Measuring comfort in caregivers and patients during late end-of-life care

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Abstract

The purpose of this study was to test several formats of end-of-life comfort instruments for patients and closely involved caregivers. Kolcaba's Comfort Theory was the theoretical framework utilized. Different response formats for two end-of-life (EOL) comfort questionnaires (for patients and caregivers, respectively), and horizontal and vertical visual analog scales for total comfort (TC) lines were compared in two phases. Evaluable data were collected from both members of 38 patient-caregiver dyads in each phase. Suitable dyads were recruited from two hospice agencies in northeastern Ohio. Cronbach's alpha for the EOL comfort questionnaire (six response Likert-type format) tested during phase I for patients was .98 and for caregivers was .97. Test-retest reliability for the vertical TC line tested during phase I for patients was .64 and for caregivers was .79. The implications of this study for nursing practice and research are derived from the American Nursing Association (ANA) position statement about EOL care, which states that comfort is the goal of nursing for this population. These instruments will be useful for assessing comfort in actively dying patients and comfort of their caregivers as well as for developing evidence-based practice for this population.

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Introduction

The concept of comfort—in both the giving of comfort measures and the assessment of the patient's state of comfort—is at the very essence of nursing practice.[1] Patients in terminal stages of illness often have comfort needs that extend beyond pain management. Such comfort needs include social support, calm environment, spiritual peace, and resolution of conflicts. Involved caregivers also have multiple and complex comfort needs in addition to their concern about their patients' comfort. Caregivers' needs include information, encouragement, positive reinforcement, rest, socialization, and nutrition. While little argument would arise as to comfort's importance to patients and families in these areas of care, comfort has only recently been measured in a holistic way.[2-4] The problem that this study addressed was the lack of instruments to measure holistic comfort in patients at the end of life and their involved caregivers. In this study, patient and caregiver comfort were assessed directly and separately; we did not measure caregivers' perception of their patients' comfort.

The *general comfort questionnaire* (GCQ) and visual analog scales for aspects of comfort, called *comfort lines*, were developed and tested previously to measure holistic comfort[2,5] and were adapted for use with patients and involved caregivers during end-of-life care. The purpose of this study was to establish psychometric properties for these adapted instruments as well as to assess correlations between self-measures of patients' comfort and comfort of their caregivers. These instruments

were developed to facilitate nursing assessment of holistic comfort needs of both patients and caregivers, and also to give nurses a means of measuring their efforts at increasing patients' and caregivers' holistic comfort. This study reports strengths of and correlations between these two types of instruments.

Background and significance

In its position statement, *Promotion of Comfort and Relief of Pain in Dying Patients*, the American Nurses Association (ANA) states, "The main goal of nursing intervention for dying patients should be maximizing *comfort* [emphasis added], through adequate management of pain and discomfort consistent with the expressed desires of the patient."[6] In a later position statement about end-of-life care, the ANA states, "Nurses are obliged to provide relief of suffering, *comfort* [emphasis added], and when possible a death that is congruent with the values and desires of the dying person."[7] Yet, in these statements as well as present nursing practice, comfort is undefined and unmeasured.

In descriptions of hospice care, comfort is consistently stated to be an important goal.[8-10] The goal of hospice care is to provide comfort for patients and families by relieving pain, reducing anxiety about being alone or unloved, providing a peaceful environment, supporting and educating families about the dying process, and helping patients and families find meaning and growth in the experience of dying.[10-12] Comfort has multidimensional and interrelated properties, which, taken together, contribute to greater comfort than would be expected by adding the parts. Also, holistic comfort designates a positive state that is more than the absence of pain or other physical symptoms, such as nausea, constipation, itching, and infection.[11,12] A holistic conceptualization of comfort is especially relevant for end-of-life care because, theoretically, an increase in comfort strengthens patients and caregivers in a spiritual sense, so to enable peaceful dying.[11]

Comfort has been defined for nursing practice and science *as the immediate experience of being strengthened by having the needs for three types of comfort (relief, ease, or renewal) met in four contexts of human experience (physical, psychospiritual, environmental, and social).*[2,11,13] This definition is congruent with the experience of dying, the interdisciplinary goals and standards of hospice care,[9,14] and specific outcomes desired by patients and families in the late stages of dying.[8,10] Previously, comfort was noted to be a dynamic concept with inherent properties of change over a brief period of time.[5] These properties also are congruent with fleeting emotions, sensations, and endurance, typical at end of life.

The instruments in this study were built on the theoretical definition of comfort cited above. Questions about each aspect of the content domain of comfort[2] were relevant to end-of-life experiences. As the comfort of patients and families is mandated in end-of-life settings, measurements to determine whether enhanced comfort has been achieved are vital to recipients of care and nursing science.

Previous research about comfort at the end of life has been limited to qualitative data about institutionalized persons that experienced traumatic injuries or life-threatening illnesses.[15-17] These studies described various reflective experiences that spanned a variety of physical and emotional comfort states. Quantitative research with persons at the end of life have used *quality of life* (QOL) instruments, which often are not relevant to the experience of active dying. The usual QOL instruments measure entities such as physical fitness, social activity, daily activity, and overall health.[18-20] Therefore, to focus on QOL cannot capture the whole trajectory of the dying experience and does not give direction for interdisciplinary care once dying becomes imminent.

On the other hand, the outcome of holistic comfort accounts for relief of physical and emotional realities of patients and caregivers, including fatigue, personal growth, supportive relationships, and peaceful environments.[10,21] Our measures of comfort take the place of separate, narrow, and multiple indicators of patients' and caregivers' issues, such as relief of pain, anxiety, or chaotic environments that detract from a good death.[11]

Ethical concerns about doing both assessments and research for persons at the end-of-life are directed to the vulnerability of this particular population. The idea that patients and caregivers approaching the end of life would be excluded from research has been described as paternalistic. While this population is indeed vulnerable, those facing the end of life often look on their participation in research as being able to contribute something to those who come after them.[22,23] However, certain considerations are important with this population to avoid physical and mental fatigue, such as simple wording, adequate time to complete the task, and extra assistance from data collectors. Thorough assessment of the patient's physical and mental ability to participate is also necessary to maintain internal validity and ethical integrity.[24]

Research questions

The research questions were: (1) Do patient and caregiver EOL comfort questionnaires and total comfort (TC) lines have acceptable reliability for future research in EOL settings? (2) What is the strength and nature of associations between the EOL comfort questionnaires and TC lines in each phase of the study? (3) What is the strength and nature of associations between comfort scores of patients and caregivers on both types of instruments? (4) Which formats for each type of instrument have the best psychometric properties?

Table 1. Description of the phase I and phase II samples				
Characteristic	**Phase I**	**Phase II**	**Chi-square statistic**	**P**
Gender of patient			0.797 (1 df)	0.372
Male	27 (51.9%)	22 (43.1%)		
Female	25 (48.1%)	29 (56.9%)		
Total	52	51		
Gender of caregiver			0.029 (1 df)	0.865
Male	11 (21.6%)	9 (23.1%)		
Female	40 (78.4%)	30 (76.9%)		
Total	51	39		
Total income			0.592 (2 df)	0.744
Below $20,000	22 (47.8%)	15 (51.7%)		
$20,000 - $50,000	18 (39.1%)	9 (31.0%)		
Above $50,000	6 (13.0%)	5 (17.2%)		
Total	46	29		
Ancestry of patient			0.888** (1 df)	0.346
European	44 (86.3%)	37 (92.5%)		
Hispanic	0 (0.0%)	0 (0.0%)		
African-American	6 (11.8%)	1 (2.5%)		
American Indian	0 (0.0%)	0 (0.0%)		
Middle Eastern	0 (0.0%)	0 (0.0%)		
Asian	0 (0.0%)	1 (2.5%)		
Other	1 (2.0%)	1 (2.5%)		
Total	51	40		
Ancestry of caregiver			0.003** (1 df)	0.959
European	44 (84.6%)	34 (85.0%)		
Hispanic	0 (0.0%)	1 (2.5%)		
African-American	6 (11.5%)	1 (2.5%)		
American Indian	1 (1.9%)	0 (0.0%)		
Middle Eastern	0 (0.0%)	1 (2.5%)		
Asian	0 (0.0%)	1 (2.5%)		
Other	1 (1.9%)	2 (5.0%)		
Total	52	40		

* Statistically significant difference at the 0.05 level of significance.
** Chi-square test based on European and Other (Hispanic, African-American, American Indian, Middle Eastern, Asian, and Other combined) due to small expected frequencies; df = 1.

Table 2. Comparison of the phase I and phase II samples on patients' diagnoses				
Categories of terminal disease	**Phase I**	**Phase II**	**Chi-square statistic**	**P**
Respiratory	18 (34.6%)	12 (23.5%)	2.945* (4 df)	0.567
Digestive	12 (23.1%)	17 (33.3%)		
Head, neck, breast	7 (13.5%)	10 (19.6%)		
Pelvic	8 (48.1%)	6 (11.8%)		
Blood, bone	6 (11.5%)	3 (5.9%)		
Unknown cancer	1 (1.9%)	3 (5.9%)		
Total	52	51		

* Chi-square test based on combining "blood, bone" and "unknown cancer" due to small expected frequencies; df = 4.

Methods

Sampling

Determination of sample size indicated that 36 evaluable dyads were sufficient to have power of 80 percent to detect associations of at least r = 0.45 between the comfort instruments, using the .05 level of significance. To allow for incomplete responses among patients and their caregivers, 52 dyads were recruited for phase I, and 51 dyads were recruited for phase II. Inclusion criteria were that both patients and caregivers were fluent in English, caregivers were closely involved in the care of their patients, and patients were cognitively able and aware of their end-of-life status. Caregivers were defined as those who gave physical and emotional support to their patients during the end of life, whether in homes or hospice care centers. Those persons were usually closely involved family members. End-of-life status was defined as being in the final stages of a progressive disease, as determined through care conferences at participating agencies. Such persons had a Karnofsky score of less than 35.[25]

Instruments

In phase I of the study, patient and caregiver questionnaires had a six-item Likert scale response set, ranging from "strongly agree" to "strongly disagree," and higher scores indicated higher comfort. Each questionnaire took about 12 minutes for patients to complete and usually less time for caregivers. Approximately equal numbers of positive and negative items were created for the caregivers' EOL questionnaire to help prevent response bias.[26] For the patients' EOL questionnaire, items were worded more simply and with less alternating between positive and negative orientation. This adaptation was necessary because of decreased mental agility in dying patients.[21] See Appendix A (patients' questionnaire) and Appendix B (caregivers' questionnaire).

Total comfort lines were oriented vertically in phase I and consisted of the stem: "I am as comfortable as I can be right now." The TC line was 10 cm in length with anchors ranging from "strongly disagree" at the bottom to "strongly agree" at the top. Participants were asked to place a slash mark on the line corresponding to how they felt at the moment. Comfort lines were measured to the nearest millimeter, providing 100 points on the line for very fine discrimination between "quantities" of total comfort.

For phase II of the study, patient and caregiver questionnaires were reduced to a four-item Likert response set and the TC line was oriented horizontally. This adjustment was based on data collectors' concerns that six responses were too many for the patients to consider, and that, perhaps, it would be easier to respond to horizontal lines. However, patients did not express any difficulty with the six-response format on the questionnaire, or with the vertical orientation of the TC lines in phase I.

Setting

Data were collected through two hospice agencies. Agency A had a census of 150-200 patients, and Agency B had a census of 300-355 patients per day. Both agencies had patients in homes and free-standing hospice care centers. One caregiver per patient was

Table 3. Descriptive statistics for end-of-life questionnaire total raw score and percentage of maximum possible total raw score										
	Phase I (6-point scale; possible range 49 - 294)					Phase II (4-point scale; possible range 49 - 196)				
	n	Observed range	Median	Mean	SD	n	Observed range	Median	Mean	SD
Patient	48	174-289 (51-98)	256.5 (84.7)	252-7 (83.1)	27.5 (11.2)	38	119-181 (48-90)	156.0 (72.8)	153.4 (71.0)	14.9 (10.1)
Caregiver	38	178-274 (53-92)	224.5 (71.6)	231.2 (74.4)	29.2 (11.9)	38	127-191 (53-97)	149.5 (68.4)	153.1 (70.8)	16.5 (11.2)

solicited to answer the caregivers' questionnaires. Usually, the caregiver who answered the telephone volunteered to participate. See Table 1 for background descriptions of the patients and caregivers.

Procedures

Data collectors were trained extensively to recruit participants, obtain informed consent, assist with answering questionnaires as necessary, and making follow-up telephone calls to home care nurses if problems arose when collecting data. Data collectors attended care conferences at participating agencies and worked with the staff nurses to identify potential participants. Data collectors then contacted families by telephone, explained the project, and obtained permission to visit. Data collectors also ascertained who would complete the caregivers' questionnaires and demographic information. Upon visiting, patients were assessed for appropriateness and willingness to participate. Data collectors assisted patients in completion of the questionnaires as necessary, using 5 × 8-inch cards with the response set in large letters and numbers corresponding to responses on the questionnaires. Patients who were too weak to circle their desired responses could hold the card, study it, and state what number best described their comfort at the moment of administration.

Each dyad, consisting of a patient and caregiver, participated in testing at one visit only. The TC line was administered to each patient, followed by the questionnaire, and the TC line one more time, about 20 minutes later (to assess test-retest reliability). This short time frame is consistent with methods for psychometric testing of dynamic concepts, such as pain and mood, some of which have been measured again in five minutes.[27-29]

Caregivers followed the same procedure with the addition of the demographic sheet. Patients and caregivers filled out their questionnaires independently and in different rooms, when possible, to allow each to respond to the questions as truthfully as possible. Any patient care issues that emerged during the visits were shared with agency nurses.

Informed consent

The institutional review boards of the two participating agencies and the University of Akron approved this study. All protocols to ensure confidentiality and usual nursing care were followed.

Data analysis

Description of sample

Both phase I and II contained 38 complete data sets. Incomplete sets, particularly in phase II, resulted when caregivers either failed to fill out the form or to complete all of the questions. This happened when data collection forms with cover letters were left at respite care centers for caregivers to complete at later times. Samples in the two phases were not significantly different on the basis of gender or ancestry of patients or caregivers. The most frequent family income category for both phases of the study was below $20,000 (about 50 percent of the sample), with the smallest number above $51,000 (about 5 percent). These statistics were reassuring to our agencies, which feared that their services were not accessed in sufficient numbers by lower income families.

Estimates of functional status

Although we did not have estimates of functional status for each patient during phase I of the study, we believe that both groups were comparable on mental functioning. Since we realized that this was a weakness in phase I, Karnofsky scores[25] were recorded on each patient during phase II. These were estimated either by the primary nurse or the data collector, each of whom was trained for consistency in scoring. The realities of data collection in this population were that patients did not enter hospice early in the trajectory of their illness. They entered when they were quite ill, all having Karnofsky scores of less than 40 (*i.e.*, limited function, alert). Often, their

Table 4. Descriptive statistics for total comfort line										
	Phase I (vertical orientation)					Phase II (horizontal orientation)				
	n	Observed range	Median	Mean	SD	n	Observed range	Median	Mean	SD
Patient										
Time 1	46	1.5-10	9.5	8.3	2.3	47	0.9-9.8	7.5	7.2	2.0
Time 2	47	1.4-10	9.5	8.7	1.8	47	1.6-9.8	8.0	7.4	1.8
Caregiver										
Time 1	48	0.3-10	8.6	7.8	2.5	38	0.5-10	7.6	7.0	2.2
Time 2	48	0.3-10	8.8	8.1	2.2	34	1.8-10	7.7	7.6	1.7

scores were lower than 25 upon admission; thus, these patients did not meet eligibility criteria for the study. Because they were very ill, data collection proceeded for patients as soon as possible after admission to hospice services, before rapid decline began.

With regard to the nature of terminal diseases, the largest category was respiratory disease in both phases, followed by digestive and head, neck, or breast cancers. Complete tabulations of sample characteristics are shown in Table 2.

Management of missing data

Two methods of data input were used to determine which produced the strongest findings. In the first method, data sets with missing information were dropped by the computer, eliminating nearly 14 data sets in each phase from statistical analysis. In the second method, missing data were calculated through regression because this method had more theoretical congruence with the nature of each item in the questionnaire.[26] That is, in items with only four or six responses, such as on both EOL comfort questionnaires, data (for each individual item) were not normally distributed. Estimation by regression is more robust for this type of data than estimation through maximum likelihood. The limit of permitted missing responses for each questionnaire was set at nine, which was 20 percent of the total possible responses for the questionnaires.

In phase I, missing data were estimated for 10 patients and 12 caregivers. In phase II, missing data were estimated for no patients or caregivers, but three data sets for patients and 13 for caregivers were eliminated because of the large amount of missing data, caused by lack of direct supervision by the data collector. As was evident in examining the raw data, direct supervision by the data collector was essential with this population. However, when comparing findings using the two methods described above, there was very little difference in the associations between instruments and between patients and caregivers.

Characteristics of the instruments

For phase I, the possible range for the six-response EOL questionnaires was 49 to 294. The mean for the caregivers' questionnaires was 231 with a standard deviation (SD) of 29. The mean for the patients' questionnaires was 253 (*i.e.*, higher comfort than the caregiver) with SD of 27. The mean for the TC line was eight with SD of two for both patient and caregiver. In phase II, the four-response EOL questionnaire had a possible range of 49 to 196. The mean for the caregiver and patient questionnaires was 153 (moderately high comfort) with SD of 17. The range for the horizontal TC line was the same at 0-10, but the mean was seven for caregivers with SD of two, and the mean for patients was 7.4 with SD of 1.8. These characteristics are detailed in Tables 3 and 4.

For each administration of TC lines in phase I, both patients and caregivers used the vertical orientation of the TC line and scored significantly higher than their counterparts who used the horizontal orientation during phase II (Wilcoxon rank sum tests comparing orientations: patients, time 1, $P < .001$; patients, time 2, $P < .001$; caregivers, time 1, $P = .017$; caregivers, time 2, $P < .021$). The raw EOL comfort scores of patients and caregivers with the six-point scale (phase I) could not be directly compared to raw EOL comfort scores of patients and caregivers with the four-point scale (phase II) because of the difference between the theoretical ranges during each phase.

Therefore, to accomplish meaningful comparisons, the raw total score for each participant was converted to a scaled score equal to the percentage of the theoretical range that the participant's raw total score was above the theoretical minimum for the phase (scaled score = 100 × (raw score - 49)/(294 - 49) for phase I; scaled score = 100 × (raw score - 49)/(196 - 49) for phase II). These scaled scores had a theoretical range of 0 to 100 for both phases. There was not a marked difference in median scaled EOL total scores between phases for caregivers (Wilcoxon rank sum test, P = .135); however, the median scaled EOL total score for patients was higher for phase I than for phase II (Wilcoxon rank sum test, P < .001).

Answering the research questions

Research Question #1. Do patient and caregiver EOL comfort questionnaires and TC lines have acceptable reliability for future research in EOL settings? The study revealed strong reliabilities for both the patients' and caregivers' EOL comfort questionnaires. For phase I, Cronbach's alpha for the caregivers' questionnaire was .97 and for the patient questionnaire was .98. For phase II, Cronbach's alpha for the caregiver questionnaire was .89 and for the patient questionnaire was .83. Thus, for patients, the six-item Likert response set questionnaire had higher reliability (.98) than the four-item Likert response set questionnaire (.83).

Item analysis of the 49-item patient and caregiver questionnaires was done in efforts to shorten the questionnaires. Based on "alphas if deleted," each item was nearly equal in strength. While these analyses failed to provide guidance for shortening the two questionnaires, the authors are amenable to deleting some items based on clinical experience. As long as the content domain is evenly covered as described in the Background section, a shorter questionnaire would be useful, although this could result in somewhat lower reliability scores.

For phase I, test-retest reliability (intraclass correlation coefficient) for the TC line was .79 for caregivers and .64 for patients. For this group, 91 percent of the caregivers and 87 percent of the patients responded at the two time points within one standard deviation (2 cm) on the 10-cm line. Or, 81 percent of the caregivers and 67 percent of the patients responded within .5 SD (1 cm). For phase II, test-retest reliability for the TC line was .61 for caregivers and .42 for patients. For this group, 85 percent of the caregivers and 80 percent of the patients responded at the two time points within one standard deviation (2 cm) on the 10 cm line. Or, 62 percent of the caregivers and 59 percent of the patients responded within .5 SD (1 cm). The vertical TC line (phase I) showed considerably higher reliability than the horizontal TC line. Given the number of possibilities for answering on a 100-mm line, we believe that the vertical TC line demonstrated adequate reliability for measuring the global, dynamic concept of comfort.

Research Question #2. What is the strength and nature of associations between EOL comfort questionnaires and TC lines for each group? This question addressed external validity, which otherwise was difficult to assess for the EOL comfort questionnaire because there were no other measures of patient or caregiver comfort available for comparison. As argued previously, comfort immediately preceding active dying was a different concept from quality of life. Therefore, we attempted to demonstrate beginning validity by comparing the traditionally formatted questionnaires to the TC lines.

The Spearman rho nonparametric measure of association was used because data for the TC lines were not normally distributed. All associations were in the moderately positive range. In phase I, with the six-item Likert response set questionnaire and vertical TC line, associations between the EOL comfort questionnaire and TC lines were .45 (first administration) and .48 (second administration) for patients and .44 (first administration) and .50 (second administration) for caregivers. In phase II utilizing the four-item Likert response set questionnaire and horizontal TC line, the association were .31 (first administration) and .45 (second administration) for patients and .35 (first administration) .52 (second administration) for caregivers. The lower associations in phase II were probably due to the four-response format having lower reliability scores.

Research Question #3. What is the strength and nature of associations between comfort scores of patients and caregivers on both types of instruments? The Spearman rho test revealed weaker associations than those in the previous research question. In phase I using comparisons between the six-item Likert response set questionnaires, the association between patients and families was .41. Associations for the vertical TC line between patient and families were .31 at both administrations. In phase II, associations for the four-item response set questionnaire between patient and families was also .31. Associations for the horizontal TC line between patient and families were .10 at both administrations.

Research Question #4. Which formats for each type of instrument have the best psychometric properties? Clearly, the instruments in phase I of the study had better psychometric properties in this data set. Both patient and caregiver versions demonstrated higher internal consistency reliability with the six-response format of the EOL comfort (.98 and .97, respectively). In turn, these higher reliability scores led to higher associations with TC lines in phase I of the study (.44 and .50, respectively).

Discussion

Results of the study revealed strong reliability and beginning validity for the use of the EOL comfort questionnaires.

Reliabilities were greater for the larger six-response Likert set. This finding is consistent with earlier studies that suggest that larger response sets facilitate greater sensitivity.[26] Vertical TC lines demonstrated greater reliability than the horizontal format, suggesting that the "thermometer" concept was easier to use when a question calls for a "lesser-to-greater" response. Again, these results support earlier findings that participants prefer vertical scales and psychometric properties are stronger with vertical scales.[28] These results affirmed that comfort can be reliably measured and the two types of comfort instruments provide early support for criterion validity.[29]

With regard to the change in comfort during the 20-minute testing interval, as indicated by moderate test-retest correlations (.79 for caregivers and .64 for patients during phase I), it is possible that comfort, being dynamic, did change over the 20-minute time frame. Such a change could be a result of fatigue or stress from answering the two verbal assessment scales (VAS) plus the 49-item traditional questionnaire that contained six possible responses. This would be expected in patients at end of life, whose endurance is low. Also, the correlations were lower for patients than they were for caregivers in all of the psychometric evaluations for phase I and II. Regardless, the scores reported here are consistent with previous research on VAS scales that measure dynamic concepts. For example, test-retest correlations were .52 for measurements of dyspnea at 20-minute intervals and .70 for two measurements of quality of life done during one interview.[29]

Although test-retest reliability may not be completely suitable for dynamic concepts such as comfort, there are no other means to assess the reliability of global concept VAS scales. That is why correlating a global single-item indicator with scores from a traditional multi-item questionnaire that measures the same concept is so important.[28,29] In this study, those correlations between the TC line and the EOL comfort questionnaire were in the moderate range for all psychometric tests in phase I (ranging from .44 to .50), demonstrating adequate criterion validity.

While the short and convenient TC line showed less reliability than did the longer EOL comfort questionnaires, the TC line could be used on an ongoing basis to discuss changes in patients' or caregivers' comfort at end of life. The vertical TC line demonstrated expected standard deviations and test-retest reliability, and would be an easy instrument to use in a clinical setting. As well, a verbally described TC continuum would be a quick measure of ongoing comfort and results of efforts to increase comfort, such as when asking patients to rate their comfort from one to 10 on an imaginary continuum before and after a comfort intervention. This is current practice when assessing pain in clinical applications.

In spite of the instability of comfort, previous studies demonstrated that patient comfort could increase gradually (and significantly) over time, given an effective nursing intervention and by using a traditional questionnaire to measure comfort.[3-5] However, the TC line by itself was unable to produce significant results in one study, perhaps because its very fine discrimination allowed for too many choices (although results approached significance at $p = .14$).[5] Nevertheless, the TC line was effective in supporting criterion validity of the traditionally formatted comfort questionnaire.

The complex issue of whether patients' and caregivers' comfort levels are mutually predictive is less clear. Caregivers' self-assessed comfort was not strongly related to patients' self-assessed comfort. This finding suggests that there were other issues for caregivers during end-of-life care of their loved ones in addition to concern for their patients' comfort. All of these issues indicate the need for further comfort research at end of life.

Suggestions for future research

Data collectors should add Karnofsky ("K") scores to demographic sheets for each patient when making comparisons across groups of terminally ill participants. Many hospice nurses already assign a K score during weekly reports; for those who do not, data collectors can be educated to do this with little difficulty. This would allow researchers to determine whether comfort varies at different functional levels and to investigate the most effective comfort measures for each functional level.

Often, patients wanted to participate in research, but could not self-administer the questionnaires. Adaptations, such as the 5 × 8-inch cards that we used, are advised for further research with this population. Because nurses feel protective of their patients, research would be easier if data collectors had an established rapport with agencies that were willing to provide direct access.

The issue of missing data was analyzed in depth to determine why several data sets in phase II were not useable. In looking at the raw data again, we realized that these nearly blank data sets resulted when data collectors left questionnaires for caregivers to complete at later dates. This was done primarily in respite care centers, where caregivers were not present at the time of data collection. This method of data collection was ineffective for participants who were experiencing the imminent death of a loved one. In the future, data collection with caregivers as well as patients should be directly supervised.

Comfort instruments are relevant to the experience of active dying, both for patients and their loved ones, and are more congruent with the goals of care at this stage of dying than most quality-of-life instruments. Comfort is a concept that is easily understood by patients and caregivers, all of whom want the interdisciplinary team to make

them as comfortable as possible. Participants responded well to the questionnaires and wanted to talk more about their comfort. This speaks to the internal validity of the instruments.

These instruments have good psychometric properties, meeting criteria of efficiency, sensitivity, reliability, and beginning validity for new measures in this setting.[21,25] Additionally, the TC line is faster to complete than traditionally formatted questionnaires and can be used clinically to discuss and address deficits in comfort.

Summary

Hospice and palliative care agencies must be able to quantify the essence of their care, namely facilitating comfort to patients and caregivers. The instruments tested in this study provide these agencies and others with the ability to assess and document ongoing efforts at providing comfort at the end of life to the patients and caregiving family members.

Research in end-of-life care is in its infancy. The critical first step in a new program of research or a new approach to a specific research problem is to develop appropriate instruments to measure outcomes of interest and relevance to the population. Psychometric testing, using a variety of analyses on collective responses from participants in the target population, determines the strengths of those new instruments. This study demonstrates that the new comfort questionnaires are suitable for assessment and research in end-of-life care. With the use of these standardized comfort assessments, comfort needs can be readily identified and addressed, thus promoting peaceful deaths. In turn, the effectiveness of interventions can be determined empirically with the use of sound instruments.

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Appendix A

Hospice Comfort Questionnaire (Patient)

Date_____ Code#_____

Thank you *very much* for helping us in the study of hospice nursing. Below are statements that pertain to your comfort right now. Six numbers are provided for each question; please circle the number you think most closely matches your feeling. Relate these questions to your comfort *at the moment you are answering the questions*.

	Strongly Disagree					Strongly Agree
1. My body is relaxed right now	1	2	3	4	5	6
2. My breathing is difficult	1	2	3	4	5	6
3. I have enough privacy	1	2	3	4	5	6
4. There are those I can depend on when I need help	1	2	3	4	5	6
5. I feel bloated	1	2	3	4	5	6
6. I worry about my family	1	2	3	4	5	6
7. My beliefs give me peace of mind	1	2	3	4	5	6
8. My nurse(s) give me hope	1	2	3	4	5	6
9. My life is worthwhile right now	1	2	3	4	5	6
10. I know that I am loved	1	2	3	4	5	6
11. These surroundings are pleasant	1	2	3	4	5	6
12. I have difficulty resting	1	2	3	4	5	6
13. No one understands me	1	2	3	4	5	6
14. My pain is difficult to endure	1	2	3	4	5	6
15. I feel peaceful	1	2	3	4	5	6
16. I sleep soundly	1	2	3	4	5	6
17. I feel guilty	1	2	3	4	5	6
18. I like being here	1	2	3	4	5	6
19. I am nauseated	1	2	3	4	5	6
20. I am able to communicate with my loved ones	1	2	3	4	5	6
21. This room makes me feel scared	1	2	3	4	5	6
22. I am afraid of what is next	1	2	3	4	5	6
23. I have special person(s) who make(s) me feel cared for	1	2	3	4	5	6
24. I have experienced changes which make me feel uneasy	1	2	3	4	5	6
25. I like my room to be quiet	1	2	3	4	5	6
26. I would like to see my doctor more often	1	2	3	4	5	6
27. My mouth and skin feel very dry	1	2	3	4	5	6
28. I'm okay with my personal relationships	1	2	3	4	5	6
29. I can rise above my pain	1	2	3	4	5	6
30. The mood around here is depressing	1	2	3	4	5	6
31. I am at ease physically	1	2	3	4	5	6
32. This chair (bed) makes me hurt	1	2	3	4	5	6
33. This view inspires me	1	2	3	4	5	6
34. I think about my discomforts constantly	1	2	3	4	5	6
35. I feel confident spiritually	1	2	3	4	5	6
36. I feel good enough to do some things for myself	1	2	3	4	5	6
37. My friends remember me with their cards and phone calls	1	2	3	4	5	6
38. I feel out of place here	1	2	3	4	5	6
39. I need to be better informed about my condition	1	2	3	4	5	6
40. I feel helpless	1	2	3	4	5	6
41. My God is helping me	1	2	3	4	5	6
42. This room smells fresh	1	2	3	4	5	6
43. I feel lonely	1	2	3	4	5	6
44. I am able to tell people what I need	1	2	3	4	5	6
45. I am depressed	1	2	3	4	5	6
46. I have found meaning in my life	1	2	3	4	5	6
47. In retrospect, I've had a good life	1	2	3	4	5	6
48. My loved ones' state of mind makes me feel sad	1	2	3	4	5	6
49. The temperature in this room is fine	1	2	3	4	5	6

Are there any other questions you wished we had asked?

Appendix B

Holistic Comfort Questionnaire (Caregiver)

Date_____ Code#_____

Thank you *very much* for helping us in the study of hospice nursing. Below are statements that pertain to your comfort right now. Six numbers are provided for each question; please circle the number you think most closely matches your feeling. Relate these questions to your comfort *at the moment you are answering the questions*.

	Strongly Disagree					Strongly Agree
1. My body feels relaxed right now	1	2	3	4	5	6
2. We do not have enough privacy	1	2	3	4	5	6
3. There are those I can depend on when I need help	1	2	3	4	5	6
4. I worry about my family	1	2	3	4	5	6
5. My beliefs give me peace of mind	1	2	3	4	5	6
6. Our nurse(s) give me hope	1	2	3	4	5	6
7. My life is not worthwhile right now	1	2	3	4	5	6
8. I know that I am loved	1	2	3	4	5	6
9. These surroundings are pleasant	1	2	3	4	5	6
10. I have difficulty resting	1	2	3	4	5	6
11. No one understands me	1	2	3	4	5	6
12. My emotional pain is difficult to endure	1	2	3	4	5	6
13. I feel peaceful	1	2	3	4	5	6
14. I am afraid to sleep	1	2	3	4	5	6
15. I feel guilty	1	2	3	4	5	6
16. I do not like it here	1	2	3	4	5	6
17. I have no appetite	1	2	3	4	5	6
18. I am able to communicate with my loved one	1	2	3	4	5	6
19. This room makes me feel scared	1	2	3	4	5	6
20. I am afraid of what is next	1	2	3	4	5	6
21. I have special person(s) who make(s) me feel cared for	1	2	3	4	5	6
22. I have experienced changes which make me feel uneasy	1	2	3	4	5	6
23. I like my loved one's room to be quiet	1	2	3	4	5	6
24. We would like to see the doctor more often	1	2	3	4	5	6
25. The temperature in this room is fine	1	2	3	4	5	6
26. When this situation is over it will be difficult to resume my former responsibilities	1	2	3	4	5	6
27. I can rise above this situation	1	2	3	4	5	6
28. The mood around here is depressing	1	2	3	4	5	6
29. I need a comfortable chair or bed	1	2	3	4	5	6
30. This view inspires me	1	2	3	4	5	6
31. In retrospect, we've had a good life	1	2	3	4	5	6
32. I feel out of place here	1	2	3	4	5	6
33. I feel strong enough to do some things for my loved one	1	2	3	4	5	6
34. I think about my loved one's discomforts constantly	1	2	3	4	5	6
35. I feel confident spiritually	1	2	3	4	5	6
36. I need to be better informed about my loved one's condition	1	2	3	4	5	6
37. I feel helpless	1	2	3	4	5	6
38. We're okay with our personal relationships	1	2	3	4	5	6
39. This room smells fresh	1	2	3	4	5	6
40. I feel lonely	1	2	3	4	5	6
41. I am able to tell people what I need	1	2	3	4	5	6
42. I am depressed	1	2	3	4	5	6
43. We have found meaning in this experience	1	2	3	4	5	6
44. My friends remember us with their cards and phone calls	1	2	3	4	5	6
45. My loved one's state of mind makes me feel sad	1	2	3	4	5	6
46. I think about the future a lot	1	2	3	4	5	6
47. My loved one is clean and dry	1	2	3	4	5	6
48. I'm concerned about finances	1	2	3	4	5	6
49. My God is helping me	1	2	3	4	5	6

Are there any other questions you wished we had asked?