

# Exploring family relationships through associations of comfort, relatedness states, and life closure in hospice patients: A pilot study

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## ABSTRACT

**Objective:** Research at the end of life tends to focus on the dying patient's symptoms, often overlooking issues associated with family interactions. However, many families struggle just to maintain or initiate these valuable connections. The purpose of our pilot study was to explore family relationships at the end of life and investigate associations among perceived comfort, relatedness states, and life closure.

**Method:** This descriptive study used a cross-sectional design, and a convenience sample ( $n = 30$ ; 18 women; mean age = 71 years) was recruited from patients admitted to a large not-for-profit hospice in northeastern Ohio. In-person interviews using the Hospice Comfort Questionnaire, Relatedness States Visual Analog Scales, and the Life-Closure Scale provided data for analyses.

**Results:** Family interactions that were *not* associated with the physical tasks of caregiving were related to life closure ( $r = 0.36$ ,  $p = 0.001$ ), and life closure and comfort were highly correlated ( $r = 0.69$ ,  $p < 0.001$ ). Participants residing in an inpatient setting had higher levels of involvement ( $t[18] = -2.07$ ,  $p = 0.05$ ) and comfort in relationships ( $t[28] = -2.06$ ,  $p = 0.05$ ) than those in the home setting.

**Significance of Results:** This is the first known study investigating the associations among comfort, relatedness, and life closure at the end of life. The majority of participants had high levels of involvement and comfort in their relationships, and they preferred interactions that required minimal effort. Studies that focus on both patients' and family members' perceptions of relationships are needed as well as outcome studies that test simple interventions.

**KEYWORDS:** Comfort, Life closure, Relatedness states, Family relationships at the end of life

## INTRODUCTION

The alleviation of physical symptoms for patients and enhancement of comfort for patients and family members are two important goals at the end of life. Family relationships influence the dying experience (Broom & Kirby, 2012), and achieving comfort for

the patient can be difficult, especially if those relationships are problematic. In addition, when there is a lack of patient support, psychological adaptation or life closure is less obtainable (Dobratz, 2006). Therefore, for the dying patient, positive family relationships and comfort can be instrumental in promoting life closure and a feeling of completeness in the patient–family relationship.

The present pilot study takes a unique view of family relationships, focusing on concepts of comfort, relatedness states, and life closure. Generally

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speaking, research on families at the end of life has focused on communication among family members, and much of it has been qualitative (Prince-Paul, 2008; Keeley, 2007; Sheehan & Draucker, 2011; Syren et al., 2006). Our findings demonstrate that, although communication between dying patients and their families can be difficult, it is important for life closure and helps create meaning for the terminally ill patient and their family (Syren et al., 2006; Prince-Paul, 2008). Moreover, studies have shown that terminally ill patients and their loved ones value the time spent with family and friends; if communication and sharing occur, family members report relief from emotional suffering and/or a desire to mend broken relationships and make the most of the time left to them (Keeley, 2007; Downy et al., 2009; Rosenbaum et al., 2006; Sheehan & Draucker, 2011). It is clear from the literature that terminally ill patients and their families view close personal relationships as important. Equally important is the need for all family members to express feelings related to their relationships (Prince-Paul, 2008; Keeley, 2007). The findings of our pilot study add to the body of literature demonstrating the significance of high levels of involvement and comfort with that involvement in relationships at the end of life and their importance from the patient's perspective. The significance of family persists throughout the dying experience.

Little evidence exists about how hospice staff can support family relationships, especially when patient acuity is high and the length of stay in the hospice program is relatively short (NHPCO, 2011). Using Comfort Theory (Kolcaba, 2003) and Relatedness Theory (Haggerty et al., 1993) as background, the aim of our pilot study was to understand associations among concepts important at the end of life: comfort, relatedness states, and life closure. The provision of comfort is a hospice tradition and is expected in the delivery of end-of-life care. Comfort theory posits four types of comfort: physical, psychospiritual, environmental, and sociocultural. Relatedness theory, based on attachment theory (Haggerty et al., 1993), which assists in understanding patient and family relationships at the end of life, poses two interconnected dimensions of relatedness experienced on a continuum: "involvement  $\rightarrow$  no involvement" and "comfort/well-being  $\rightarrow$  no comfort/well-being" with the level of involvement in a relationship (Haggerty et al., 1993). Life closure involves psychological adaptation to the changing circumstances that the dying patient face and is attained in part through supportive relationships. Understanding the patient's comfort and relational needs is a step toward understanding family relationships at the end of life. Ours is the first known study to explore family relationships at the end of life using these concepts.

## METHODS

### Design, Sample, and Setting

This descriptive correlational pilot study employed a cross-sectional design and a convenience sample ( $n = 30$ ) of patients admitted to a large not-for-profit hospice in northeastern Ohio between July of 2011 and October of 2012. The hospice provided both inpatient and home-based care, and all terminally ill hospice patients were eligible if they were 18 years or older. Patients were excluded if their illness state was evaluated as high acuity (Palliative Performance Scale [PPS] score greater than 40%) (Anderson et al., 1996) and/or they exhibited cognitive impairment at the time of screening (more than three wrong on the six-item screener) (Callahan et al., 2002).

### Ethical Considerations, Recruitment and Enrollment

The Case Western Reserve University Human Subjects Review Board approved the study, and all participants provided written consent. To minimize patient/family burden, the hospice staff identified and contacted potentially eligible participants. Interested participants provided verbal consent for the researcher to contact them; the first author then arranged a meeting time for study enrollment and data collection. The researcher provided opportunities for participants to take rest breaks and told them they could decline to answer questions.

We enrolled 30 participants in the study. Of the 64 participants who did not enroll (68%), 15 did not meet eligibility criteria and 2 died before consenting. Most patients declined without giving a reason, but some stated that they did not wish to participate due to feeling too sick or they provided a variety of other responses, such as it involved too much paperwork.

### Questionnaires and Data Collection

Data were collected from each participant through a face-to-face interview, which lasted approximately 30 minutes. Demographic data such as age, gender, length of stay in hospice, location of participants (home or hospice residence), and acuity level (based on the PPS) were collected first, followed by questionnaires that assessed participants' comfort status, relatedness states, and life closure.

#### *Palliative Performance Score (PPS)*

The Palliative Performance Scale (PPS) is an observer-rated scale that evaluates hospice patients' functional status and care needs based on five categories: ambulation, activity level/evidence of disease, self-care, intake, and level of consciousness (Anderson

et al., 1996; Lau et al., 2006; Ho et al., 2008). The scale has 11 categories in 10% increments (0–100). The lower a patient’s score, the poorer the function and the closer she is to death. The PPS, adapted from the Karnofsky Performance Scale, is a validated instrument widely used by hospice and palliative clinicians (Ho et al., 2008).

To investigate potential differences in questionnaire scores based on participants’ illness acuity, two groups were created using a clinical cutpoint for the PPS. A participant with a score greater than 50% is considered to have lower acuity compared to a score under 40%, which indicates higher acuity (Anderson et al., 1996; Ho et al., 2008; Lau et al., 2006).

*Comfort*

The Hospice Comfort Questionnaire, a validated 49-item Likert-type scale (strongly disagree to strongly agree), measured comfort (Kolcaba, 2003) according to how participants felt at the time of the interview (Kolcaba, 2003; Novak et al., 2001) (sample items: “my body is relaxed right now” and “I am afraid of what is next”).

A second measure of comfort, with a previously established concurrent validity, is the one-item Verbal Rating Comfort Scale (Dowd et al., 2007), which is easy to administer and carries a minimal burden for study participants. With ratings from 0 to 10 and corresponding descriptive words (such as no comfort at all [0] to highest comfort possible [10]), this scale provided a description of study participants’ overall comfort.

*Relatedness States*

Participants identified one family member and rated their level of involvement in the relationship and the

corresponding level of comfort with that involvement with two 10-centimeter visual analog scales (VASs), scoring related level of involvement and level of comfort (Lee & Higgins, 2011; Haggerty et al., 1993). Participants were not given specific criteria on which family member to choose while thinking about rating the visual analog scales. They were told to choose a person they considered to be family and rate their relationship based on level of involvement and level of comfort with that involvement. We did not conduct test–retest measures of reliability for these two visual analog scales.

The scores were graphically modeled, with the two curves intersecting at the five-centimeter mark to create four equal quadrants, one for each state of relatedness (see Figure 1): enmeshment, connectedness, disconnectedness, and parallelism. Individuals experience enmeshment (high involvement, low comfort) when involvement with another coexists with discomfort and anxiety (Haggerty et al., 1993). Unlike enmeshment, connectedness (high involvement, high comfort) includes a sense of comfort, well-being, and anxiety reduction when involved with others (Haggerty et al., 1993). Disconnectedness (low involvement, low comfort) occurs when a person is not involved with others and there is emotional and social estrangement (Haggerty et al., 1993). Parallelism (low involvement, high comfort) occurs when a person is not involved with others but this experience is comfortable and promotes well-being (Haggerty et al., 1993).

*Life Closure*

The Life-Closure Scale (Dobratz, 2006), a 20-item Likert-type scale (“not at all” to “most of the time”), measures psychological adaptation at the end of life

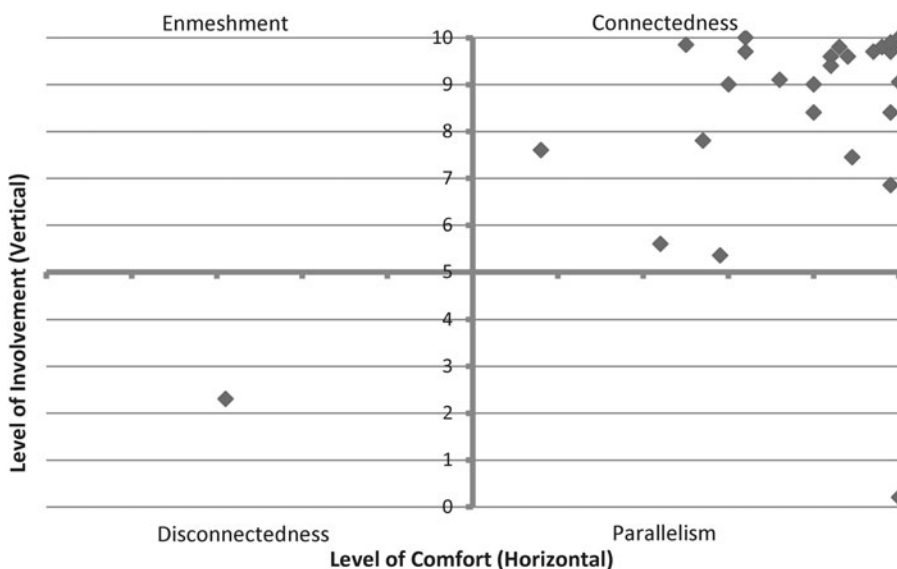


Fig. 1. States of relatedness (n = 30).

(Dobratz, 1990), and is a valid measure of psychological adaptation (Dobratz, 1990; 2004; 2006, 2011). It consists of two subscales: self-reconciling and self-restructuring. Self-reconciling refers to resolving events with reasoning, focusing, and rationalizing (Dobratz, 1990, p. 5; Dobratz, 2004). Self-restructuring relates to reframing a situation by transferring, fixating, and displacing with expressions of negotiating, seeking, and choosing (Dobratz, 1990, p. 5; Dobratz, 2004). Participants responded to 20 items using the stem question “How often do you feel or act (. . .)?” (sample items: “(. . .) that your life has been worthwhile” and “(. . .) like you are overwhelmed by everything”).

### Patient–Family Interactions

Two open-ended questions asked participants to name recent interactions and estimate the amount of time spent on activities. To explore the types of activities and the amount of time spent on activities, participants were asked:

1. What types of family interaction activities do you do with your families?
2. How much time have you spent interacting with each other in non-healthcare-related matters since enrolling in the hospice program?

## METHODS

Three analytical approaches were utilized in this mixed-methods study to investigate relationships among the concepts of comfort, state of relatedness, and life closure. SPSS<sup>®</sup> (version 19.0, 2011) and Microsoft Excel<sup>®</sup> (2007) were employed for data entry, management, and analysis. Multivariate, graphical, and content analyses were conducted to evaluate our results.

### Multivariate Analyses

Independent *t* tests examined the mean differences on scores for comfort, relatedness, and life closure based on place of residence (home or inpatient) and participants’ level of acuity. Pearson product–moment correlation analyses determined the associations among the variables comfort, relatedness states, and life closure.

### Graphical Analysis

Using an *x–y* coordinate scattergram created in Excel, level of involvement scores were plotted on the *y*-axis and scores from level of comfort with involvement were plotted on the *x*-axis, with the two axes intersecting at the five-centimeter mark (see Figure 1).

## Content Analysis

A qualitative method, content analysis, categorized participants’ responses. These categories are a description of the manifest content of the text (Graneheim & Lundman, 2004). The first two authors independently analyzed participants’ responses, resolved differences, and determined categories and frequencies for each interaction activity.

## RESULTS

### Statistical Analyses

Table 1 provides a summary of the sample’s demographic statistics, and Table 2 presents descriptive statistics for the questionnaire results. Participants in our sample were overwhelmingly Caucasian, and the majority had a cancer diagnosis. The average length of stay in the hospice program was 233 days (median = 56), and 38% of participants were in the hospice program for more than 180 days. Length of stay data were not collected on the first six study participants (*n* = 24 for the variable). The majority of participants (63%) were evaluated as “low acuity” (PPS score  $\geq 50\%$ ) at the time of the interview.

Several instruments demonstrated good reliability. In this sample, the Hospice Comfort Questionnaire demonstrated a Cronbach’s alpha of 0.86. Concurrent validity between the Verbal Rating Comfort Questionnaire and the Hospice Comfort Questionnaire was  $r = 0.66, p = < 0.001$ . Cronbach’s

**Table 1.** Demographics of the sample (N = 30)

	<i>M</i> ( <i>SD</i> ; Range)	<i>N</i>
Age (years)	71 (10.8; 45–88)	30
Length of stay in hospice (days)	228 (357.8; 3–1460)	24
		<i>N</i> (%)
Gender	Female	18 (60)
	Male	12 (40)
Race/ethnicity	Caucasian	29 (97)
	African American	1 (3)
Diagnosis	Cancer	16 (53)
	Pulmonary disease	7 (23)
	Cardiac disease	5 (17)
	Amyotrophic Lateral Sclerosis (ALS)	2 (7)
Marital status	Married	16 (53)
	Single	3 (10)
	Divorced	4 (13)
	Widowed	7 (23)
Location of participant	Home	15 (50)
	Inpatient	15 (50)
Acuity level (PPS)	$\leq 40\%$ (high acuity)	11 (37)
	$\geq 50\%$ (low acuity)	19 (63)

**Table 2.** Questionnaire scores

Questionnaire Scores	Sample Scores <i>M</i> ( <i>SD</i> ; Range)	Theoretical Range
Verbal rating comfort score	7.5 (2.1; 4–10)	0–10
Hospice Comfort Questionnaire	230 (27.8; 171–277)	49–294
Life-Closure Scale	80 (13.2; 53–100)	0–100
Relatedness states comfort	8.8 (1.7; 2.1–10)	0–10
Relatedness states involvement	8.4 (2.3; 0.2–10)	0–10

alpha for the Life-Closure Scale was 0.86 for the total scale, 0.77 for the 10-item self-reconciled subscale, and 0.82 for the 10-item self-restructuring subscale.

**Differences in Participants’ Scores by Location**

For *relatedness states*, participants residing in a hospice house reported statistically significant higher *levels of involvement* in their relationships compared to participants in their homes ( $t[18] = -2.07, p = 0.05$ ) ( $d = 0.76$ ). Similarly, participants residing in a hospice house reported higher *levels of comfort* in their relationship compared to participants at home ( $t[28] = -2.06, p = 0.05$ ) ( $d = 0.76$ ).

There were no statistically significant differences in Life-Closure Scale (LCS) scores based on participant location ( $t[28] = -0.58, p = 0.56$ ) or in scores on Comfort [Hospice Comfort Questionnaire (HCQ)] ( $t[28] = -0.80, p = 0.43$ ).

**Differences in Participants’ Scores by Acuity Level**

There were no statistically significant differences between the two groups in terms of life closure ( $t[28] = 0.39, p = 0.70$ ), comfort (HCQ) ( $t[28] =$

$-0.94, p = 0.36$ ), or levels of comfort in relationships ( $t[28] = 1.38, p = 0.18$ ) ( $d = 0.58$ ). However, there were statistically significant differences in *levels of involvement* in relationships. Participants with higher acuity (40%) reported higher *levels of involvement* in their relationships compared to participants with lower levels of acuity ( $\geq 50%$ ) ( $t[24] = 2.19, p = 0.04$ ) ( $d = 0.74$ ).

**Associations Among Comfort, Relatedness States, and Life Closure**

Table 3 summarizes the correlations among all concepts. Each concept had at least one statistically significant relationship with one of the other concepts, with the exception of the Hospice Comfort Questionnaire and level of involvement in relationships ( $r = 0.23, p = 0.23$ ) and the Verbal Rating Comfort Scale and level of involvement in relationships ( $r = 0.23, p = 0.13$ ) or level of comfort with involvement ( $r = 0.23, p = 0.22$ ).

**Graphical Analysis**

Some 28 of the 30 participants reported scores that plotted in the state of connectedness (see Figure 1). One participant’s scores plotted in the state of disconnectedness and the other in parallelism. The states of relatedness (enmeshment, connectedness, disconnectedness, and parallelism) were plotted from the participants’ scored visual analog scales. Some 40% of participants chose their spouse to rate and 37% chose their child, while the remaining chose grandchildren, friends, parents, and siblings.

**Content Analysis**

Seventeen participants provided responses to the open-ended question, and the following categories were created: **companionship** ( $n = 14$ ), **nourishment and companionship** ( $n = 6$ ), **companionship and**

**Table 3.** Correlation matrix

<i>N</i> =30	LCS <sup>1</sup>	HCQ <sup>2</sup>	Relatedness States Comfort	Relatedness States Involvement	Verbal Rating Comfort Scale
Total LCS	1				
Total HCQ	0.69**	1			
Relatedness states comfort	0.35	0.43**	1		
Relatedness states involvement	0.36*	0.23	0.46*	1	
Verbal rating comfort scale	0.56**	0.67**	0.23	0.28	1

**Notes.** <sup>1</sup> Life-Closure Scale; <sup>2</sup> Hospice Comfort Scale; \* $p < 0.05$ , two-tailed; \*\* $p < 0.001$ , two-tailed.

**exercise** ( $n = 2$ ), and **social support** ( $n = 2$ ). One person reported no interaction.

Examples of activities varied from playing word games, which was categorized as companionship, to “we stopped for lunch and reminisced,” which was categorized as nourishment and companionship. An example of social support was “my brother lives in Colorado and came to help me move.” Swimming with family was categorized as companionship and exercise.

## DISCUSSION

Although this was a preliminary study with a small convenience sample, there were a number of important outcomes. Notably, we found strong correlations among the variables of comfort, relatedness states, and life closure, and we have effect sizes for future studies.

The participants with higher acuity reported higher *levels of involvement* in their relationships compared to participants with lower levels of acuity ( $\geq 50$ ), a finding that is supported in the literature; that is, supportive relationships become more important as physical function declines (Dobratz, 2011; Knight & Emanuel, 2007). Another interesting finding was that inpatient hospice participants had higher *levels of involvement* and *comfort* in their relationships compared to participants in the home setting. A possible explanation is supported by findings from other studies that report hospice patient concerns of “being a burden” as one of the more distressing problems they faced (Chochinov et al., 2009; McPherson et al., 2007; 2010). Many of our participants validated this finding, as they reported that they felt they were a burden to their families.

Not surprisingly, most participants reported interactions that were low-energy activities. When specifically asked about the amount of time spent on activities, participants indicated that time limitations were important and were imposed by either themselves or family members. For example, participants requested that family members limit their visits or phone calls to avoid fatigue. The intent of the exploratory question about time spent on activities was to gather information in terms of minutes or hours to determine potential time constraints and to guide future interaction intervention studies. It was often difficult for participants to answer the question about time spent on activities, and the participants frequently answered the question with vague concepts of time such as “all of the time” or “sometimes.”

Our pilot study did have some limitations. First, there was a low conversion rate of patients referred (94) to participants enrolled in the study (30). Low

conversion rates ranging from 35 to 65% in hospice populations have been reported in the literature (Bakitas et al., 2006; Wohleber et al., 2012). Second, this study sample was somewhat distinctive in its unusually long length of stay within the hospice program. Nine participants had lengths of stay greater than 100 days, in contrast to 67 days, which is the national average length of stay in a hospice program (NHPCO, 2011). In addition to the unusual length of stay, our sample size was small and our findings thus cannot be generalized to all hospice patients. Finally, the content analysis only revealed a description of what was said and did not provide reasons for participant responses.

Further investigation is needed to determine why participants had higher levels of involvement and comfort in their relationships within the inpatient setting. It is possible that inpatients and their families felt more relaxed to engage in personal interactions and that this was reflected in higher scores of involvement and comfort with that involvement. Additionally, it would be useful to explore if there are dimensions of comfort that influence the psychological adaptation (life closure) process. Dobratz (2011) suggests that pain is one of the regulators of life closure. While comfort is more than the absence of pain, a larger study is needed to examine if comfort is a confounding variable or an independent predictor of life closure.

In conclusion, when faced with a terminal illness, hospice patients do not expect a cure of their illness; however, they do seek comfort and meaning in their lives. Supporting hospice patient and family relationships through the journey and trials at the end of life presents challenges, but this area of research also has potential to identify easy but effective family interaction interventions that would increase patient and family comfort and, consequently, facilitate life closure.

## DISCLOSURES AND ACKNOWLEDGMENTS

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