

# **The Occurrence Of Positive Emotion In Hospice Family Caregiver And Nurse Communication**

W. Matthew Meredith  
B.S. Cell/Molecular Biology  
University of Utah  
Salt Lake City, UT 84112 USA

Faculty Advisors: Kevin K. John MFA, Maija Reblin PhD

## **Abstract**

Family caregivers emotionally suffer equal to or more than cancer patients. Indeed, they have been described as the “forgotten patient” and often their needs are overlooked by health care providers. The objectives of this study are to examine digitally recorded hospice nurse home visits to describe the occurrence, type (categorize), frequency, and nature of exchange surrounding family caregivers’ expression of positive affect. Examination will determine the relative percentage of positive emotion codes, percentage of positive emotion by speaker, frequency of positive emotion codes per visit, and percentage of positive emotion codes relative to total visit codes. The data for this project will be derived from a large National Cancer Institute funded parent project (P01CA138317). The parent project is a longitudinal descriptive study of family caregivers of cancer patients’ communication with their hospice nurses. The UROP project will use a descriptive approach. From the parent study, a sample of 19 visits have been randomly selected. All home visits in the parent study have been coded using a widely used and validated coding system, Roter Interaction Analysis System “RIAS” (Ong, L.M, 1998, Pgs. 387-401). Statements of positive affect will identified and classified to sub-domains; e.g. gratitude, benefit finding, personal growth, humor, etc. Descriptive statistics will be calculated for frequency, relative concentration, and intended direction. Correlational analyses will be conducted to assess for relationships between family caregiver positive affect and caregiver outcomes. The results of this study will elucidate the nature of conversations during hospice between family caregivers of cancer patients and hospice nurses. The nature of conversations during hospice are rarely studied. The current data set of collection of conversations allows a unique and unparalleled look into these as of yet, unstudied conversations. It may suggest new interventions encouraging positive emotion for the 1,600,000 families currently enrolled in hospice.

**Keywords: Hospice, communication, psychology, positive emotion, well-being, caregiver, cancer**

## **1. Introduction**

Family caregivers emotionally suffer equal to or more than cancer patients. Indeed, they have been described as the “forgotten patient” and often their needs are overlooked by health care providers (Schneiderman, N. et al. 2012, Pgs. 1721-1722). Family caregiver demands in hospice care can be overwhelming because they provide 24/7 care for the patient while facing impending loss (Doorenbos AZ et al. 2007, Pgs. 270-281; McGuire et al. 2012, Pgs. 351-356).

The hospice nurse’s role is to support the whole family but typically nurses focus on the needs of the patient first. When nurses do attend to family caregiver needs, their focus is often on caregiver burden, distress, and fatigue. While focusing on caregiver adverse effects may be helpful, there is promising research indicating that enhancing positive affect can improve physical health, wellbeing, confidence and personal growth (Kim Y. et al. 2007, Pgs. 283-291). Little is known about the presence of hospice family caregiver positive affect and nurse facilitation of family caregiver positive mood.

Patient's and family caregiver's mood should be of the utmost priority for the hospice system. Exorbitant amounts of money are spent to keep patients alive in their final months; we should be concerned that these final months are of quality for the patient. In 2011, Medicare spent \$554B on healthcare related costs; of that \$554B, \$170B was spent on the last 6 months of a patient's life. This significant investment in a patient's end of life should be followed by an investment in the quality of life during this time; in both the patient and their caretakers.

## 2. Research Objectives

The objectives of this study are to examine digitally recorded hospice nurse home visits and acquire descriptive statistics; namely percentage of positive emotion codes, percentage of positive emotion by speaker, frequency of positive emotion codes per visit, and percentage of positive emotion codes relative to total visit codes. Additionally, it aims to establish a system to describe certain positive emotions; as such a system does not current exist.

This study shows promising utility, especially so in a hospice care setting. According to the *National Hospice Care and Palliative Organization (NHPCO)*, approximately 1,600,000 patients received hospice care in 2012 (NHPCO, 2014, Pg. 1). Distress and burden are the chief complaints among family caregivers. One goal of hospice care is to ease these complaints as the caregiver provides care for the dying patient. Utilizing positive emotions may prove to be a helpful means towards improving caregiver coping and wellbeing.

## 3. Methodology

### 3.1 Research Design

The data for this project is derived from a large National Cancer Institute funded parent project (P01CA138317). The visits have already occurred and the recordings have all been collected. The Nation Cancer Institute has allowed permission for this use of the recordings. The parent project is a longitudinal descriptive study of family caregivers of cancer patients' communication with their hospice nurses. The NCUR project used a descriptive approach to analyze its findings.

### 3.2 Study Procedures

#### 3.2.1 sample

From the parent study, a sample of 19 unique cases were randomly selected out of a total of 8,056. These were selected through the use of a random number generator provided through the website: <https://www.random.org/>. Each visit is assigned a unique id, from 1-8,056; thus allowing a random number generator to select for a random participant. Unfortunately descriptive statistics about the sample such as mean age, gender, race, etc. were not collected at the time of sample selection. The parent study from where the sample was obtained had a majority of geriatric patients from hospice facilities in Boston, MA and Salt Lake City, UT.

#### 3.2.2 coding

All home visits in the parent study have been coded using a widely used and validated coding system, Roter Interaction Analysis System (Ong, L.M, 1998, Pgs. 387-401). This is a method which is used for coding medical dialogue; with a focus on interpersonal exchange between patients and their providers. These exchanges can be broadly categorized as either reflecting occupational duties or socio-emotional statements of affect. The general process is someone listens to a tape and "codes" utterances or exchanges; e.g. when a nurse asks a patient, "How are you feeling today?" this is coded as – Nurse, Medical Question, Patient. The format can vary but the format we used was Speaker, Utterance Category, Intended Direction of Statement. Prior to this research through the work for the National Cancer Institute funded parent project (P01CA138317) discussed in Section 3.1; conversations were already coded and broken down into the following main groups: Medical Questions/Information, Psychosocial Questions/Information, Despair, Positive Emotion, and Other. The statements of positive emotion were identified and listened to on an individual basis

to allow further description of these statements. Statements of positive affect have been identified generally, but there are many different domains of positive affect (e.g., gratitude, benefit finding, personal growth, humor, etc.).

### 3.2.3 positive emotion codes

Positive emotion codes were decided upon by an inductive basis and through examination of positive emotion literature. A review of positive psychology literature was conducted and common topics which fit utterances in the communication we analyzed were chosen as codes (Fredrickson, B. (2001), 218-226). Additionally, if any remaining utterances did not fit into previously defined topics we created new topics inductively; e.g. phrases which expressed support or praise to the patient or caregiver were discussed and grouped as “Praise and Support. Figure 1 below displays the six main categories of positive emotion which we identified and coded utterances into.

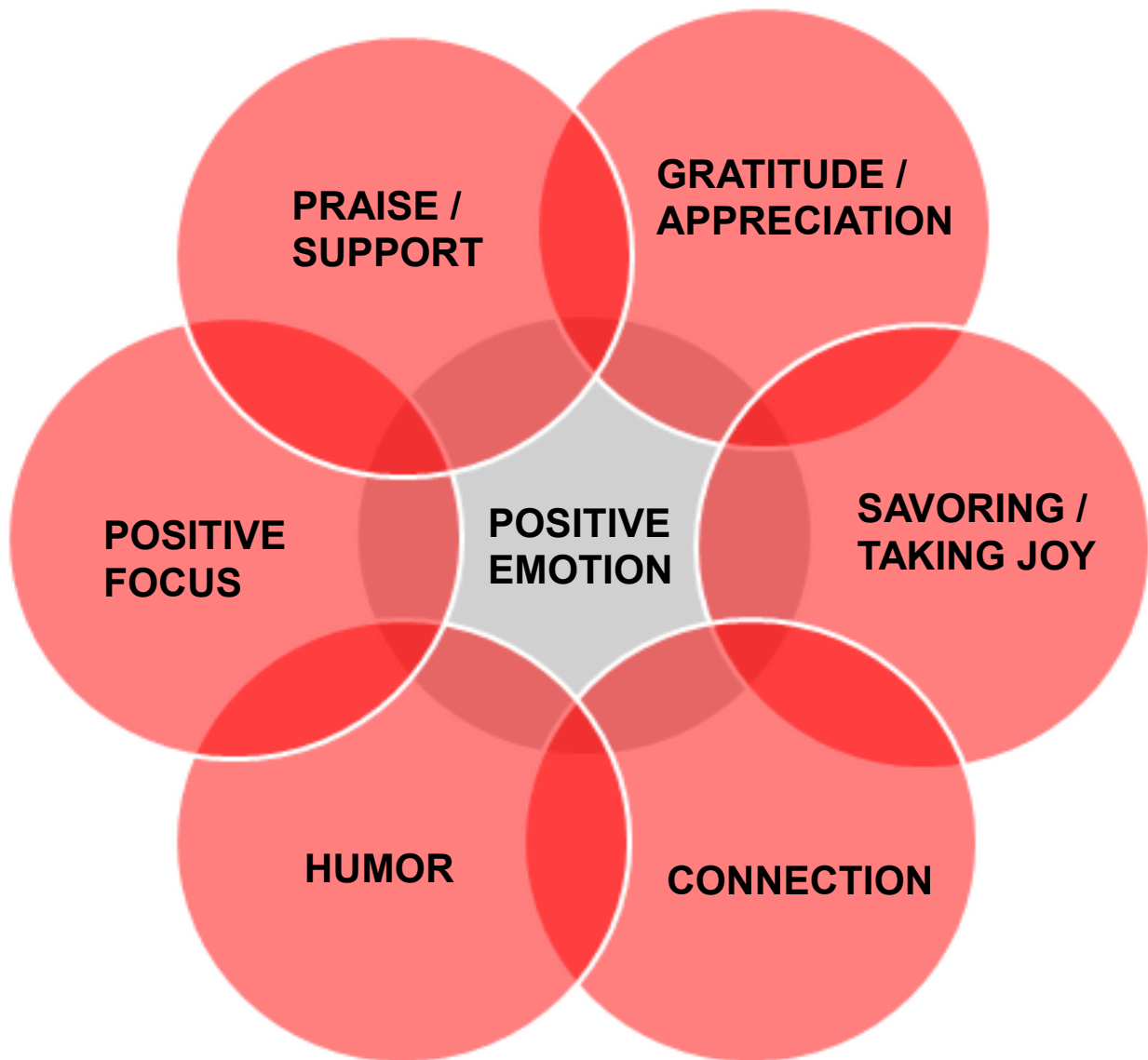


Figure 1. Graphic depicting positive emotion codes that were used for the descriptive analysis.

### *3.2.4 descriptions and representative examples of positive emotion codes*

- Praise and Support: Statements where the speaker is either affirming someone's decision or complimenting them.

Example: "I think it's wonderful you can eat what you want and you're enjoying yourself".

- Connection: Statements which foster relationships and connections; or have a supportive, reassuring, endearing, or affectionate quality.

Example: "I drove by McCools the other day and thought of you guys".

- Humor: Statements which are of a joking nature or contain implicit humor.

Example: "He's like a little kid; he can fall asleep wherever."

- Positive Focus: Statements which frame positively one's physical or emotional state.

Example: "You guys seem to have a lot of support."

- Savoring/Taking Joy: Statements which show delight in life's current experiences or reminiscing life's past pleasures and wonders.

Example: "Wasn't it a beautiful weekend?"

- Gratitude/Appreciation: Statements where the speaker counts their blessings or shows appreciation of circumstances and gratitude towards others.

Example: "You didn't have to do that but thank you so much!"

### *3.2.5 analysis*

Descriptive statistics were calculated to identify percentage of positive emotion codes, percentage of positive emotion by speaker, frequency of positive emotion codes per visit, and percentage of positive emotion codes relative to total visit codes.

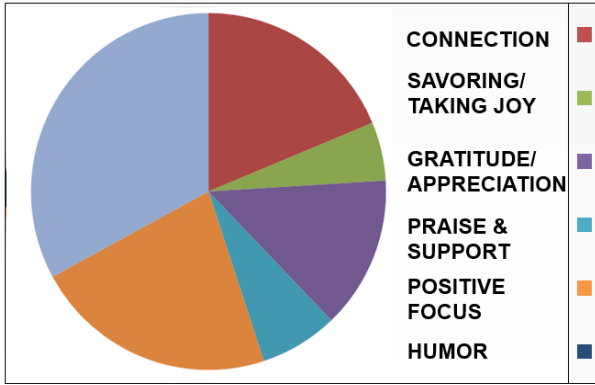
## **4. Results**

Descriptive statistics for the identified positive emotion codes were collected and calculated. Figures 2-4 display these statistics described in Section 3.2.3.

As Figure 2 displays, Humor (32%) was used most frequently by hospice participants; followed by Positive Focus (23%), Connection (21%), Gratitude/Appreciation (14%), Savoring/Taking Joy (6%), and Praise and Support (5%).

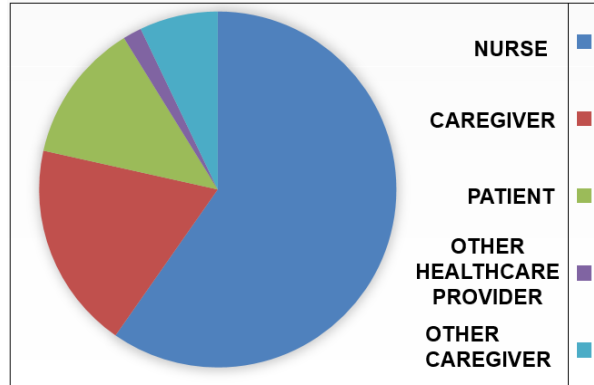
As Figure 3 displays, the Nurse (57%) was the primary user of positive emotion during hospice conversations. This is followed by the Caregiver (20%), Patient (13%), Other Caregiver (8%), and Other Healthcare Provider (2%).

Figure 4 displays the frequency of positive emotion codes per visit and percentage of positive emotion codes versus total visit codes.



**Percentage of Positive Emotion Codes**

Figure 2. Pie graph displaying percentages of various positive emotion codes.



**Percentage of Positive Emotion by Speaker**

Figure 3. Pie graph displaying percentages of positive emotion codes used by hospice care speakers.

Figure 4 displays the Frequency of Positive Emotion Codes Per Visit and the Percentage of Positive Emotion Versus Total Visit Codes.

	Frequency of Positive Emotion Codes Per Visit	Percentage of Positive Emotion Versus Total Visit Codes
<b>Mean</b>	33.47	6.30%
<b>SD</b>	19.09	.045%
<b>Range</b>	5-68	2.04-22.54%

Figure 4. Descriptive statistics (Frequency of Positive Emotion Codes Per Visit and Percentage of Positive Emotion Versus Total Visit Codes) of positive emotion found in the visits.

## 5. Analysis

We can conclude that our aim to establish a system to track positive emotions was effective. The codes effectively covered all utterances encountered with little conflict or overlap. They also allow us to gain a very preliminary insight into the conversations and positive emotion present in the visits. Care must be used in drawing too many theories from this small data set. Our team has thousands of these visits digitally recorded and coded using the RIAS system. Before in depth analysis can occur, a larger sample should be used to allow more power in the reported descriptive statistics.

## 6. Discussion

Positive emotion is an important measure of an individual's mental health and physiological state. Hospice participants, especially caregivers encounter stressful and trying times. Analyzing their response to these trying times is an important tool to see how well they cope with the situation.

The system created to track positive emotion for this study was successful in this aim. It successfully tracked positive emotions and tracked descriptive statistics; namely percentage of positive emotion codes, percentage of positive emotion by speaker, frequency of positive emotion codes per visit, and percentage of positive emotion codes relative to total visit codes.

Further studies should be conducted on a larger sample size to reevaluate the descriptive statistics and improve confidence in their values. Additionally, further studies should be performed on attempting to improve the positive emotion used by all hospice participants; especially the caregiver as they encounter a high degree of stress and fatigue. These further studies could be instrumental in assisting the 1,600,000 patients and their families currently enrolled in hospice care.

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