Communication of emotion in home hospice cancer care: Implications for spouse caregiver depression into bereavement

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Abstract

Objective: Family caregivers of cancer hospice patients likely benefit from clinician provision of verbal support and from expression of positive emotions. Our aim was to identify the effects of hospice nurse supportive communication as well as caregiver-nurse exchange of positive emotions on family caregiver depression during bereavement.

Method: This prospective, observational longitudinal study included hospice nurses (N=58) and family caregivers of cancer patients (N=101) recruited from 10 hospice agencies in the U.S. Digitally recorded nurse home visit conversations were coded using Roter Interaction Analysis System to capture emotion-focused caregiver-nurse communication and supportive nurse responses. Caregivers completed the Hospital Anxiety and Depression Scale Anxiety Subscale and Geriatric Depression Scale-Short Form at study enrollment and at 2, 6 and 12 months after patient death.

Results: Caregivers had moderate levels of depression at study enrollment and throughout bereavement. Multilevel modeling revealed that caregiver positive emotion communication and nurse emotional response communication are associated with caregiver depression in bereavement. There was no significant association between caregiver distress communication and depression in bereavement.

Conclusions: This is the first study to demonstrate that communication demonstrating emotional expression between cancer spouse caregivers and nurses during home hospice may have

implications for caregiver depression up to a year after patient death. Our findings may help identify caregivers who may be coping well in the short term, but may struggle more over time.

Keywords

Family caregiver; hospice; nurse; cancer; communication; depression

As cancer care in the U.S. is increasingly being provided at home, including at end of life, families are taking on more responsibility for care.(1) Cancer caregivers have a disproportionately high level of burden, based on the number and complexity of tasks they manage, as well as the amount of time they put in to providing care.(2) As a result of high levels of burden, cancer caregivers are at higher risk for elevated stress levels, depression, and anxiety both during care and into bereavement.(2, 3)

In recognition of the high level of burden placed on caregivers and the emotional difficulty associated with bereavement, the hospice team's mission is to evaluate and address both patient and family distress and all hospice agencies offer some form of bereavement support. However, the support provided to family caregivers is often in direct response to caregivers' expression of emotions related to the loss of their family member, and may often be insufficient to counter the psychological distress, including depression, many caregivers face.(4, 5) Providers' response to caregivers' negative emotions of fear, sadness, and grief is recognized as a critical support process for guiding family caregivers through the process of loss and hopefully onto bereavement adjustment.(6, 7) In addition to supportive responses to caregivers' distress communication, other interpersonal processes are also critical for providers to recognize to attenuate caregiver psychological distress during the patient's life and into bereavement. For example, providers' use of strengths-based responses such as the focus on positive life experiences and expression of positive emotions may impact bereavement outcomes for caregivers.(8)

Provider communication which includes positive emotional expression as a way to form connection, has been linked to improved patient psychological health outcomes.(9, 10) Positive emotional expression can include humor and joking, which can be either adaptive—as a means to reframe a bad situation--or maladaptive—as an avoidance mechanism.(11) However, positive emotion expression can also include expression of hope, gratitude, and mindfulness, which have been shown to be important for key caregiver outcomes.(12) Specific provider communication behaviors can enhance relationships and improve a therapeutic alliance, validate and help manage emotions, or be received as emotional support.(9, 10) Significant research to date has been directed at the clinician response to patients' expression of distress and negative emotion; whereas the fostering of positive emotional expression has only recently been recognized as important for well-being and adjustment.(13–15) Providers' facilitation of positive emotional expression, alongside offering verbal support, may be equally important for family caregivers and have important implications for caregiver adjustment post the patient's death.

Evidence shows the benefits of positive emotional expression for patients managing many diagnoses, including cancer.(16, 17) Specifically, there is promise for managing depression associated with these diseases.(18) The broaden-and-build theory of positive emotions

predicts that positive emotions broaden the scopes of attention and cognition, which can build new resources and skills, ultimately improving coping and well-being.(19) However, the majority of this work in cancer and end of life has focused on patients, rather than family caregivers.(20) It is important to take a longitudinal perspective with caregivers facing the impending death of a family member, because poor adjustment, including high levels of depression, during bereavement is influenced by psychological distress during caregiving. (21) Some prospective longitudinal work exists following cancer family caregivers from hospice to bereavement. For example, research has mostly looked at emotional expression that occurs after widowhood, rather than in the preparatory period before bereavement begins.(22) Additionally, most research ignores the cumulative effect of repeated communication,(9) focusing instead on one-time encounters. Additionally, most work focuses on one-way communication of positive emotion, rather than a more dynamic focus that captures the exchange of positive emotion.

Evidence strongly suggests that family caregivers may benefit from provider provision of verbal support and from expression of positive emotions. Our objective was to identify the effects of U.S. hospice nurse supportive communication as well as caregiver and nurse emotional expression during home hospice care on family caregiver depression in bereavement. We hypothesized that caregiver-nurse positive emotion talk would be significantly correlated and that higher caregiver positive emotion and lower distress communication would be associated with less depression. No hypothesis was proposed in relation to nurse emotional response communication.

Methods

Data in this manuscript was gathered from a large, multisite, prospective, program project grant focused on advanced cancer home hospice caregivers. As part of this larger study, caregivers completed questionnaires at hospice enrollment. Hospice nurse participants recorded their home visits to participating families from enrollment until patient death. Questionnaires were repeated with caregivers at 2, 6 and 12 months after patient death.

Participants

Nurse participants were recruited from 10 hospice agencies in the Intermountain West (n=8) and Northeastern (n=2) regions of the United States between August 2011 and December 2014. Caregiver-patient dyads were recruited from participant nurse caseloads. Eligibility criteria for the current sample included caregivers who were spouses or partners to individuals with cancer as their primary diagnosis newly enrolled in-home hospice, over 45 years of age, spoke English, cognitively able to participate, and had at least one visit with their hospice nurse recorded. All participants provided written consent. This study was approved by the Institutional Review Board at the University of Utah (IRB_00033122) and home hospice agencies.

Measures

In addition to demographic and health questionnaires, caregivers completed the following measures at all time points:

Depression is the primary outcome and was measured using the Geriatric Depression Scale-Short Form (GDS-SF).(23) Each of the 15 items asks a yes/no question and 1 point is assigned to each answer. After reverse scoring, a summed score is calculated between 0 and 15. A score of 5–9 is considered to suggest depression, while a score of 10 and above almost always indicates depression. The GDS has good reliability and validity and is successful in differentiating depressed from non-depressed adults.(23)

State anxiety was captured using the 7 item anxiety subscale of the Hospital Anxiety and Depression Scale (HADS)(24) as a strong covariate with depression. Each item on the questionnaire is scored from 0–3 (no to high anxiety); a summed score is calculated between 0 and 21. A score of 8 and above is considered indicative of high anxiety.

Visit communication was coded using the Roter Interaction Analysis System (RIAS).(25) RIAS is widely used to coder health care interactions and has been validated across care settings including home hospice.(26) We selected up to 10 audio recordings of visits per caregiver-patient dyad to code for communication (range: 1–91). We analyzed complete data for those with 10 or fewer recordings. For those with more than 10 recorded visits (24 dyads), we randomly chose recordings within quartiles of hospice enrollment to ensure representation of the full hospice trajectory. Trained coders categorize each utterance or statement from nurses, caregivers, and patients into content and process categories. In this analysis, we focus on emotion-focused caregiver and nurse communication and supportive nurse responses: Caregiver and nurse positive emotion (humor, gratitude), caregiver distress, and nurse emotional response (reassurance, validation) communication statements. Examples are found in Table 1; further details about communication coding can be found elsewhere (20, 27). A random sample of 10% of audio-recordings were double coded for inter-rater reliability and drift throughout the coding process and Cohen's Kappa scores were good at 0.68.(28)

Analysis

Demographic information was calculated using descriptive statistics and correlations were calculated among key variables. Study hypotheses were tested using a two level, multilevel model where depressive symptoms were regressed onto main effects and two-way interactions between symptoms of anxiety, time, caregiver frequency of positive emotions, nurse frequency of positive emotions, and nurse frequency of emotional responses. Time was centered at the first assessment so that the intercept represents average levels of depression at the first assessment, at study/hospice enrollment. Anxiety symptoms were decomposed into level-1 (i.e., relative level of anxiety for an individual relative to his/her average level of anxiety across all assessments) and level-2 (i.e., an individual's average level of anxiety relative to the mean levels of other individuals) using person-mean and grand-mean centering respectively. Finally, observational coding variables were not centered to preserve the interpretation of 0 as indicating that the behavior did not occur at all. Table 2 presents results of the full model.

Results

Description

Our sample consisted of 101 spouse caregivers of hospice patients and 58 nurses. Demographics are presented in Table 3. Caregiver average age was 65.7 years (SD=10.2) and 60% of caregivers were female. Similar to national hospice statistics,(29) our sample is overwhelmingly white (87% of patients, 92% of caregivers). Nurses were 92% female, with an average age of 42.1 (SD=14.6). The average number of years practicing in hospice was 4.5 (SD=4.9). Each caregiver had an average of 5.32 visit recordings (SD=3.53) in this sample, spanning from enrollment in home hospice to patient death. The average length of visit was 40.2 minutes (SD=20.69; Range 5–114 minutes). Patients in this sample had a median of 54 days in hospice.

Caregivers had an average of 4.34 distress communication statements (SD=3.09) and 10.02 positive emotion statements (SD=6.85) per visit, while nurses had an average of 23.43 positive emotion statements (SD=6.85) and 12.58 emotional response statements (SD=9.60) per visit. The correlation between caregiver and nurse positive emotion statements was moderately strong (r=.3969), while the association between nurse positive emotion and emotional response talk was even greater (r=.4878). Caregiver distress statements were also moderately correlated with caregiver positive emotion (r=.2712) and nurse emotional response (r=.4004) statements, but not nurse positive emotion statements (r=.0047). As expected, there was a strong relationship between anxiety and depression (r=.6199).

Prediction

Beginning with the intercept, results revealed that the average level of depression at hospice enrollment was 3.75 points on the GDS scale (95% CI = 2.22, 5.29) indicating a moderate level of depression in this sample. A significant interaction between time and caregiver positive emotion talk ($\beta = 0.02$, $p = 0.032$) indicates that change in levels of depressive symptoms over time depends on the frequency of caregiver positive emotion talk during interactions with the nurse. More specifically, and counter to our hypothesis, when the interaction is broken down, our findings indicate that caregivers who express an average of 9 or more positive emotion statements per visit demonstrate significant increases in depressive symptoms over time (simple slope for 9 positive emotions: $\beta = 0.38$, $p = 0.038$).

Results also reveal a significant interaction between caregiver positive emotion talk and symptoms of anxiety ($\beta = 0.02$, $p = 0.04$). When this interaction is broken down, our findings revealed greater frequency of caregiver positive emotion talk is associated with lower levels of depressive symptoms for caregivers who report symptoms of anxiety that are two standard deviations or more below their own average (simple slope at 2 SD below the mean on anxiety symptoms: ($\beta = -0.11$, $p = 0.048$). Caregiver positive emotion talk was not significantly related to depressive symptoms for individuals reporting symptoms of anxiety at or above their mean (p .46). In other words, although overall high positive emotion is linked to increasing depression into bereavement, the pattern is reversed only when caregivers report significantly lower anxiety at any given time point in bereavement. When an individual who expressed high positive emotion during care reports a much lower anxiety

level at a time point in bereavement, they are more likely to report lower levels of depression at that same bereavement time point. No significant relationships were found with nurse positive emotion or caregiver distress communication.

Turning to nurse emotional responses, results show a marginally significant association between higher levels of nurse emotional responding and higher levels of caregiver depressive symptoms at hospice enrollment ($\beta = 0.07$, $p = 0.054$). A non-significant interaction between nurse emotional responses and time indicates that this association at baseline does not change into bereavement.

Finally, a significant main effect emerged for grand-centered symptoms of anxiety ($\beta = 0.48$, $p < 0.001$). This effect indicates that caregivers whose average level of anxiety is higher than the overall average level of all caregivers' anxiety also report higher average levels of depression relative to other participants.

Conclusion

Psychological distress is often elevated during caregiving and the initial phase of bereavement, decreasing over the course of the first year.(30) There is evidence that patient-provider communication relevant to information exchange is a good predictor for preparedness for end of life and caregiver bereavement.(31, 32) However, to date there has been little prospective work to show that emotional communication between caregivers and health care providers can impact caregiver depression, especially with long term effects. Our study demonstrates the potential impact of caregiver and nurse communication during home hospice on caregiver depression during bereavement.

Contrary to our hypotheses, we found no relationship between caregiver expression of distress communication and depression in bereavement. This may be due to the normative nature of caregivers expressing distress to a hospice during hospice care. As such, expressing distress to other individuals in other contexts during this time may be a better predictor of caregiver depression in bereavement. Additionally, the *expression* of distress may serve to attenuate the impact of the emotion.(16, 17)

Also contrary to our hypotheses, we found high levels of caregiver positive emotion talk during hospice care were associated with an overall greater increase in depression over time. This was somewhat surprising given the theory and research outlining the benefits of positive emotion.(18, 19) However, specifically for caregivers reporting time points with individual lower levels of anxiety, more positive emotion in visits with the hospice nurse actually may serve a protective function against depression. Taken together, these findings suggest that positive emotion may not be the most effective coping strategy overall, but there may be periods, including when caregivers have lower-than-normal anxiety, where it may be beneficial.

Humor comprised the majority of our positive communication talk,(20) and has been characterized as both an adaptive and maladaptive strategy for coping with cancer.(11) For example, it may serve to reframe an issue, or it may serve simply as a distraction. Perhaps some caregivers are coping with the patient's end of life with humor and not fully processing

the potential death of the patient in the moment. This may be an effective strategy when caregivers experience lower levels of anxiety, but the long-term effects of humor as a coping strategy during hospice care may be less effective more broadly.

In addition to humor, our positive emotion code included broader statements of gratitude and mindfulness. One possibility for the complexity of our findings around humor is that these different forms of positive emotion expression were not disentangled; recent work suggests that though related, different forms of positive emotion are distinct.(33) While many caregivers engaged in humor, some engaged in more meaning-making talk. More expressive and supportive caregiver communication could signal more engagement in the grief process and acceptance, and produce better long-term outcomes.(34) Previous research on anticipatory grief has shown that some family members experience loss and subsequent depression before the death of the patient;(35) however, other caregivers may be less prepared for death and experience the loss more profoundly later.(36) Future research is needed to tease apart the expression of positive emotion as a coping strategy with death and to determine how clinicians can direct humor into more effective means of coping.

Clinical Implications

The communication strategies used by caregivers may be reinforced by nurse communication. In hospice, the goal is often to meet the family where they are;(37) as such, nurses may try to respond to the emotional tone taken by the family to address the needs of caregivers. For example, in our study, we find a strong correlation between caregiver and nurse positive emotion. Our study also found that nurse emotional responses during hospice visits were associated with higher initial levels of caregiver depression. This suggests that nurses may be able to recognize caregiver depression and are responding with validation and reassurance during their interactions. Our finding that caregiver positive emotion may also signal future depression may also be a cue for providers to focus more attention to helping these families process their loss during hospice care, but perhaps especially into bereavement.

The lack of significant change in depression over time may suggest that the nurse response during home visits is not sufficient to improve long-term outcomes, particularly into bereavement. Our previous work suggests that bereavement support provided by hospice agencies was seen as insufficient by caregivers; many regretted the abrupt end to a strong relationship with the nurse.(5) Contact by nurses after death as part of bereavement support was appreciated and missed when not provided.(38) Boosters of validation and reassurance from a supportive nurse after death may be important to explore to reduce depression in bereavement. More research is needed to determine when and how to target support for family caregivers in preparing for loss and experiencing grief to prevent prolonged depression in bereavement.(35, 39)

Study Limitations

Our study captured only communication of families who received hospice care with their nurses during visits. Certainly other factors, including the quality of interactions among families and the caregiving requirements across the patient's disease trajectory will impact

caregiver anxiety and depression across time. A comparison of distress trajectories with families not receiving hospice would be informative, particularly as hospice use has been shown to be a modest protective effect for depression in bereaved former caregivers (40). More research is needed to capture longitudinal impacts of interpersonal health communication on psychological well-being, particularly in critical periods such as hospice care and caregiver bereavement, to examine how mechanisms identified in more cross-sectional work may change over time.

Summary

This is the first study to show that communication demonstrating emotional expression between cancer spouse caregivers and nurses during home hospice care may potentially have implications for caregiver depression up to a year later, into bereavement. Our findings have implications for identifying caregivers who may be coping well in the short term, but may struggle more over time. This research also suggests more intensive contact from hospices in caregiver bereavement could be beneficial; the relationships developed with nurses during that critical time may be important as caregivers cope with loss.

Acknowledgements

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Table 1.

Examples and frequencies of caregiver and nurse emotional statements and nurse emotional responses

		COMMUNICATION STATEMENT FREQUENCIES					
		Total Number of Statements: M=499,SD=226					
		NURSE			CAREGIVER		
VARIABLE	EXAMPLES	MEAN	SD	MIN/MAX	MEAN	SD	MIN/MAX
Positive Emotion	I love that we can be here together. Haha, isn't that a hoot!	23.43	6.85	1–75	10.02	6.85	0–37
Distress	I'm just not sure what to do. That sore looks like it hurts so much.	--	--	--	4.34	3.09	0–71
Emotional Response	A lot of people have that experience. I'm sorry to hear that.	12.58	9.60	1–51	--	--	--

Table 2.

Parameter estimates of the multilevel model

Variable	β	SE β	95% CI
Level-1			
Intercept	3.75	0.78	2.22, 5.29
Anxiety symptoms$_{\text{person centered}}$	0.14	0.12	−0.09, 0.38
Time	0.09	0.21	−0.33, 0.52
Caregiver distress	−0.02	0.05	−0.02, 0.83
Caregiver positive emotions	−0.03	0.04	−0.11, 0.06
Nurse positive emotions	−0.04	0.02	−0.08, 0.01
Nurse emotional responses	0.07*	0.03	0.00, 0.13
Anxiety symptoms$_{\text{person centered}}$ X Caregiver distress	0.00	0.00	−0.02, 0.02
Anxiety symptoms$_{\text{person centered}}$ X Caregiver positive emotions	0.02*	0.01	0.00, 0.04
Anxiety symptoms$_{\text{person centered}}$ X Nurse positive emotions	0.03	0.01	−0.01, 0.02
Anxiety symptoms$_{\text{person centered}}$ X Nurse emotional responses	−0.01	0.01	−0.01, 0.00
Time X Caregiver distress	0.00	0.01	−0.03, 0.03
Time X Caregiver positive emotions	0.03*	0.01	0.00, 0.06
Time X Nurse positive emotions	−0.01	0.01	−0.02, 0.01
Time X Nurse emotional responses	0.00	0.01	−0.01, 0.02
Level-2			
Anxiety symptoms$_{\text{grand centered}}$	0.48***	0.06	0.35, 0.61

Note.

*
p .05

**
$p < .01$

***
$p < .001$

Table 3.

Patient, caregiver, and nurse demographics

Demographics			
	Patient N=101	**Caregiver n=101**	**Nurse N=58**
	n (%)	**n (%)**	**n(%)**
Gender			
Male	60 (60.0)	40 (40.0)	5 (8.9)
Female	40 (40.0)	60 (60.0)	51 (91.9)
Ethnicity			
Hispanic	1 (1.0)	7 (7.0)	2 (3.7)
Non-Hispanic	89 (91.8)	92 (92.0)	50 (92.9)
Race			
Asian	2 (2.0)	0 (0)	2 (3.5)
Black/African American	2 (2.0)	1 (1.0)	4 (7.0)
White	87(87.0)	98 (98.0)	52(91.2)
Other	10 (9.0)	2 (1.0)	4 (7.0)
Nursing Education			
Diploma	--	--	1 (1.8)
Associate	--	--	38 (67.9)
Bachelors	--	--	15 (26.8)
Masters	--	--	2 (3.6)
Education			
High school graduate	--	21 (21.0)	--
Some college	--	37(37.0)	--
Bachelor's degree	--	19 (19.0)	--
Some graduate education	--	5 (5.0)	--
Graduate degree	--	18 (18.0)	--
Annual Household Income			
Less than $10,000	--	2 (2.0)	--
$10,000–24,999	--	12 (12.0)	--
$25,000–39,999	--	15 (15.0)	--
$40,000–59,999	--	14 (14.0)	--
$50,000–74,999	--	27 (27.0)	--
$75,000 or more	--	25 (25.0)	--
Declined to answer	--	5 (5.0)	--

Demographics			
	Patient N=101	**Caregiver n=101**	**Nurse N=58**
	n (%)	**n (%)**	**n(%)**
Employment			
Not working	--	57 (56.4)	--
Part-time	--	11 (10.9)	--
Full time	--	33 (32.7)	--
Self-reported Health			
Excellent	--	15 (14.9)	--
Very good	--	49 (48.5)	--
Average	--	30 (29.7)	--
Poor	--	6 (5.9)	--
Very Poor	--	1 (1.0)	--
Primary Insurance			
Private	--	32 (30.8)	--
Medicaid	--	5 (4.8)	--
Medicare	--	57 (54.8)	--
Self Pay	--	1 (1.0)	--
Other (e.g. TriCare)	--	4 (3.8)	--
	M (SD)	**M (SD)**	**M (SD)**
Age			
	67.4 (10.8)	65.7(10.2)	42.1 (14.6)
Length of Relationship			
	34.9 (17.9)		--
Days on Hospice			
	82.6 (75.9) Median=54		--
Years Hospice Experience		--	4.5 (4.9)