167) clinics were screening for eligibility. Of these patients only 448 had metastatic cancer, effectively excluding 62% of the total patient population. Of those patients with a confirmed metastatic cancer diagnosis (448), 12% were not

recommended for the study by their physician. The remaining patients were then assessed for the remaining study eligibility criteria. Marital status was the primary reason for exclusion in nearly half of the sample (43%), followed by geographical location of residence preventing retreat attendance or follow up (24%), a poor performance status with a predicted survival time of less than 6 months (15%), the inability to speak or understand English sufficient to complete the questionnaires (3%), psychological impairment as determined by the research psychiatrist (2%) and the presence of a partner with a poor performance status (1%).

This left 149 patients as eligible for study participation. We were able to successfully approach 72% of those patients identified as eligible for study participation (the remainder were not approached due to logistical difficulties, such as patients missing appointments). Of the patients approached, 60% declined program participation. The primary reason for study refusal was the patient not being ready to discuss their disease and its effects (34%), followed by not being interested in the focus of the intervention or the study (32%), having a spouse that was unavailable or uninterested (15%), and having other commitments for their time. The reason for study refusal was unknown or unrecorded in 12% of the sample. This resulted in a final sample of 43 couples consenting to study participation. Eight couples consented but did not participate because they changed their mind or became ineligible before the baseline assessment. Fifteen couples chose to participate in the Tapestry program and 20 couples formed the natural history group. In total, this study was able to successfully recruit 32% (35/108) of those patients eligible and approached for study participation.

*Objective 2: Suitability of Research Project*

Secondary to the primary objective, we sought to determine whether patients and their partners would be able to complete the study protocol. Adherence was calculated by comparing the number of forms expected to the number of forms received. Mortality rate was calculated and expected assessments by deceased individuals were not included in the total. In the Tapestry group, a total of 164 assessments were expected and 108 were actually received, resulting in a total response rate of 66% over the full duration of the study period. The mortality rate for the Tapestry group was 27% over the year following the baseline assessment. There was a downward trend noted in the number of assessments completed over the 12 month follow up. At baseline and post retreat, 100% of assessments were completed, followed by 73% at 3 months, 43% at 6 months, 33% at 9 months and 27% at 12 months. In the natural history group, a total of 210 assessments were expected and 114 were actually received, resulting in a lower total response rate than the Tapestry group of 54%. The mortality rate for the natural history group was 35%. The negative trend in assessment completion was also observed for the natural history group. At 1 month follow up, adherence fell to 70%, followed by 58% at 3 months, 41% at 6 months, 25% at 9 months and 8% at 12 months. The adherence and mortality rates for both groups are presented in Table 1 (p. 38).

Attrition was defined as withdrawal from the study for reasons other than death. Attrition rate, reasons for missed assessments and study withdrawal are presented in Table 2 (p. 39). Attrition rates were 67% and 80% in the Tapestry and natural history groups, respectively. Three couples in the Tapestry group and 1 couple in the natural history group completed the entire study protocol. Declining health and planned travel

were the primary reasons for missing assessments in both groups. In the Tapestry group, declining health and time commitments were the reasons most often given for study withdrawal. Other couples mentioned that the study made them think about their negative future when they wanted to be positively focused on the present. In the natural history group, declining health was also the main reason for study withdrawal. Many couples also reported that they were not ready to think about the issues dealt with in the study and withdrew for emotional reasons.

*Objective 3: Measurement Utility*

In order to better design future studies, an objective of this pilot work was to determine which measurements were sensitive to change and useful to administer to this population. The test battery used was extensive and not practical in a number of applied settings with impaired patients. Hence, paring down the battery to include only useful tools was an objective of the study. Paired sample t-tests were performed on scores of patients who attended the Tapestry retreat. Complete data is provided in Appendix D (p. 49). Patients demonstrated improved spirituality (FACIT-Sp; $t$ (14) = -1.550, $p$ = .143), marital satisfaction (IMS: $t$ (14) = 1.614, $p$ = .129), and attitudes towards death and dying (ADAD: $t$ (14) = .135, $p$ = .135). Partners experienced significantly less overall symptoms (BSI-global severity index: $t$ (14) = 2.037, $p$ = .061) and anxiety (BSI-Anxiety subscale: $t$ (14) = 1.974, $p$ = .068), a reduction in fatigue (FACIT-F: $t$ (13) = -1.706, $p$ = .112), and hopelessness (BHS: $t$ (14) = 2.041, $p$ = .061) and an improvement in marital satisfaction (IMS: $t$ (14) = 2.933, $p$ = .011).

*Objective 4: Patient follow-up assessment*

Patient and partner demographics for the Tapestry and natural history group are presented in Table 3 (p. 40). T-tests and Pearson's or Fisher's exact chi-square analyses were performed in order to determine whether significant differences between patients and partners were present on any of the demographic variables. Patients in the Tapestry group were significantly more likely to be women ($\chi^2$ (1) = 2.81, $p$ = .091), had received prior psychological support ($\chi^2$ (1) = 2.81, $p$ = .091) and were less comfortable with their finances ($\chi^2$ = 7.89, $p$ = .034). Patients in the Tapestry cohort had a mean age of 55 and at least a high school education (67%). The majority had 1-2 children (47%) and had received some psychological support (73%) previously but had not tried any complementary therapies (60%). Just over half of the patients in the natural history group were male (55%), and had a trade certificate or college diploma (50%). Most had between 1 and 4 children (80%), and were retired (45%). The majority of the patients in the natural history group had not received prior psychological support (55%) or tried complementary therapies (75%).

Partners attending the Tapestry retreat were also significantly more likely to have received prior psychological support ($\chi^2$ (1) = 2.16, $p$ = .130). Partners attending the Tapestry retreat had a mean age of 56 years, a skilled trade or college education (40%) and were still employed full time (53%). Most had between 1 and 4 children (67%) and an equal number considered themselves financially stable (40%) and unstable (40%). Very few of the partners had tried complementary therapies (7%). Partners in the natural history group had a mean age of 60 years, a skilled trade or college education (50%) and were working full time (45%). The majority had 3-4 children (45%) and considered

themselves financially stable (50%). Most had not had any previous psychological support (65%) or tried any complimentary therapies (85%). In summary, both patients and partners in the Tapestry group were more likely to have had prior experience with psychological assistance or intervention than those in the natural history group.

Patient disease demographics are presented in Table 4 (p. 41). The primary tumor site was breast (53%) in the Tapestry group compared to an equal number of individuals with breast (35%) and colon (35%) cancer in the natural history group. The patients in the Tapestry group had an average cancer duration of 4.38 years and were diagnosed with metastatic sites 2.56 years prior. Patients in the natural history group were diagnosed with cancer an average of 3.77 years previously and had metastatic cancer for 2.35 years. These differences were not statistically significant ($t$ (33) = -.429, $p$ = .671; $t$ (33) = -.162, $p$ = .872). The primary metastatic tumor site in the Tapestry group was bone (60%) whereas in the natural history group there were an equal number of individuals with bone (40%) and liver (40%) metastases. The majority of the patients in both groups had received prior surgical, chemotherapy and radiotherapy treatments.

T-tests were performed on baseline scores of patients and partners to determine whether significant differences existed on any of the quality of life, distress, marital satisfaction or existential concern measurements and are presented in Appendix E (p. 50). Patients in the Tapestry group reported significantly less psychological well being ($t$ (20.485) = 2.35, $p$ = .029), support ($t$ (33) = 2.42, $p$ = .021) and overall quality of life ($t$ (33) = 1.84, $p$ = .075) than did patients in the natural history group as measured by the MQOL and its subscales. Patients in the Tapestry group also reported poorer social well being ($t$ (33) = 2.74, $p$ = .01) and overall quality of life ($t$ (33) = 1.67, $p$ = .10) as

measured by the FACT-G and its subscales. Additionally, patients in the Tapestry group had higher levels of depressive symptoms ($t$ (33) = -1.60, $p$ = .12), anxiety ($t$ (33) = -1.76, $p$ = .09) and more overall symptomotology ($t$ (33) = -1.81, $p$ = .08) than those in the natural history group. Partners of patients in the Tapestry group reported more financial worries ($t$ (33) = 2.05, $p$ = .05), somatization ($t$ (17.115) = -1.80, $p$ = .09) and less marital satisfaction ($t$ (33) = -2.01, $p$ = .05) than partners of patients not attending the retreat. These variables were used as covariates in the repeated measures 2 x 3 ANCOVAs to account for their pre-existing mean group difference.

Results of the ANOVAs are presented in Appendix F (p. 51). There was a significant interaction for patients in the Tapestry and natural history groups in their attitudes towards death and dying over time ($F$ (2,30) = 2.517, $p$ = .098). Patients in the Tapestry group maintained improvements in attitudes at 3 month follow-up whereas the patients in the natural history group reported declines. This interaction is illustrated in Appendix A, Figure 2 (p.43). For patients, there was a significant main effect of cohort on marital satisfaction ($F$ (1,15) = 5.768, $p$ = .030), in that patients in the natural history group consistently reported more satisfaction than those patients in the Tapestry group. Lastly there was a significant main effect of time on the fatigue scores of patients ($F$ (2,30) = 3.453, $p$ = .045), such that both the Tapestry and natural history groups reported more fatigue as time progressed, regardless of group.

Results of the ANCOVAs are detailed in Appendix G (p. 53). The analyses revealed a significant interaction for overall patient QL as measured by the FACT-G when baseline levels of social well-being were controlled for ($F$ (2,28) = 2.584, $p$ = .093). Patients in the natural history group initially reported higher QL, but declined sharply in

comparison to the Tapestry group. For a graphical representation, refer to Appendix A, Figure 3 (p. 44). A significant time effect was also observed on overall patient QL ($F$ (2,28) = 3.198, $p$ = .056), in that both groups rated their QL worse at 3 month follow-up. A significant time effect was also seen for overall patient symptomotology as measured by the BSI when baseline levels of depression were controlled for ($F$ (2,28) = 3.341, $p$ = .050), indicating that both groups reported more symptoms as time progressed. No significant effects were observed for partners. Means, standard deviations and range of scores for all measures over the 12 month follow up are presented in Appendix H (p. 54) for the Tapestry group and Appendix I (p. 56) for the natural history group.

## Discussion

Research with palliative populations can be fraught with logistical difficulties, some of which were demonstrated here. Rinck (1997) summarized the extent of the issues often encountered while conducting research with patients at the end of life in his review of 11 studies. Problems with participant recruitment and attrition, sample homogeneity and outcome selection were predominant. Serious issues actually prevented the publishing of results in 2 of the 11 studies. Hence, there has been a prevailing view of many in the research community that methodologically sound palliative research is not possible. Fortunately, this belief that research with palliative patients "just doesn't work" (Hughes et al., 2004) is changing. The results of the current recruitment strategy were similar to that reported by Steinhauser (2006) in their large longitudinal study with palliative cancer patients. They approached patients for a longitudinal descriptive study of the transition from serious illness to death. The comparative percentages for the Steinhauser et al. (2006) paper and the current work are 9% vs. 13% for overall

eligibility, 74% vs. 72% for the number of eligible patients contacted and 32% vs. 40% for those patients consenting to participate. Given that the Steinhauser et al. (2006) study did not involve an intervention our numbers compare favourably. While the recruitment rate may be acceptable and comparable, there are some suggested techniques for improving participant recruitment. For example, part of our recruitment strategy relied on physician approval, an approach that has been criticized as being overly restrictive. Steinhauser et al. (2006) suggest that physicians may negatively affect recruitment as a result of inaccuracies in predicting time to death, protecting patients by acting as study gatekeepers, inaccurately gauging the patient's receptiveness to the research or allowing their personal opinions about the study's worth to affect referral. Other suggestions to improve recruitment include offering tangible incentives to referring physicians and participating patients.

Recruiting palliative patients may be less of a problem than keeping participants in the study. It is understandable that as the patient's health decreases, completing a battery of forms becomes laborious. We observed a decrease in the number of forms returned over the 12 month follow up period for both groups. Specifically, there was an overall response rate of 66% in the Tapestry group and 54% in the natural history group. This is higher than the response rate of 51% reported by Sherman et al. (2005) in their quality of life study with 38 palliative cancer patients. The primary reasons for missing assessments were related to health or travel. Many of the patients and spouses were using their remaining time to visit with family and friends or vacation. We saw more people in the natural history group withdraw from the study for reasons other than death. Declining health and emotional or personal reasons were the primary reason for study

withdrawal. It may also be the case that participants in the natural history group felt less compelled to "give back", since they did not receive an intervention as part of the study. Sherman et al. (2005) reported similar results with many patients not wanting to talk about their cancer or finding that completing the questionnaires caused them too much stress. At times it was the caregiver who instigated study withdrawal as they felt the questionnaires were too much of a burden because they were already overwhelmed with the care of their dying partner. Making the assessments easier for the patients and spouses to complete may improve the likelihood that they remain in the study and provide more balanced results. The current battery was lengthy and sometimes required an hour or more for participants to complete. Although one of the objectives was to investigate measurement sensitivity, the time commitment required may have contributed to participant withdrawal. Recent evidence suggests that a single item measure, such as the Distress Thermometer, may be as informative as a more lengthy instrument like the Brief Symptom Inventory while reducing the encumbrance placed on participants (Kelly, McClement, & Chochinov, 2006). Easing participant burden can also be accomplished by allowing participants to complete assessments by phone or during interviews, being flexible on assessment timing, and ensuring the measurements are clear and easily understood (Sherman et al., 2005).

Measurement of issues central to patients at the palliative stage of their illness is still in its infancy. Other researchers have expressed frustration with traditional QL measurement instruments such as the European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC-QLQ) because they do not seem able to detect the more emotional changes that may occur as a result of participation in

psychosocial interventions (Bordeleau et al., 2003). As such, this research tested the sensitivity of a battery of measurements to detect change in patients and partners as a result of program participation. The instruments sensitive to change pre to post retreat were primarily addressing specific life domains – such as marital satisfaction – as compared to general QL instruments. Patients participating in the Tapestry program reported an increase in their spirituality and improved attitudes towards death and dying. Partners found that they had less symptomotology, fatigue and hopelessness. The couple reported improvements in their marital satisfaction. The absence of results for the more broad QL instruments may indicate that they are not sensitive to the changes observed, that our sample size was not large enough, or that the Tapestry retreat did not have a large enough impact on overall QL to be detected. More research is needed with broad QL instruments, such as the FACT-G, in palliative populations to determine its usefulness. Additional studies may want to include a measure of caregiver burden, an area identified as particularly important in palliative care (Clark et al., 2006). Future studies should remove repetitive questionnaires and continue to include specific measures that target areas of great importance to palliative patients and their partners – such as spirituality and relational quality.

This research provides some preliminary results to suggest that retreat participation may positively influence outcomes for patients. Specifically, Tapestry participants reported better attitudes toward death and dying and overall QL, even when initial differences were statistically controlled for. These changes combined with the pre/post changes seen within the Tapestry group of increased spirituality suggest that the Tapestry retreat program may have been successful in achieving a fluid transition towards

the end of life in these patients, and helping their partners to cope with distressing psychological symptoms such as anxiety, depression and hopelessness. Current results confirm past research documenting the general downward trend reported by individuals with terminal cancer (Hwang et al., 2003; Morris & Sherwood, 1987). Patients, regardless of group, reported declines in QL over time and an increase in fatigue and overall symptoms. The results also suggest that quality of the marital relationship may influence the decision to participate in a couple's intervention at the end of life. An important result not predicted or expected was the positive impact of retreat participation on relationship satisfaction, which highlights this as an important area of clinical and research attention.

There are several limitations inherent in this research that may have influenced study outcomes. First of all, this study may have been underpowered to accurately detect changes. Other research has suggested that investigators set accrual targets that allow for a predicted amount of ineligibility and attrition (Northouse et al., 2006). Also of importance, there was significant patient attrition observed within both groups with the main reason for study withdrawal being psychological or emotional health. The remaining patients were more likely to be healthier and higher functioning, resulting in a loss of valuable information from those patients who were experiencing more difficulty. The patient's perception of their illness can also affect QL measurement over time. Individuals with serious illness often re-examine and change their standards, values and conceptualizations over the course of their illness, a process called response shift (Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Response shift can be adaptive for the patient, but it is a problem in longitudinal QL research designs because it calls into

question whether observed changes in QL over time are a result of the patient's perceptual change and not due to interventions or treatments that may be evaluated (Sprangers & Schwartz, 1999). They can also mask actual changes within QL domains because differences may average out across QL measurements, resulting in the inability to detect clinically significant differences. Response shift has been documented in cancer patients and is suggested to be particularly important in palliative cancer patients, due to the effect of declines in physical functioning that typically occur with the progression of disease (Echteld, Deliens, Ooms, Ribbe, & van der Wal, 2005). In addition, due to the exploratory nature of this study, the significance level chosen for these results was only at $p < .10$. Future research should be more focused in choosing outcome measures, correcting for multiple comparisons and selecting more rigorous significance levels.

In summary, this research demonstrates that, although recruitment and retention may be challenging, research with palliative patients is feasible. Specifically, we offered couples an intensive psychosocial intervention – something that has not been attempted or evaluated in the past – and found the intervention to be not only possible, but welcomed by participants. This being said, we also discovered that having patients choose whether or not to attend the retreat allowed those patients who could benefit from the program most access to the assistance. This design may pose problems for establishing efficacy but it strengthens real life applicability and effectiveness. This research has important implications for future studies with palliative patients. Subsequent research should ensure that measurement instruments are brief and specific in order to minimize associated burden. In addition, we found that a 12 month follow-up may have been unreasonable and suggest that researchers may want to distinguish

between conducting research with patients in the palliative phase of their disease from the time of immanent death (Steinhauser et al., 2006). These periods are very different and can determine health-related withdrawal, change the research location from home to hospital or hospice, and impact outcomes. Specifying the period of most interest and relevance to the research objectives may minimize patient attrition and increase the relevance of results. Lastly, these results emphasize the importance of including the partner as an integral and important component of palliative research, both as an independent focus of investigation and in combination with the patient.

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Table 1

Completion rates for couples and mortality of patients

| Data collection point | Tapestry (n = 15 couples) | | | Natural History (n = 20 couples) | | |
|---|---|---|---|---|---|---|
| | Deceased | Alive/Forms Expected | Forms received | Deceased | Alive/Forms Expected | Forms Received |
| Baseline | 0 | 30 | 30 (100%) | 0 | 40 | 40 (100%) |
| Post-retreat / 1month | 0 | 30 | 30(100%) | 0 | 40 | 28 (70%) |
| 3 months | 0 | 30 | 22 (73%) | 1 | 38 | 22 (58%) |
| 6 months | 1 | 28 | 12 (43%) | 2 | 34 | 14 (41%) |
| 9 months | 2 | 24 | 8 (33%) | 1 | 32 | 8 (25%) |
| 12 months | 1 | 22 | 6 (27%) | 3 | 26 | 2 (8%) |
| Total | 4 (27%) | 164 | 108 (66%) | 7 (35%) | 210 | 114 (54%) |

Table 2

Attrition rate, reasons for participant missed assessments and study withdrawal

| | Tapestry | Natural History |
|---|---|---|
| **Reasons for Missed Assessments** | | |
| Health-related | 4 | 3 |
| Travel | 2 | 4 |
| Emotional / Personal Issues | | 1 |
| Partner absent | | 1 |
| Study administration | | 2 |
| **Reasons for Study Withdrawal** | | |
| ***Completed study*** | 3 | 1 |
| Death | 2 | 3 |
| Declining Health | 3 | 6 |
| Emotional / Personal Issues | 2 | 4 |
| Study administration | 1 | 2 |
| Lost to follow-up | 1 | 2 |
| Other commitments / Time | 3 | 2 |
| **Attrition Rate** | **67%** | **80%** |

Table 3

Comparison of patient and partner demographics using t-tests or chi-square analyses

| Demographic Variable | Patient (n=35) | | | Partner (n=35) | | |
|---|---|---|---|---|---|---|
| | Tapestry (n=15) | Natural History (n=20) | p-value | Tapestry (n=15) | Natural History (n=20) | p-value |
| Age | | | | | | |
| Mean | 54.65 | 59.55 | .211 | 56.29 | 59.50 | .437 |
| Range | (38-78) | (38-75) | | (40-84) | (37-79) | |
| Gender | | | | | | |
| Female | 11 | 9 | **.091*** | 4 | 11 | **.091*** |
| Male | 4 | 11 | | 11 | 9 | |
| Employment | | | | | | |
| Full-time | 4 | 5 | .813 | 8 | 9 | .815 |
| Part-time | | 2 | | 2 | 3 | |
| Unemployed | | | | | 1 | |
| Homemaker | 1 | 1 | | | 2 | |
| Disabled | 4 | 3 | | | | |
| Retired | 6 | 9 | | 5 | 5 | |
| Education | | | | | | |
| >High School | 5 | 3 | .503 | 3 | 2 | .750 |
| High School | 3 | 2 | | 3 | 1 | |
| Trade/College | 3 | 10 | | 6 | 10 | |
| University | 4 | 5 | | 3 | 7 | |
| # of Children | | | | | | |
| None | 2 | 3 | .431 | 3 | 3 | .795 |
| 1-2 | 7 | 8 | | 5 | 7 | |
| 3-4 | 3 | 8 | | 5 | 9 | |
| 5+ | 3 | 1 | | 2 | 1 | |
| Prior Psychological Support | | | | | | |
| Yes | 11 | 9 | **.091*** | 9 | 7 | **.130*** |
| No | 4 | 11 | | 6 | 13 | |
| Prior Complimentary Therapies | | | | | | |
| Yes | 6 | 5 | .281 | 1 | 3 | .419 |
| No | 9 | 15 | | 14 | 17 | |
| Financial Status | | | | | | |
| Comfortable | 2 | 9 | **.034**** | 3 | 6 | .173 |
| Stable | 8 | 8 | | 6 | 10 | |
| Unstable | 5 | 1 | | 6 | 2 | |
| Precarious | | 2 | | | 2 | |

* $p < .10$; ** $p < .05$; *** $p < .01$

Table 4

Comparison of patient disease demographics using t-tests or chi-square analyses

| Demographic Variable | Tapestry (n=15) | Natural History (n=20) | p-value |
|---|---|---|---|
| Cancer Site | | | |
| Breast | 8 | 7 | .512 |
| Prostate | 2 | 6 | |
| Colon | 5 | 7 | |
| Duration of Cancer Diagnosis | | | |
| Mean years | 4.38 | 3.77 | .671 |
| Range | (.75-9.47) | (.21-20.4) | |
| Duration of Metastatic Diagnosis | | | |
| Mean years | 2.56 | 2.35 | .872 |
| Range | (.00-7.32) | (.00-15.32) | |
| Primary Metastatic Site | | | |
| Lung | 2 | 4 | .589 |
| Bone | 9 | 8 | |
| Liver | 4 | 8 | |
| Prior Treatment | | | |
| Surgery | 13/15 | 15/20 | .340 |
| Chemotherapy | 15/15 | 19/20 | .571 |
| Radiotherapy | 12/15 | 13/20 | .279 |
| Endocrine | 6/15 | 12/20 | .204 |

* $p < .10$; ** $p < .05$; *** $p < .01$

Appendix A: Figures

Figure 1: Patient Recruitment Flowchart

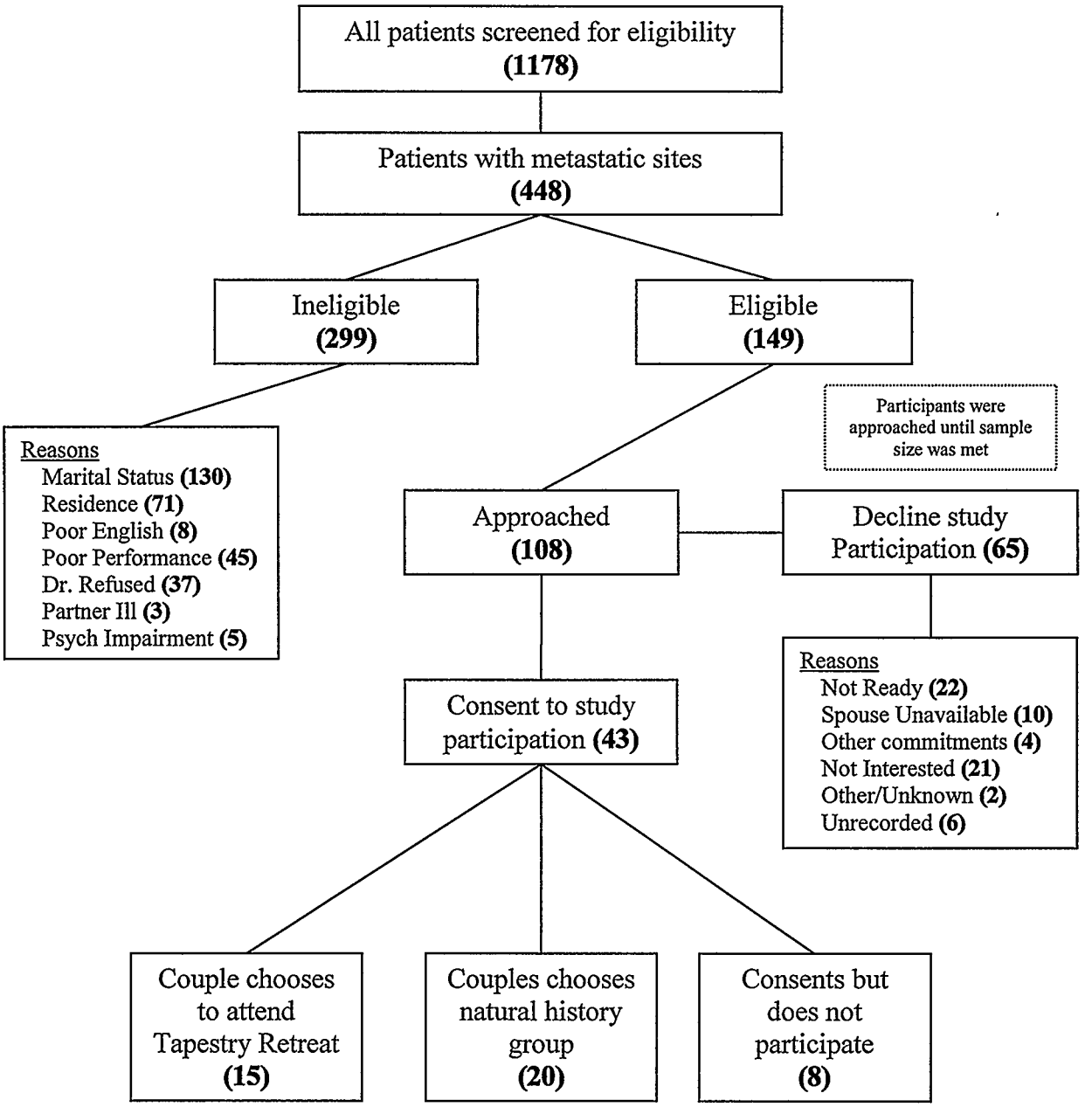
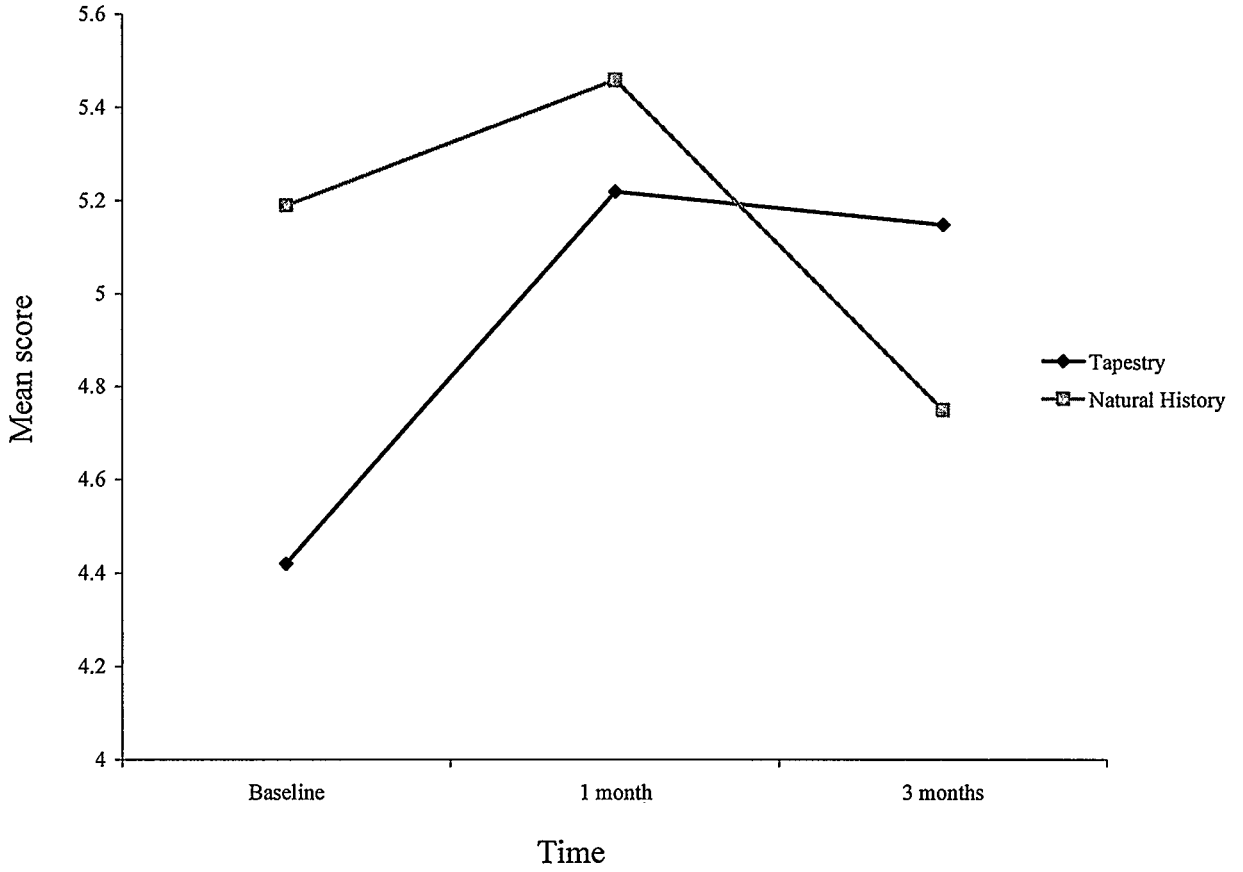
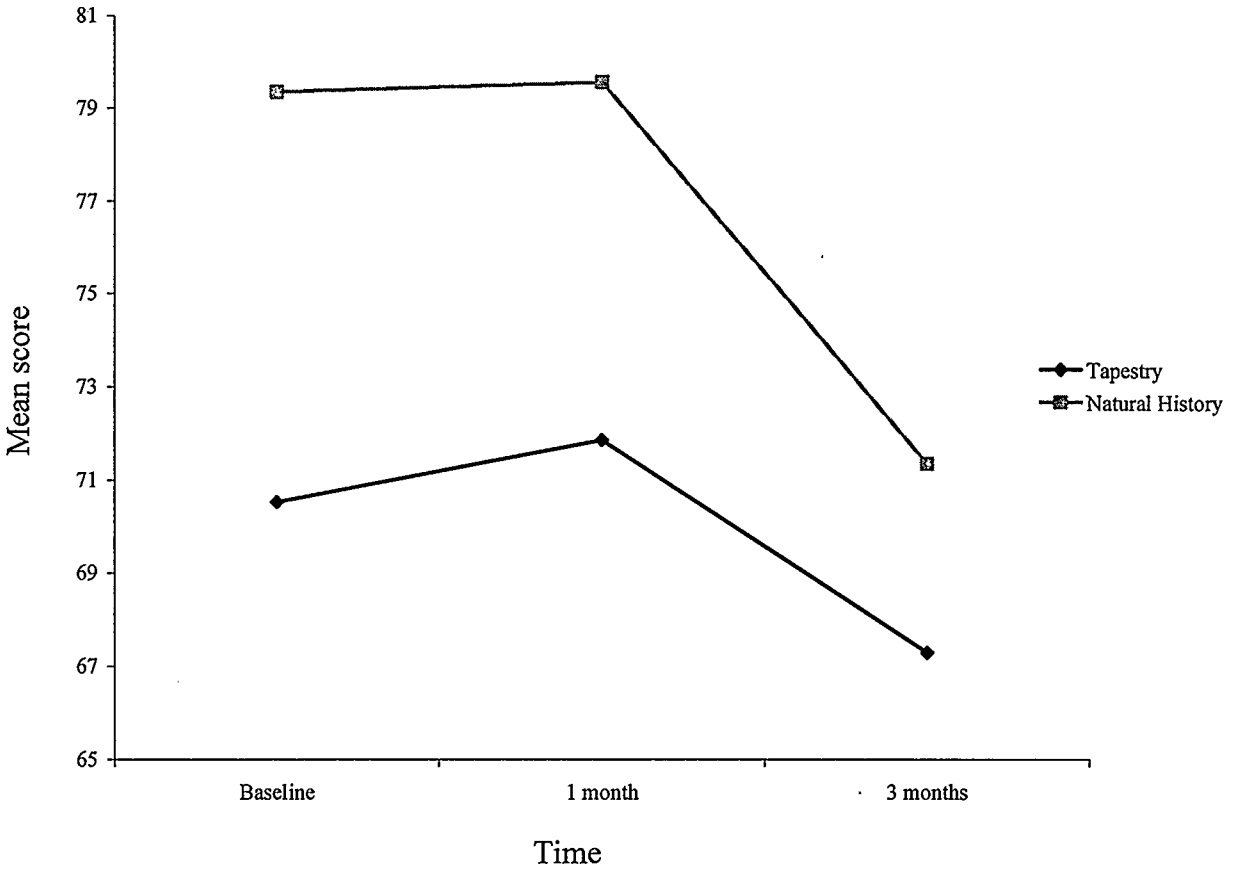


Figure 2: Interaction between group and time on attitudes towards death and dying (ANOVA)




($F$ (2,30) = 2.517, $p$ = .098)

Figure 3: Interaction between group and time on overall quality of life, controlling for initial levels of social well-being (ANCOVA)




($F$ (2,28) = 2.584, $p$ = .093)

Appendix B: Daily Program Description

A daily breakdown of the program is as follows:

Day 1: The first day begins with the participant's arrival and registration with ample time provided for the couples to settle into their private rooms. Each room is personally detailed with handmade nametags, a Tapestry sweatshirt or vest, a pampering gift package, and a folder with a welcome note, retreat map, program schedule, journal, crayons and a pen and pencil for each participant. After all the participants have arrived, introductions take place and the group is oriented to the program schedule and retreat facilities, with opportunity for questions throughout. A group lunch is provided and the couples are encouraged to get to know their fellow retreat participants and the facilitators. Each meal is introduced and ended with the ritual ringing of the Tibetan Tengshaw bells followed by a moment of silence. After lunch, the first narrative group is held. The narrative groups last 1 hour and there are separate groups for patients and partners. The rest of the afternoon is set aside for free time and exploring of the retreat facilities and surrounding area. Prior to supper, the couples begin creating relationship collages. These collages are comprised of pictures from magazines that highlight important aspects of their relationship with their partner. At 6 pm, a home-cooked family style supper is served and is accommodating to any special dietary requirements that the participants may have. After supper, the couples are introduced to one of the educational videos followed by a discussion of the content. Each day is ended with the opportunity to participate in gentle hatha yoga exercises and meditation, ending at 10 pm. Participants are offered an evening snack and are then free to relax or retire to their rooms.

Day 2: Each morning begins with yoga and meditation followed by a group breakfast at 8:30 am. The morning meal is followed by narrative groups for patients and partners. After group, participants have free time until the creative arts session begins at 11:00 am. In the first creative arts session the participants are introduced to a "beaded life" exercise. The participants are provided with a variety of beads of different sizes, shapes, colors, textures and images. They are encouraged to choose beads which represent significant aspects of their life and string them together on the twine provided in order to tell a story about their life. After lunch, participants can take part in a personal massage provided by a registered massage therapist, explore free time or continue to work on their art projects until supper. After supper, the couples are introduced to the next educational video, followed by discussion. The opportunity for meditation and yoga is once again offered.

Day 3: After morning yoga and breakfast, the separate narrative groups are held followed by the introduction of the "Story'd Basket" creative arts exercise. In this exercise, participants are provided with a variety of different colors and textures of yarn as well as wooden cane. The participants are encouraged to choose colours and/or textures of yarn that have a special symbolic meaning and the technique of weaving the basket is explained. After lunch, the afternoon is again devoted to free time, the development of creative projects, and the opportunity to utilize personal massage sessions. After supper, the couples participate in a drumming circle designed to facilitate connection with themselves and each other and to tap into the healing, educational and joyful power of music. The day is completed by yoga and meditation.

Day 4: After morning yoga, meditation, and meal, the participants are introduced to a Jungian sand tray exercise instead of the narrative group. Sand tray groups are also divided by patients and their partners. Individuals are provided with baskets and are asked to examine tables of objects representing an assortment of people, places, things, feelings, etc and choose a selection of objects with personal meaning. Sand tray participants are provided with a section of the sandtray and are asked to create a diorama (a story or miniature world) by arranging their object selections in the sandtray. This session if followed by free time and the opportunity to continue developing the creative project of their choice. After lunch, the participants are then encouraged to share and describe the meaning of their sandtray to the rest of the group. The rest of the afternoon is devoted to free time or creative pursuits. Supper is followed by a group sharing exercise. Prior to retreat participation, the couples were asked to each bring a personal item of importance that they were willing to let go of and give away to another member of the group. The individual describes the item and its significance before giving it to one of the other participants. The evening ends with free time, yoga and meditation.

Day 5: The final day begins with yoga, meditation, breakfast and the last narrative group. Participants are then brought together to describe the relationship collages that they began on the first day and completed throughout the week. After lunch, the group has free time until the closing ceremony at 3 pm. In this final group exercise, participants are encouraged to share their Story'd Basket with the rest of the group, and the retreat is brought to a close with a final ringing of the Tengshaw bells and a moment of reflective silence.

Appendix C: Exclusion Criteria

1. Inability to speak or read English sufficiently to complete the questionnaires and/or retreat.
2. The presence of cognitive impairment, psychosis, severe depression or intense anxiety as defined by a Confusion Assessment Method (CAM) Instrument indicating delirium (Inouye et al., 1990), a score of more than 32 on the Beck Depression Inventory (Beck et al., 1974), or a score of more than 21 on the Brief Symptom Inventory-18 (Derogatis, 2001).
3. A prognosis of survival less than 3 months at initial file review as determined by the palliative physician.
4. A performance status of 60% or less on the Palliative Performance Scale (PPS) or unstable medical conditions such that they could not expect to spend 5 days away from the hospital, as determined by the palliative physician (Morita, Tsunoda, Inoue, & Chihara, 1999).
5. The presence of a psychiatric condition, as determined by the program psychiatrist (e.g. history of personality disorder, substance abuse).
6. A partner with a significant illness or mental health issue and a Global Assessment of Function Score of less than 60 (American Psychiatric Association, 2000).
7. The initiation of new medical, psychological or psychiatric treatment within 4 weeks prior to baseline assessment.

Appendix D: Measurement change in Tapestry participants using paired samples t-tests

| | Patients | | | Partners | | |
|---|---|---|---|---|---|---|
| n=15 | Baseline | Post-retreat | p-value | Baseline | Post-retreat | p-value |
| BDI | | | | | | |
| Mean | 13.67 | 12.07 | .200 | 11.60 | 8.73 | .210 |
| SD | 7.89 | 7.96 | | 11.61 | 8.02 | |
| BSI | | | | | | |
| Mean | 13.53 | 12.27 | .495 | 11.80 | 8.27 | **.061*** |
| SD | 6.17 | 9.60 | | 12.74 | 9.95 | |
| *BSI-Som* | | | | | | |
| *Mean* | | | | 3.20 | 2.00 | .164 |
| *SD* | | | | 4.59 | 3.23 | |
| *BSI-Dep* | | | | | | |
| *Mean* | | | | 4.13 | 3.20 | .150 |
| *SD* | | | | 4.19 | 3.82 | |
| *BSI-Anx* | | | | | | |
| *Mean* | | | | 4.47 | 3.07 | **.068*** |
| *SD* | | | | 5.55 | 3.65 | |
| MQOL | 6.42 | 6.22 | | | | |
| Mean | 1.44 | 2.02 | .757 | | | |
| SD | 4-10 | 2-10 | | | | |
| FACT-G | | | | | | |
| Mean | 70.53 | 71.87 | .585 | | | |
| SD | 13.52 | 17.44 | | | | |
| QOLLTI-F | | | | | | |
| Mean | | | | 7.25 | 7.13 | .781 |
| SD | | | | 1.94 | 1.90 | |
| FACIT-F | | | | | | |
| Mean | 30.07 | 29.13 | .617 | 37.40 | 40.14 | **.112*** |
| SD | 10.38 | 10.77 | | 10.19 | 11.60 | |
| FACIT-Sp | | | | | | |
| Mean | 33.13 | 35.27 | **.143*** | 31.33 | 32.64 | .378 |
| SD | 10.88 | 11.37 | | 9.94 | 8.31 | |
| BHS | | | | | | |
| Mean | 5.47 | 5.07 | .516 | 7.73 | 5.87 | **.061*** |
| SD | 5.13 | 4.33 | | 5.24 | 5.38 | |
| IMS | | | | | | |
| Mean | 14.09 | 11.16 | **.129*** | 24.49 | 16.31 | **.011**** |
| SD | 10.08 | 9.19 | | 17.24 | 13.80 | |
| ADAD | | | | | | |
| Mean | 4.42 | 5.22 | **.135*** | 4.92 | 4.96 | .973 |
| SD | 1.79 | 1.35 | | 1.59 | 1.27 | |

* $p < .10$; ** $p < .05$; *** $p < .01$

Appendix E: Differences between group (patient, partner) and cohort (Tapestry, natural history) at baseline using independent samples t-tests.

| | Patient | | | Partner | | |
|---|---|---|---|---|---|---|
| | Tapestry (n=15) | Natural History (n=20) | *p*-value | Tapestry (n=15) | Natural History (n=20) | *p*-value |
| **McGill Quality of Life Questionnaire** | | | | | | |
| *Physical Symptoms* | | | | | | |
| Mean | 3.84 | 4.93 | .232 | | | |
| SD | 2.07 | 2.86 | | | | |
| *Physical Well Being* | | | | | | |
| Mean | 6.20 | 7.00 | .315 | | | |
| SD | 2.01 | 2.45 | | | | |
| *Psychological* | | | | | | |
| Mean | 6.87 | 8.51 | **.029**** | | | |
| SD | 2.44 | 1.36 | | | | |
| *Existential* | | | | | | |
| Mean | 7.34 | 7.82 | .404 | | | |
| SD | 1.67 | 1.62 | | | | |
| *Support* | | | | | | |
| Mean | 7.87 | 8.88 | **.021**** | | | |
| SD | 1.47 | 1.00 | | | | |
| *Total* | | | | | | |
| Mean | 6.42 | 7.26 | **.075*** | | | |
| SD | 1.44 | 1.24 | | | | |
| **Functional Assessment of Cancer Therapy-General** | | | | | | |
| *Physical* | | | | | | |
| Mean | 18.07 | 20.35 | .184 | | | |
| SD | 4.27 | 5.36 | | | | |
| *Social* | | | | | | |
| Mean | 19.53 | 23.10 | **.010***** | | | |
| SD | 4.05 | 3.63 | | | | |
| *Emotional* | | | | | | |
| Mean | 16.33 | 17.25 | .559 | | | |
| SD | 5.22 | 3.97 | | | | |
| *Functional* | | | | | | |
| Mean | 16.60 | 18.65 | .317 | | | |
| SD | 5.18 | 6.39 | | | | |
| *Total Score* | | | | | | |
| Mean | 70.53 | 79.35 | **.104*** | | | |
| SD | 13.52 | 16.69 | | | | |
| **Quality of Life in Life Threatening Illness-Family Caregiver Version** | | | | | | |
| *Environment* | | | | | | |
| Mean | | | | 7.73 | 8.10 | .664 |
| SD | | | | 2.46 | 2.44 | |
| *Patient State* | | | | | | |
| Mean | | | | 7.47 | 7.40 | .947 |
| SD | | | | 3.18 | 2.74 | |

| | | | | | | |
|---|---|---|---|---|---|---|
| *Own State* | | | | | | |
| Mean | | | | 7.28 | 7.41 | .859 |
| SD | | | | 2.44 | 1.85 | |
| *Outlook* | | | | | | |
| Mean | | | | 7.44 | 7.48 | .961 |
| SD | | | | 2.43 | 2.21 | |
| *Quality of Care* | | | | | | |
| Mean | | | | 8.78 | 8.30 | .430 |
| SD | | | | 1.28 | 2.23 | |
| *Relationships* | | | | | | |
| Mean | | | | 7.07 | 7.36 | .744 |
| SD | | | | 2.99 | 2.34 | |
| *Financial Worries* | | | | | | |
| Mean | | | | 5.00 | 7.25 | **.048**** |
| SD | | | | 3.14 | 3.26 | |
| *Total Score* | | | | | | |
| Mean | | | | 7.25 | 7.62 | .559 |
| SD | | | | 1.94 | 1.69 | |
| **Beck Depression Inventory** | | | | | | |
| Mean | 13.67 | 11.15 | .289 | 11.60 | 9.55 | .527 |
| SD | 7.89 | 5.93 | | 11.61 | 7.32 | |
| **Brief Symptom Inventory** | | | | | | |
| *Somatization* | | | | | | |
| Mean | 5.00 | 3.90 | .280 | 3.20 | 0.95 | **.089*** |
| SD | 2.36 | 3.29 | | 4.59 | 1.76 | |
| *Depression* | | | | | | |
| Mean | 4.67 | 2.90 | **.120*** | 4.13 | 3.20 | .478 |
| SD | 3.60 | 2.95 | | 4.19 | 3.50 | |
| *Anxiety* | | | | | | |
| Mean | 3.87 | 2.40 | **.088*** | 4.47 | 2.70 | .262 |
| SD | 2.64 | 2.28 | | 5.55 | 2.32 | |
| *Global Severity Index* | | | | | | |
| Mean | 13.53 | 9.20 | **.080*** | 11.80 | 6.85 | .180 |
| SD | 6.17 | 7.58 | | 12.74 | 6.06 | |
| **Functional Assessment of Chronic Illness Therapy -Fatigue** | | | | | | |
| Mean | 30.07 | 34.65 | .261 | 37.40 | 41.75 | .146 |
| SD | 10.38 | 12.64 | | 10.19 | 7.09 | |
| **Functional Assessment of Chronic Illness Therapy - Spirituality** | | | | | | |
| Mean | 33.13 | 33.50 | .915 | 31.33 | 31.80 | .897 |
| SD | 10.88 | 9.18 | | 9.94 | 10.84 | |
| **Beck Hopelessness Scale** | | | | | | |
| Mean | 5.47 | 5.60 | .935 | 7.73 | 5.80 | .257 |
| SD | 5.13 | 4.45 | | 5.24 | 4.65 | |
| **Index of Marital Satisfaction** | | | | | | |
| Mean | 14.09 | 9.63 | .179 | 24.49 | 14.87 | **.046**** |
| SD | 10.08 | 9.03 | | 17.24 | 10.02 | |
| **Attitude to Death and Dying** | | | | | | |
| Mean | 4.42 | 5.19 | .184 | 4.92 | 5.09 | .730 |
| SD | 1.79 | 1.57 | | 1.59 | 1.32 | |

* p < .10; ** p< .05; *** p < .01

Appendix F: Outcome by Treatment Group (ANOVA)

| Variable | Group | Cohort | Baseline Mean (SD) | Post-retreat / 1 month Mean (SD) | 3 month Mean (SD) | Time Effect F (df) [p] | Cohort Effect F (df) [p] | Interaction F (df) [p] |
|---|---|---|---|---|---|---|---|---|
| **BDI** | *Patient* | *Tapestry* | 13.67 (7.89) | 12.07 (7.96) | 14.30 (5.64) | .168 (2,30) [.846] | 1.010 (1,15) [.331] | .168 (2,30) [.846] |
| | | *Natural History* | 11.15 (5.93) | 10.00 (6.69) | 14.27 (6.96) | | | |
| | *Partner* | *Tapestry* | 11.60 (11.61) | 8.73 (8.02) | 9.50 (10.61) | .022 (2,30) [.978] | .013 (1,15) [.909] | .581 (2,30) [.565] |
| | | *Natural History* | 9.55 (7.32) | 9.00 (7.11) | 10.36 (8.20) | | | |
| **FACIT-F** | *Patient* | *Tapestry* | 30.07 (10.38) | 29.13 (10.77) | 27.20 (8.59) | **3.453 (2,30) [.045]**** | .367 (1,15) [.554] | 1.061 (2,30) [.359] |
| | | *Natural History* | 34.65 (12.64) | 32.93 (12.25) | 25.45 (13.87) | | | |
| | *Partner* | *Tapestry* | 37.40 (10.19) | 40.14 (11.60) | 37.11 (13.39) | .782 (2,28) [.467] | .323 (1,14) [.579] | .142 (2,28) [.866] |
| | | *Natural History* | 41.75 (7.09) | 40.86 (9.26) | 40.00 (8.44) | | | |
| **FACIT-Sp** | *Patient* | *Tapestry* | 33.13 (10.88) | 35.27 (11.37) | 33.10 (11.41) | 1.831 (2,30) [.178] | .004 (1,15) [.948] | .581 (2,30) [.566] |
| | | *Natural History* | 33.50 (9.18) | 35.43 (8.84) | 27.64 (12.74) | | | |
| | *Partner* | *Tapestry* | 31.33 (9.94) | 32.64 (8.31) | 33.44 (10.33) | 1.631 (2,28) [.214] | .446 (1,14) [.515] | .028 (2,28) [.972] |
| | | *Natural History* | 31.80 (10.84) | 33.29 (12.20) | 32.00 (12.93) | | | |
| **BHS** | *Patient* | *Tapestry* | 5.47 (5.13) | 5.07 (4.33) | 7.80 (3.55) | .510 (2,30) | .251 (1,15) | .382 (2,30) |

| Variable | Group | Cohort | Baseline Mean (SD) | Post-retreat / 1 month Mean (SD) | 3 month Mean (SD) | Time Effect F (df) [p] | Cohort Effect F (df) [p] | Interaction F (df) [p] |
|---|---|---|---|---|---|---|---|---|
| | | *Natural History* | 5.60 (4.45) | 4.43 (3.80) | 8.27 (5.93) | [.606] | [.624] | [.686] |
| | *Partner* | *Tapestry* | 7.73 (5.24) | 5.87 (5.38) | 7.40 (6.00) | .798 (2,30) [.460] | .808 (1,15) [.383] | 1.082 (2,30) [.352] |
| | | *Natural History* | 5.80 (4.65) | 5.07 (5.18) | 5.36 (5.12) | | | |
| **IMS** | *Patient* | *Tapestry* | 14.09 (10.08) | 11.16 (9.19) | 14.60 (7.89) | .535 (2,30) [.591] | **5.768 (1,15) [.030]**** | .128 (2,30) [.881] |
| | | *Natural History* | 9.63 (9.03) | 7.48 (8.82) | 10.97 (9.50) | | | |
| | *Partner* | *Tapestry* | 24.49 (17.24) | 16.31 (13.80) | 18.27 (15.65) | .598 (2,30) [.556] | 1.702 (1,15) [.212] | 2.015 (2,30) [.151] |
| | | *Natural History* | 14.87 (10.02) | 11.52 (9.08) | 16.61 (11.12) | | | |
| **ADAD** | *Patient* | *Tapestry* | 4.42 (1.79) | 5.22 (1.35) | 5.15 (1.33) | 1.367 (2,30) [.270] | .640 (1,15) [.436] | **2.517 (2,30) [.098]*** |
| | | *Natural History* | 5.19 (1.57) | 5.46 (1.15) | 4.75 (1.06) | | | |
| | *Partner* | *Tapestry* | 4.92 (1.59) | 4.96 (1.27) | 5.37 (1.54) | .159 (2,30) [.854] | .523 (1,15) [.481] | .983 (2,30) [.420] |
| | | *Natural History* | 5.09 (1.32) | 5.27 (1.06) | 4.23 (1.46) | | | |

* $p < .10$; ** $p < .05$; *** $p < .01$

Appendix G: Outcome by Treatment Group (ANCOVA)

| Variable | Group | Cohort | Baseline Mean (SD) | Post-retreat/ 1 month Mean (SD) | 3 month Mean (SD) | Time Effect F (df) [p] | Cohort Effect F (df) [p] | Interaction F (df) [p] |
|---|---|---|---|---|---|---|---|---|
| **BSI** | *Patient* | *Tapestry* | 13.53 (6.17) | 12.27 (9.60) | 15.50 (7.96) | .612 (2,28) [.549] [a] | 1.93 (1,14) [.186] [a] | .513 (2,28) [.604] [a] |
| | | | | | | **3.341 (2,28) [.050] [b]**** | 1.718 (1,14) [.211] [b] | .510 (2,28) [.606] [b] |
| | | *Natural History* | 9.20 (7.58) | 7.93 (7.53) | 11.55 (8.56) | 1.55 (2,28) [.230] [c] | 1.121 (1,14) [.308] [c] | .155 (2,28) [.857] [c] |
| | *Partner* | *Tapestry* | 11.80 (12.74) | 8.27 (9.95) | 8.33 (8.69) | .236 (2,26) [.792] [a] | .005 (1,13) [.947] [a] | .886 (2,26) [.425] [a] |
| | | | | | | .072 (2,26) [.931] [b] | .029 (1,13) [.867] [b] | 1.824 (2,26) [.181] [b] |
| | | *Natural History* | 6.85 (6.06) | 5.93 (6.49) | 8.55 (9.90) | .108 (2,26) [.898] [c] | .000 (1,13) [.992] [c] | 1.450 (2,26) [.253] [c] |
| **QOLLTI-F** | *Partner* | *Tapestry* | 7.25 (1.94) | 7.13 (1.90) | 7.39 (1.77) | .116 (2,28) [.891] [d] | .071 (1,14) [.794] [d] | 1.032 (2,28) [.369] [d] |
| | | *Natural History* | 7.62 (1.69) | 8.19 (1.47) | 7.36 (1.89) | | | |
| **MQOL** | *Patient* | *Tapestry* | 6.42 (1.44) | 6.22 (2.02) | 6.52 (1.59) | 1.061 (2,28) [.360] [e] | .026 (1,14) [.824] [e] | .085 (2,28) [.919] [e] |
| | | *Natural History* | 7.26 (1.24) | 7.20 (1.38) | 6.55 (1.37) | .318 (2,28) [.730] [f] | .370 (1,14) [.553] [f] | .295 (2,28) [.747] [f] |
| **FACT-G** | *Patient* | *Tapestry* | 70.53 (13.52) | 71.87 (17.44) | 67.30 (12.79) | | | |
| | | | | | | **3.198 (2,28) [.056] [g] *** | .503 (1,14) [.490] [g] | **2.584 (2,28) [.093] [g] *** |
| | | *Natural History* | 79.35 (16.69) | 79.57 (14.81) | 71.36 (18.64) | | | |

Controlling for baseline differences in subscales of: [a] Somatization; [b] Depression; [c] Anxiety; [d] Financial Worries; [e] Psychological Well-being; [f] Social Support; [g] Social Well-being * $p < .10$; ** $p < .05$; *** $p < .01$

Appendix H: Means, standard deviations and range of scores for all measures for patients and partners in the Tapestry program

| | Tapestry | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Patient | | | | | | Partner | | | | | |
| **Time** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** |
| **N** | 15 | 15 | 10 | 6 | 3 | 3 | 15 | 15 | 10 | 5 | 3 | 3 |
| **BDI** | | | | | | | | | | | | |
| **Mean** | 13.67 | 12.07 | 14.30 | 16.50 | 11.00 | 16.67 | 11.60 | 8.73 | 9.50 | 8.20 | 9.75 | 11.67 |
| **SD** | 7.89 | 7.96 | 5.64 | 8.71 | 8.66 | 8.33 | 11.61 | 8.02 | 10.61 | 4.87 | 12.89 | 9.02 |
| **Range** | 2-30 | 0-27 | 6-24 | 10-29 | 1-16 | 10-26 | 0-34 | 0-25 | 0-28 | 3-15 | 2-29 | 3-21 |
| **BSI-G** | | | | | | | | | | | | |
| **Mean** | 13.53 | 12.27 | 15.50 | 14.67 | 7.67 | 18.00 | 11.80 | 8.27 | 8.33 | 7.00 | 9.00 | 11.67 |
| **SD** | 6.17 | 9.60 | 7.96 | 13.13 | 5.69 | 12.53 | 12.74 | 9.95 | 8.69 | 8.97 | 8.54 | 14.57 |
| **Range** | 2-24 | 0-28 | 3-27 | 1-31 | 3-14 | 5-30 | 0-46 | 0-27 | 0-20 | 0-21 | 0-17 | 0-28 |
| **QOLLTI-F** | | | | | | | | | | | | |
| **Mean** | | | | | | | 7.25 | 7.13 | 7.39 | 3.34 | 6.56 | 5.55 |
| **SD** | | | | | | | 1.94 | 1.90 | 1.77 | 3.78 | 1.53 | 1.45 |
| **Range** | | | | | | | 3-10 | 4-10 | 4-10 | 0-9 | 5-8 | 4-7 |
| **MQOL** | | | | | | | | | | | | |
| **Mean** | 6.42 | 6.22 | 6.52 | 6.11 | 7.75 | 4.93 | | | | | | |
| **SD** | 1.44 | 2.02 | 1.59 | 1.62 | 2.04 | 2.08 | | | | | | |
| **Range** | 4-10 | 2-10 | 4-10 | 4-9 | 6-10 | 3-7 | | | | | | |
| **FACT-G** | | | | | | | | | | | | |
| **Mean** | 70.53 | 71.87 | 67.30 | 63.83 | 79.00 | 63.67 | | | | | | |
| **SD** | 13.52 | 17.44 | 12.79 | 14.22 | 17.58 | 12.66 | | | | | | |
| **Range** | 52-99 | 40-105 | 55-94 | 46-79 | 66-99 | 50-75 | | | | | | |
| **FACIT-F** | | | | | | | | | | | | |
| **Mean** | 30.07 | 29.13 | 27.20 | 25.83 | 32.33 | 21.00 | 37.40 | 40.14 | 37.11 | 34.80 | 31.00 | 34.67 |
| **SD** | 10.38 | 10.77 | 8.59 | 12.95 | 12.86 | 7.21 | 10.19 | 11.60 | 13.39 | 17.11 | 12.54 | 15.18 |
| **Range** | 13-48 | 13-52 | 16-42 | 4-43 | 23-47 | 13-27 | 21-52 | 18-52 | 18-50 | 11-52 | 17-47 | 21-51 |

| | Tapestry | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Patient | | | | | | Partner | | | | | |
| **Time** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** |
| **N** | 15 | 15 | 10 | 6 | 3 | 3 | 15 | 15 | 10 | 5 | 3 | 3 |
| **FACIT-Sp** | | | | | | | | | | | | |
| **Mean** | 33.13 | 35.27 | 33.10 | 28.17 | 43.00 | 30.33 | 31.33 | 32.64 | 33.44 | 29.40 | 27.50 | 25.67 |
| **SD** | 10.88 | 11.37 | 11.41 | 10.67 | 6.25 | 4.73 | 9.94 | 8.31 | 10.33 | 11.89 | 9.00 | 17.16 |
| **Range** | 10-48 | 10-48 | 14-44 | 16-42 | 36-48 | 25-34 | 14-47 | 19-48 | 20-48 | 11-39 | 20-40 | 10-44 |
| **BHS** | | | | | | | | | | | | |
| **Mean** | 5.47 | 5.07 | 7.80 | 6.50 | 4.33 | 8.67 | 7.73 | 5.87 | 7.40 | 7.00 | 9.75 | 10.33 |
| **SD** | 5.13 | 4.33 | 3.55 | 3.15 | 3.06 | 2.08 | 5.24 | 5.38 | 6.00 | 6.12 | 8.62 | 8.33 |
| **Range** | 0-15 | 0-15 | 2-12 | 2-11 | 1-7 | 7-11 | 1-16 | 0-17 | 0-18 | 1-17 | 1-19 | 1-17 |
| **IMS** | | | | | | | | | | | | |
| **Mean** | 14.09 | 11.16 | 14.60 | 14.00 | 12.67 | 11.78 | 24.49 | 16.31 | 18.27 | 20.93 | 28.50 | 29.67 |
| **SD** | 10.08 | 9.19 | 7.89 | 10.10 | 10.09 | 6.34 | 17.24 | 13.80 | 15.65 | 13.95 | 12.92 | 24.98 |
| **Range** | 0-28 | 0-29 | 5-33 | 4-32 | 5-24 | 5-18 | 3-73 | 2-46 | 2-49 | 12-45 | 11-43 | 12-47 |
| **ADAD** | | | | | | | | | | | | |
| **Mean** | 4.42 | 5.22 | 5.15 | 5.20 | 5.75 | 5.42 | 4.92 | 4.96 | 5.38 | 4.90 | 5.56 | 4.92 |
| **SD** | 1.79 | 1.35 | 1.33 | 1.19 | 1.95 | 0.38 | 1.59 | 1.27 | 1.54 | 0.63 | 0.43 | 1.38 |
| **Range** | 0-7 | 3-7 | 3-7 | 4-7 | 4-7 | 5-6 | 1-7 | 2-7 | 2-7 | 4-6 | 5-6 | 4-6 |

Appendix I: Means, standard deviations and range of scores for all measures for patients and partners in the natural history group

| | Natural History | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Patient | | | | | | Partner | | | | | |
| **Time** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** |
| **N** | 20 | 14 | 11 | 7 | 4 | 1 | 20 | 14 | 11 | 7 | 4 | 1 |
| **BDI** | | | | | | | | | | | | |
| **Mean** | 11.15 | 10.00 | 14.27 | 12.71 | 13.75 | 14.00 | 9.55 | 9.00 | 10.36 | 7.71 | 8.00 | 6.00 |
| **SD** | 5.93 | 6.69 | 6.96 | 5.99 | 6.24 | | 7.32 | 7.11 | 8.20 | 7.20 | 8.17 | |
| **Range** | 2-23 | 2-22 | 4-27 | 7-24 | 8-22 | | 0-23 | 0-26 | 1-29 | 0-19 | 0-16 | |
| **BSI-G** | | | | | | | | | | | | |
| **Mean** | 9.20 | 7.93 | 11.55 | 12.29 | 10.75 | 13.00 | 6.85 | 5.93 | 8.55 | 6.86 | 4.25 | 4.00 |
| **SD** | 7.58 | 7.53 | 8.56 | 8.04 | 8.73 | | 6.06 | 6.49 | 9.90 | 6.49 | 4.79 | |
| **Range** | 0-28 | 0-26 | 2-24 | 3-25 | 4-23 | | 0-17 | 0-23 | 0-32 | 0-18 | 0-11 | |
| **QOLLTI-F** | | | | | | | | | | | | |
| **Mean** | | | | | | | 7.62 | 8.19 | 7.36 | 3.84 | 8.33 | 9.22 |
| **SD** | | | | | | | 1.69 | 1.47 | 1.89 | 4.07 | 1.97 | |
| **Range** | | | | | | | 5-10 | 5-10 | 5-10 | 0-10 | 6-10 | |
| **MQOL** | | | | | | | | | | | | |
| **Mean** | 7.26 | 7.20 | 6.55 | 7.17 | 7.80 | 7.78 | | | | | | |
| **SD** | 1.24 | 1.38 | 1.37 | 1.42 | 1.78 | | | | | | | |
| **Range** | 5-10 | 5-9 | 3-8 | 5-9 | 5-9 | | | | | | | |
| **FACT-G** | | | | | | | | | | | | |
| **Mean** | 79.35 | 79.57 | 71.36 | 73.57 | 73.00 | 55.00 | | | | | | |
| **SD** | 16.69 | 14.81 | 18.64 | 17.25 | 20.93 | | | | | | | |
| **Range** | 44-102 | 57-103 | 33-93 | 53-101 | 46-97 | | | | | | | |
| **FACIT-F** | | | | | | | | | | | | |
| **Mean** | 34.65 | 32.93 | 25.45 | 31.86 | 30.00 | 37.00 | 41.75 | 40.86 | 40.00 | 41.57 | 39.00 | 44.00 |
| **SD** | 12.64 | 12.25 | 13.87 | 14.37 | 11.63 | | 7.09 | 9.26 | 8.44 | 7.57 | 2.94 | |
| **Range** | 6-50 | 14-51 | 1-47 | 10-52 | 14-40 | | 27-52 | 22-50 | 19-48 | 29-52 | 36-43 | |

| | Natural History | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Patient | | | | | | Partner | | | | | |
| **Time** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** | **Base line** | **1 month** | **3 month** | **6 month** | **9 month** | **12 month** |
| **N** | 20 | 14 | 11 | 7 | 4 | 1 | 20 | 14 | 11 | 7 | 4 | 1 |
| **FACIT-Sp** | | | | | | | | | | | | |
| **Mean** | 3.50 | 35.43 | 27.64 | 32.14 | 29.75 | 26.00 | 31.80 | 33.29 | 32.00 | 38.57 | 37.25 | 46.00 |
| **SD** | 9.18 | 8.84 | 12.74 | 6.04 | 9.74 | | 10.84 | 12.20 | 12.93 | 8.56 | 13.82 | |
| **Range** | 3-47 | 20-48 | 6-45 | 23-38 | 23-44 | | 11-47 | 9-45 | 12-48 | 24-48 | 17.48 | |
| **BHS** | | | | | | | | | | | | |
| **Mean** | 5.60 | 4.43 | 8.27 | 8.43 | 9.25 | 10.00 | 5.80 | 5.07 | 5.36 | 4.71 | 5.00 | 0 |
| **SD** | 4.45 | 3.80 | 5.93 | 4.69 | 5.91 | | 4.65 | 5.18 | 5.12 | 4.35 | 6.78 | |
| **Range** | 0-19 | 0-13 | 1-20 | 4-17 | 2-15 | | 0-15 | 0-16 | 0-14 | 0-11 | 0-15 | |
| **IMS** | | | | | | | | | | | | |
| **Mean** | 9.63 | 7.48 | 10.97 | 10.89 | 13.50 | 4.67 | 14.87 | 11.52 | 16.61 | 16.48 | 13.00 | 5.00 |
| **SD** | 9.03 | 8.82 | 9.50 | 3.59 | 10.09 | | 10.02 | 9.08 | 11.12 | 10.21 | 9.37 | |
| **Range** | 0-29 | 0-27 | 0-31 | 5-16 | 6-28 | | 0-31 | 0-28 | 3-31 | 4-33 | 5-27 | |
| **ADAD** | | | | | | | | | | | | |
| **Mean** | 5.19 | 5.46 | 4.75 | 4.58 | 4.75 | 4.50 | 5.09 | 5.27 | 4.23 | 4.89 | 5.19 | 6.00 |
| **SD** | 1.57 | 1.15 | 1.06 | 1.13 | 1.21 | | 1.32 | 1.06 | 1.46 | 2.07 | 1.64 | |
| **Range** | 2-7 | 3-7 | 3-6 | 4-6 | 4-7 | | 3-7 | 3-7 | 2-6 | 1-7 | 3-6 | |

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2004-06-03

Dr. J.S.A. Simpson
Department of Psychiatry
Foothills Hospital
Calgary, Alberta

Dear Dr. Simpson:

**RE: A Pilot Project to Assess the Impact of a Novel Psychosocial Intervention on the Quality of Life, Attitudes to Death and Dying and Spirituality of Palliative Cancer Patients**

**Grant-ID: 17801**

The above-named research project, letters of introduction (Cohort I and II), Consent Forms (Cohort I and II both dated September 8, 2003, Summer Student Consent Form dated April 10, 2004), Pilot Project Cover Sheet, Demographic Information (Patient and Partner dated May 8, 2003), Interview Feedback Questionnaires (Patient and Partner) have been granted ethical approval by the Conjoint Health Research Ethics Board of the Faculties of Medicine, Nursing and Kinesiology, University of Calgary, and the Affiliated Teaching Institutions. The Board conforms to the Tri-Council Guidelines, ICH Guidelines and amendments to regulations of the Food and Drug Act re clinical trials, including membership and requirements for a quorum.

You and your co-investigators are not members of the CHREB and did not participate in review or voting on this study.
Please note that this approval is subject to the following conditions:

(1) i) appropriate procedures for consent for access to identified health information has been approved,
ii) consent for access to personal identified health information in retrospective chart review is not required on grounds considered under Section X of the Health Information Act,
iii) access to personal identifiable health information was not requested in this submission;

(2) a copy of the informed consent form must have been given to each research subject, if required for this study;

(3) a Progress Report must be submitted by 2005-06-03, containing the following information:
i) the number of subjects recruited;
ii) a description of any protocol modification;
iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
v) a copy of the current informed consent form;
vi) the expected date of termination of this project.

(4) a Final Report must be submitted at the termination of the project.

Please accept the Board's best wishes for success in your research.
Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC

Chair, Conjoint Health Research Ethics Board

CJD/am
c.c. Adult Research Committee Dr. D. Addington (information) Research Services Ms. E. Moss (Research Coordinator)
Office of Information & Privacy Commissioner

FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

August 30, 2004

OFFICE OF MEDICAL BIOETHICS

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Dr. J.S.A. Simpson
Department of Psychiatry
Foothills Hospital
Calgary, Alberta

Dear Dr. Simpson:

**RE: A Pilot Project to Assess the Impact of a Novel Psychosocial Intervention on the Quality of Life, Attitudes to Death and Dying and Spirituality of Palliative Cancer Patients**

**GRANT ID: 17801**

Your request to modify the above-named protocol has been reviewed and approved.

I am pleased to advise you that it is permissible for you to use the revised protocol and the revised Consent Forms - Cohort I and II, *(Versions dated August 9, 2004)*, and the Letters of Introduction – Cohort I and II, based on the information contained in your correspondence of August 09, 2004. Also, thank you for a copy of the letter of reward from the CIHR dated July 2, 2004 for our information and file.

A progress report concerning this study is required annually, from the date of the original approval (2004-06-03). The report should contain information concerning:

(i) the number of subjects recruited;
(ii) a description of any protocol modification;
(iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
(iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
(v) a copy of the current informed consent form;
(vi) the expected date of termination of this project;

Thank you for the attention which I know you will bring to these matters.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC
Chair, Conjoint Health Research Ethics Board

/nv

cc: Adult Research Committee
Ms. Erin Moss, Research Coordinator