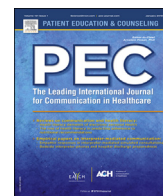




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# Positive emotion communication: Fostering well-being at end of life

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### ABSTRACT

**Objective:** Little is known about positive emotion communication (PEC) in end-of-life care. This study aims to identify types and patterns of PEC among hospice nurses, caregivers, and patients.

**Methods:** A coding system based on positive psychology theory was applied as a secondary analysis to audio recordings of hospice nurse home visits with cancer patients and family caregivers, collected as part of a prospective longitudinal study. Eighty recordings (4 visits from 20 triads) were coded for humor, connection, praise, positive focus, gratitude, taking joy/savoring, and perfunctory statements.

**Results:** Descriptive statistics revealed the greatest proportion of PEC was made by nurses. Humor was most frequently used across all speakers. Cluster analysis revealed four PEC visit types: Savor/Take Joy; Humor; Perfunctory; and Other-focused Expressions of Positive Emotions. Linear mixed effect regression was used to estimate the trajectory of PEC over time, but no significant change was found.

**Conclusion:** We found that positive emotions are common in nurse, caregiver and patient communication at end-of-life and do not decline closer to death.

**Practice implication:** This study is among the first to explore PEC at end-of-life, and offers a way to bring strengths-based approaches into end of life communication research.

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## 1. Introduction

As the proportion of the aging population grows so does the need for end-of-life care [1]. Hospice services provide holistic care to patients with life-limiting illness and their family members. In the U.S., about 1.7 million patients receive hospice services, the majority within their home or place of residence [2]. Hospice is made available to patients of any age with a life-limiting diagnosis and a life expectancy of less than 6 months. Care, in the U.S., is made available through Medicare or other health insurance providers. Typically, a family member serves as the primary caregiver with members of the hospice team (e.g., social worker, chaplain, nurse) making regular visits to provide care and other services. The unit of care is considered to be patient and family. Over a third of U.S. hospice patients have advanced cancer which is associated with a rapid, yet highly variable, decline [3]. This places unique stress on the hospice care team and indicates a need for

attention to home hospice communication. Family caregivers are a vital member of the hospice care team, and as the patients' health declines the caregiver role expands, often placing them at significant negative psychological, physical, social, and financial risk [4–8]. The increased engagement by caregivers in hospice care is in contrast to earlier in the cancer care trajectory where the caregiver's voice is largely absent and much of the communication is between the patient and clinician [9–11]. It is important for hospice care team members to use communication strategies that strengthen relationships and positively engage all family members.

Little is known about positive emotions at end-of-life care. Positive and negative emotions are independent constructs (e.g., [12]) and can be experienced at the same time. Because positive and negative emotions have different implications for health and well-being, it is important to learn about risks associated with negative emotion as well as potential benefits of positive emotion for patients and caregivers. Cancer patient positive emotion has been associated with lower symptom reports, less functional impairment, and fewer cancer-related medical appointments [13–15]. Research available on caregiver positive emotion suggests

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that caregiving “uplifts” are associated with well-being [16], and experiencing positive emotion is associated with greater post-traumatic growth [17,18].

Positive emotions are associated with better health and longevity, thus serving a protective function [19,20]. Similarly, positive emotions are associated with enhanced coping, meaning-making, and building resilience to stressful events [21–23]. Meaning-making or benefit-finding might be particularly relevant to cancer patients and caregivers, as it is associated with more positive emotion, less distress, and better mental health [24]. The Broaden-and-Build Theory [25] may explain some of these associations as it posits that positive emotions *broaden* an individual’s thought-action repertoire and *build* physical, intellectual, and social resources, thereby promoting resilience. In contrast to negative emotions, which carry direct and immediate adaptive benefits by prompting a specific threat response (e.g., fear prompts fleeing), positive emotions carry more indirect and long-term adaptive benefits because broadening builds enduring resources to manage future threats. In the short term, positive emotions counteract negative emotion and enhance stress recovery [26]. When shared, positive emotions create mutual enjoyment and social bonds.

### 1.1. Positive emotion communication

Effective communication is a key component of healthcare interactions and serves many functions, including information exchange and relationship-building [27]. Beyond the required information exchange in nurse-patient-caregiver interactions, high quality relationships that encompass trust and support are important and contribute to better care and improved health and well-being [28]. One way to build high quality relationships is through positive emotion. Due to the intimate and intensive nature of home hospice care, nurses, patients, and families can quickly develop relationships built on trust and support that assist caregivers and patients to navigate end-of-life care.

Positive emotion can be a shared experience, and is frequently communicated verbally. This is also the case in nurse-patient-caregiver communication. Alpert and Womble [29] examined how caregivers used communication as a coping strategy when caring for a family member in an analysis of over 150 caregiver stories, and found that stories using emotion-based techniques—such as humor and positive framing—fostered meaningful bonds between caregivers and family members, and may help with coping. Humor, in particular, has received the most attention as a coping strategy, as it represents a safe way to share challenging, frustrating, and/or upsetting experiences [30]. Using positive emotion words has been associated with better overall health [31]. These effects have been replicated in written and verbal expressive disclosure paradigms in chronically stressed caregivers of older adults [32]. There is relatively little research on positive emotion expression in patients at end-of-life; however, a study comparing blog posts of terminally ill cancer patients to posts from healthy participants who imagined they were terminally ill found that the patients used similar amounts of positive words and far more positive than negative emotion words overall than those who imagined being terminally ill [33].

There is limited research on positive emotion communication (PEC) between patients, nurses, and caregivers at end-of-life. The nature of the emotional experience in hospice care is tremendously complex, and includes positive and negative emotions across the continuum from admission, to caregiving, and bereavement. Hospice nurses have been shown to use PEC to elicit caregiver and patient concerns [34]. Patients have been shown to use humor and positive emotion when discussing sensitive topics such as end-of-life discussions or embarrassing moments to lighten the mood

[18]. Generally speaking, PEC is also associated with less caregiver distress during palliative home care and greater resilience during bereavement (e.g., [35–38]). For example, recently bereaved caregivers who were genuinely smiling and laughing while discussing their recent loss adjusted better over time compared with other bereaved individuals [39,40].

### 1.2. Objective

In a large study of palliative nurse-caregiver-patient communication [41], we were surprised to find a significant proportion of PEC at end-of-life [42]. More surprising, during nurse visits, positive emotion occurred more frequently than distress for caregivers, and in equal amounts for patients. In other research, hospice nurses were found to use PEC as a strategy to elicit caregiver and patient concerns that they may otherwise have been reluctant to express [34]. These findings prompted a closer look at the occurrence of PEC during in-home palliative care. The purpose of this study was to conduct a secondary analysis of nurse-caregiver-patient communication to explore PEC in hospice, and to identify types and patterns of PEC at end-of-life.

## 2. Methods

### 2.1. Study design, participants and setting

The data for this study were derived from a large prospective observational project described in detail elsewhere [41,42]. The study was approved by the University’s Institutional Review Board and participating hospice agencies. Study participants included hospice nurses and family caregivers of hospice cancer patients at seven home hospice agencies located in two different geographic locations in the U.S. (intermountain West, urban East coast). All caregiver and hospice nurse participants completed demographic surveys at baseline. Hospice nurses who agreed to participate recorded their home visits with consenting family caregivers of cancer hospice patients. Visits from the larger study were coded using the Roter Interactional Analysis System (RIAS) [43], followed by secondary coding for PEC. Because we wanted to examine communication over the course of home hospice visits, we chose cases with at least four recorded home visits. Sampling four time points allowed us to assess for patterns of change and variability in positive emotion across a patient’s end-of-life trajectory by capturing both “good and bad days” as the patient declined. Choosing more time points would have limited our sample size as many patients had limited number of home visits. Twenty cases were randomly selected from a larger group of cases that had one visit recording in each of the four quartiles of time from study consent to death, resulting in a total of 80 recorded home visits. A home visit was randomly selected if there was more than one recorded visit in that quartile.

### 2.2. Data collection

Nurses were invited to participate at a staff meeting. Those who agreed completed informed consent and questionnaires. Research staff assessed for eligibility at each hospice to identify family caregivers of cancer patients 45 years or older, were English-speaking, and cognitively able to participate. Family caregivers were contacted by phone and, if interested, a home meeting was scheduled to obtain consent from caregivers and to complete questionnaires. Patients were invited to consent when able, and if not, caregivers served as proxy. Nurses wore digital recorders around their neck during home visits. This allowed nurses to capture the entire visit as they moved throughout the home. Upon entering the home, nurses reminded those present they were

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