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Relationship with God, Loneliness, Anger and Symptom Distress in Patients with Cancer Who are Near the End of Life

Linda Olson Scott, M.Div. [Chaplain Resident],

James A. Haley Veterans Hospital, Tampa, FL

Johnathon M. Law, M.Div., MBA [Chaplain Resident],

James A. Haley Veterans Hospital, Tampa, FL

Daniel P. Brodeur, M.Div. [Chaplain Resident],

James A. Haley Veterans Hospital, Tampa, FL

Christopher A. Salerno, M.Div. [Chaplain Resident],

James A. Haley Veterans Hospital, Tampa, FL

Anzette Thomas, M.Div. [Chaplain Resident], and

James A. Haley Veterans Hospital, Tampa, FL

Susan C. McMillan, PhD, ARNP, FAAN [Distinguished University Professor]

Thompson Professor of Oncology Nursing, University of South Florida College of Nursing,
Tampa, FL

Introduction

Patients receiving hospice care have a variety of distressing symptoms and problems facing them¹, with fatigue and pain being among the most distressing^{2–3}. As patients near the end of life, priorities may shift from concerns about work and health to concerns about what comes after death. Thus, many patients may strengthen or renew their relationship with God, however they may define that relationship⁴, confirming the need for clergy to be included in the interdisciplinary team. However, spiritual care for these patients is often lacking⁵, and this area of need and concern is not often the topic of research.

Relationship with God

Only very limited research was found related to a relationship with God. In a study that included 225 Christians, it was found that God is experienced as meeting basic psychological needs with tangible effects on symptoms of depression and stress⁶. A study of 69 men and 132 women found differences in men and women in regard to perceptions of a loving God; men who perceived a loving God had *higher* self-esteem/competence, while women who perceived a loving God had *low* self-esteem⁷. Further, a study of 34 men who were prostate cancer survivors, reported, in general, that they turned to God for meaning when confronted with distressing or difficult circumstances⁸. In general, near the end of life, relationship with God is valued. A quality of life study that included 68 hospice patients

found that the highest satisfaction scores across all domains were reported for the item asking about relationship with God (McMillan & Mahon 1994)⁹.

Symptom Distress

Patients with cancer who are near the end of life typically have multiple symptoms, and many of them are reported by these patients to be very distressing³. Symptom distress may be defined as the amount of bother or distress caused by the patients' cancer related symptoms. Patients near the end of life are reported to have significant symptom distress¹⁰. A descriptive study which included 298 patients receiving treatment with either palliative or curative intent revealed distress levels associated with varying symptoms to be both prevalent and persistent in cancer patients³. Although only limited research has been reported on this topic, spiritual well-being has been shown to be negatively correlated with symptom distress¹¹. And palliative care patients who perceived punishment or abandonment by God reported greater distress and worse quality of life¹².

Anger

Kubler-Ross described the stages experienced by persons approaching death. One of these stages was anger, which might be directed at God, at the environment, or at themselves¹³. More recent studies have found that anger toward God was commonly reported in relationship to negative events. Research with cancer patients near the end of life confirms that anger can be an issue¹⁴. While anger scores have generally been low in studies of patients with cancer¹⁵, one study of advanced cancer patients found that 53% of interactions between patients and clinicians contained patient expressions of anger¹⁶. Anger toward God has been reported in response to negative events¹⁷. And anger has been shown to be related negatively to quality of life in persons with cancer¹⁸.

A byproduct of suffering can be a tendency toward spiritual estrangement from God. Anger might emerge when people grapple with their experiences of illness, pain and grief in view of their belief in the goodness of God. Disillusionment and perceived abandonment can lead patients to doubt in the power and existence of divinity¹⁹. As individuals try to resolve their spiritual conflict, a minority default to unbelief. In a study of undergraduate students, only 9% of respondents said they resolved their negative feelings toward God by deciding not to believe in God, while 80% reported that their anger decreased over time²⁰. Resolution of the bitterness that affects spiritual well-being often seems to come with time, reflection, and acceptance. Suffering may cause a faltering of faith but need not do indelible damage and may even lead to a more robust spirituality²¹.

Loneliness

When patients are facing death they may experience a profound loneliness,¹⁴ and a person's view of God has significant bearing on their experience of loneliness. Research with a group of 115 women and 91 men who were 15 to 87 years old revealed that an image of a helpful God has a negative correlation with loneliness, and an image of a wrathful God was related positively to loneliness. An image of God as punishing and rejecting elicits negative feelings toward God, increasing feelings of distance and loneliness²². Research also has shown that those with better self-esteem have a positive image of God and experience less loneliness,

and further, that loneliness correlates significantly with a feeling of distance from God. An experimental study included 72 healthy young adults, primarily (98%) self-identified as Christian and at least moderately interested in religion. These individuals confirmed that feelings of loneliness increased religious devotion²³.

In summary, little research has been conducted evaluating the issues of relationship with God, loneliness and anger at the end of life and whether these are affected by the distress the patient is experiencing from symptoms. Studies have revealed that a relationship with God is important to a person toward the end of life when loneliness, anger and symptom distress may be overriding factors in that life. Thus, this is a meaningful area of research. The purpose of this study was to further explore issues of relationship with God, symptom distress and feelings of anger and loneliness in patients with advanced cancer who were near the end of life.

Research Questions

The following research questions are addressed in this study:

1. What are the levels of satisfaction with relationship God, symptom distress, anger and loneliness among cancer patients who are near the end of life?
2. What are the relationships between hospice patients' satisfaction with their relationship with God and the variables of anger, loneliness and symptom distress?

Methods

Sample

This study was conducted using a sample from a previously completed study²⁴. The original study sample consisted of 354 patients with cancer who were receiving hospice home care from one large not-for-profit hospice. Patients were identified by admission face sheets as those who had a cancer diagnosis, an identified family caregiver, were adults (18+ years old), male or female, able to read and understand English, and able to pass mental status screening. Patients were excluded if they had Karnofsky performance status (0–100) scores in the record of less than 40 or were confused, excessively debilitated, comatose or actively dying. Because the study focused primarily on management of three common problems (pain, dyspnea, and constipation), patients were excluded if they did not have two of these three problems as documented by baseline data collection. Patients with complete data were included in this analysis.

Instruments

Memorial Symptom Assessment Scale—Several researchers have called for differentiating symptom distress from symptom intensity and frequency^{25–27}. One expert defined symptom distress as “how bothered” the patients were by the symptom²⁵. The Memorial Symptom Assessment Scale (MSAS) is designed to differentiate among frequency, intensity, and distress from symptoms. The original MSAS has 33 items reflecting symptoms commonly associated with cancer²⁸.

For this study, a revised MSAS was used that was developed and validated for use with hospice patients with cancer, and included 25 items. Items are rated from 0–4 for distress, resulting in subscale scores for distress that range from 0–100 for each patient¹⁰. Total (Global) distress scores were used for this analysis.

Validity and Reliability: Validity of the MSAS for use with cancer patients receiving hospice home care was conducted and included correlation with Hospice Quality of Life Index (HQLI) scores. As predicted, the correlation between MSAS distress scores and HQLI scores were moderately strong and negative ($r = -.72$; $p < .001$). This provided support for construct validity of the MSAS for use with cancer patients near the end of life. In addition, reliability of the distress scores was good ($r = .74$) using coefficient alpha¹⁰.

Hospice Quality of Life Index—The Hospice Quality of Life Index is a 28 item scale, with each item rated on a 0–10 point numeric rating scale. Total scores can range from 0–280. The HQLI includes three aspects of overall quality of life: Psychophysiological Well-being; Functional well-being; and Social/spiritual Well-being^{29–30}.

Validity and Reliability: Evidence of validity was provided by the ability of the HQLI to differentiate between hospice patients and apparently healthy controls using both discriminate analysis ($p = .00$) and comparison of means ($p = .00$). Previously, the HQLI has been validated for use with hospice patients with cancer. Further, the finding that HQLI scores correlated at the expected level ($r = .26$; $p = .00$) with functional status scores provides further evidence of validity. Finally, factor analysis confirmed the factor structure of the HQLI. Reliability of the HQLI was provided by generation of coefficient alphas for both total scale scores and subscale scores. Subscale alphas all were .84 and the total scale alpha was high for both cancer ($r = .88$) and AIDS ($r = .93$) patients³⁰. For this analysis, three items were included: relationship with God, feelings of loneliness, and feeling anger.

Demographic Data—Standard Demographic data were collected from patients and patient records. The following data were collected from the patient record: age, gender, and marital status. The remainder of the data came from the patient including: education level, race/ethnicity, and religious affiliation.

Data Analysis

Demographic data was analyzed using means, standard deviations, frequencies and percentages to describe the sample. To answer the research questions, further analyses were conducted. To determine the levels of satisfaction with relationship God, symptom distress, anger and loneliness among cancer patients in the sample, means and standard deviations are reported. To evaluate the relationships among study variables, including relationship with God, symptom distress, anger and loneliness, Pearson correlations were used.

Results

Sample

The sample consisted of 354 hospice patients newly admitted to hospice home care. The patients were more male (60%) than female and the majority (65%) were married, white (84%) and non-Catholic Christian in their religious affiliation, while 32 patients (9%) denied having any religious affiliation (Table 1). The mean age of the sample was 71.1 and they had an average of about 12 years of formal education (Table 2).

Descriptive Results

The mean score on the item: Satisfaction with Relationship with God was high (9.2). Anger (8.0) and loneliness (8.2) mean scores also were relatively high, meaning that these patients reported relatively little anger or loneliness. Symptom distress mean scores were 21.9 (Table 2).

Correlations Among Variables

All of the study variables, Relationship with God, Anger, Loneliness, and Symptom Distress, were intercorrelated. More specifically, Satisfaction with Relationship with God scores were weakly but significantly correlated with the other three variables. Demographic variables of marital status, age and years of education were also evaluated. Only age had any relationships with the study variables of Anger, Loneliness, and Symptom distress (Table 3).

Discussion

Satisfaction with Relationship with God scores in this group of primarily Christian hospice patients with cancer were very high (mean=9.2 on a 0 to 10 scale). Previous research with palliative care patients has reported that most patients reported having faith in God³². This high satisfaction score may be related to the fact that because these patients were facing death, they might have been actively working on improving their relationships with God, although we cannot know that for certain. Although most patients were satisfied, it must be acknowledged that some patients were not. More research is needed about patients' relationships with God and whether they might be different as they get closer to death. Whether patients are satisfied with their relationship with God or are not, they may benefit from a visit from clergy, and nurses may be the ones who make the referral. Even patients who are satisfied may find a visit from a chaplain or their own clergy person to be affirming and encouraging.

The next highest score was the item asking about loneliness. It should be noted that this item was worded so that a higher score indicated LESS loneliness. Therefore, this mean score can be interpreted to mean relatively little loneliness being reported by this sample. This might be related to the fact that these patients were newly admitted (within 48 hours) to hospice home care and thus had been surrounded by hospice staff members who were coming into the home to assess and support them. In addition, all of the patients had designated family caregivers who were, in most cases, spouses (65% of patients were married). Thus, this

sample had a support system available to help assuage any possible loneliness making the results less generalizable to other groups of patients with advanced cancer.

Interestingly, there was a weak but significant relationship between loneliness and satisfaction with relationship with God ($r=.25$, $P=.000$). It is possible that patients who felt that they had a good relationship with God were less lonely because they felt they were communicating with God through prayer or reading scripture. Thus, for them it is possible that religion was more than a set of beliefs but was a source of comfort, care and support. Patients from a Judeo-Christian background who are familiar with scriptures may have read in the book of Deuteronomy 31: 6(Holy Bible)³³ “He is the One who goes with you. He will not leave you nor forsake you.” This could help defray feelings of loneliness and help to support satisfaction with a relationship with God.

Anger scores also were high (mean=8.0). Again, the item was scored such that a high score on this item means relatively little anger. This is not consistent with the findings of Kubler-Ross¹³ who interviewed 200 dying patients and found that many of them expressed anger. One possible explanation is that patients did not feel comfortable admitting to anger, especially if that anger was directed at God for allowing this disease to happen to them. However, the actual reason is not clear and further study might help to clarify this.

A weak but significant relationship ($r=.28$; $P=.000$) was found between the anger and relationship with God items. If patients felt that they did not have a good relationship with God, they might feel anger and ask as patients often do, “*How could a loving God allow this to happen to me?*” Conversely, if patients felt that they had a good relationship with God, they might have felt encouraged and comforted by the knowledge that after death they would be in God’s presence.

The total symptom distress scores do not look very high in relation to a possible range of scores from 0 to 100. However, in order to have the maximum score of 100, patients would have to have reported maximum distress on a total of 25 symptoms, and the average number reported by cancer patients is 12 symptoms³. Thus, for the *average* patient with 12 symptoms, the highest possible total distress score would be 48 not 100, meaning that a distress score of almost 22 is not really at the bottom of the scale as it might first appear. These patients were experiencing measurable levels of distress from their symptoms, and thus, these symptoms deserve attention. Further, it is reasonable to assume that significant symptom distress would have an influence on other feelings, like anger and loneliness.

Patients who perceived a satisfactory relationship with God reported less symptom distress. It is not clear why this would be the case, but it may be that this sample that was mostly Christians identified with Christ being present in their suffering. Chaplains and other health care providers may hear patients with symptoms express this thought as, “*This is my cross to bear.*” This may come from Christian scripture in verses such as Corinthians 12:9–11³³ where it says, “My grace is sufficient for you, for my strength is made perfect in weakness. Therefore most gladly I will rather boast in my infirmities, that the power of Christ may rest upon me. Therefore I take pleasure in infirmities, in reproaches, in needs, in persecutions, in distresses, for Christ’s sake. For when I am weak, then I am strong.” Other sources might

include Psalms 39:7³³ which says, “And now Lord, what do I wait for? My hope is in you.” As well Christians are encouraged in Romans 12:12³³ to remain “rejoicing in hope, patient in tribulation, continuing steadfastly in prayer.” This seems to pair the idea of communicating with God through prayer and bearing the distress of symptoms.

Correlations Among Variables

The focus of this study were the correlates of the Satisfaction with Relationship with God item, including anger, loneliness and symptom distress in a sample of persons in hospice care who have cancer and were primarily Christian. However, other significant relationships also were found among anger, loneliness and symptom distress, with the strongest correlation being between anger and loneliness ($r=.56$; $P=.000$). Loneliness near the end of life can be distressing, and it can feel as if no one cares. It may be more frightening to go through the difficult times alone, and this may be experienced as anger. Further, when people are angry, they may isolate themselves, actually creating the isolation they are experiencing. Whatever, the cause, it is clear that to some extent, these two issues can co-occur.

The relationship between anger and symptom distress ($r=-.41$; $P=.000$) might be more easily understood. Patients may say, *‘I don’t deserve this; this is not fair’*. Sometimes when patients have lived a very healthy life and still get cancer, they may lash out at God, telling him that it isn’t fair that they should be the ones who have this disease.

Loneliness and symptom distress scores also were significantly negatively correlated ($r=-.41$; $P=.000$). This result means that as loneliness got worse, symptom distress got worse also. This may mean that suffering alone is more difficult than suffering with some support. Thus, it would appear that, while we are managing symptoms, supporting patients simply by our presence can help to alleviate symptom distress to some degree.

Age affected results in that younger patients appeared to have greater feelings of anger, loneliness and symptom distress. It is not known why this would be the case, but it appears to be consistent with earlier research wherein younger patients reported more severe symptoms and suffering regardless of stage of disease³⁴. It is possible that this greater level of distress, anger and loneliness was in some way related to the expectation that disease and infirmity were normal in older age but less so in younger age; thus, being faced with a life-threatening condition at a younger age caused more negative feelings. However, it should be noted that age did not seem to have any association with the patients’ satisfaction with their relationship with God.

Sample

The sample was relatively large ($N=354$) for a group of cancer patients in hospice care, offering confidence that the results were not biased by a small sample. However, the patients all lived and received hospice home care in the same county in Florida, limiting the generalizability of results. The sample was more male than female, but this is consistent with other studies that included patient-caregiver dyads where the caregivers were primarily females caring for male patients^{29–30}. The majority (65%) was married; however, this result

probably occurred because the study required that patients be in home care and have designated informal/family caregivers. Thus, the design of the study biased the sample in this way. In a study that included patients who did not have caregivers available, the results might have been different. The sample was predominantly white and non-Hispanic, which is typical of all hospice patients in the county where the study was done.

The breakdown by religion was roughly reflective of the surrounding community where the majority is non-Catholic Christians, and the next largest group is Catholic. Only a relatively small number of patients denied any religious affiliation (9%); this is consistent with findings from earlier studies^{12,17}. It should be noted that the way the patients were asked about their relationships with God allowed even non-believers to rate themselves as satisfied because the question stated: “How satisfied are you with your relationship with God (however you define that relationship)”. The item was worded like this so that the subset of patients who did not believe in God could respond to that item and still have a range of satisfaction scores. They were told that if they did not believe in God and they were satisfied with that belief, that they should score the item accordingly. Thus, care must be taken not to misinterpret these results.

The mean age of 71 years is consistent with other hospice samples of cancer patients^{29–30}. The mean years of formal education (12 years) might be related to the age of the group. The average patient would have lived through World War II, so that high school graduation was considered to be more of an educational accomplishment than it would be today.

Implications of the Study

According to the National Hospice and Palliative Care Organization³⁵, hospices “assist the patient with the emotional, psychosocial and *spiritual aspects* of dying” (p. 11). This national organization seems to put spiritual care on a par with all other care being provided by hospices. Patients near the end of life need and deserve spiritual support whether nurses feel competent to address these problems or not. Problems like anger and loneliness may be related to spiritual issues for patients, but may not always be apparent. Thus, interdisciplinary team members need to be sensitive to the possibility that these issues are present but not expressed. Nurses spend more time with patients than other team members but may feel inadequate to address spiritual issues. Nurses should actively seek chaplain consultation when it appears to be needed. Chaplains or visiting clergy should attempt to make contact with and conduct a spiritual assessment of *all* patients near the end of life, whether in hospice care or elsewhere, and to support these patients directly or to put patients in touch with their own faith leaders.

Conclusions

In spite of advanced cancer and awareness of approaching death, patients appear to be able to maintain their relationships with God. However, they still have other problems, such as anger, loneliness and symptom distress that are associated with their God-relationships and that deserve attention. Nurses and physicians may not feel able to support patients in these end of life issues, but may not think to call on others to support the patients. Thus, the

interdisciplinary team, which includes chaplains and other clergy, is critical to comprehensive patient care and should remain the standard.

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Table 1

Frequency and Percent of Patients by gender, Marital Status, Race or Ethnicity and Religious Affiliation (N=354)

Variable	Frequency	Percent
Gender		
Male	212	60
Female	142	40
Marital Status		
Married	231	65
Widowed	68	19
Divorced	39	11
Never married	10	3
Separated	2	<1
Race/Ethnicity		
White, non-Hispanic	298	84
African American	30	8
Hispanic	17	5
Asian-Pacific Islander	1	<1
Eskimo/native American	1	<1
Mixed	1	<1
Other	1	<1
Missing data	3	<1
Religious Affiliation		
Non-Catholic Christian	227	64
Catholic Christian	83	23
Other	3	<1
None	32	9
Missing data	9	2

Table 2

Mean and Standard Deviation of Patient Age, Education, and Scores on Relationship with God, Anger, Loneliness and Symptom Distress (N=354)

Variable	Possible Range of Scores	Mean	Standard Deviation
Age		71.1	12.0
Years of Education		12.0	3.2
Satisfaction with Relationship with God	0–10	9.2	1.8
Anger	0–10 *	8.0	2.9
Loneliness	0–10 *	8.2	2.5
Symptom Distress	0–100	21.9	12.4

* Scores range 0–10 with high scores meaning less anger or loneliness

Table 3
Pearson Correlations Among Variables: Age, Relationship with God, Anger, Loneliness, and Symptom Distress

Variable	Age	Relationship w. God	Anger	Loneliness	Symptom Distress
Age	r 1.0				
	P	-	-	-	-
	N				
Relationship with God	r .11	1.0			
	P .07		-	-	-
	N 288				
Anger*	r .23	.28	1.0		
	P .000	.000		-	-
	N 296	.288			
Loneliness*	r .27	.25	.56	1.0	
	P .000	.000	.000		-
	N 296	.288	.296		
Symptom Distress	r -.27	-.23	-.41	-.41	1.0
	P .000	.000	.000	.000	
	N 299	.287	.295	.295	

* Scores range 0–10 with high scores meaning less anger or loneliness