

**Final Conversations: Messages of Love**

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## Final Conversations: Messages of Love

*When we accept this challenge of caring for the dying, we are not merely doing our duty. We are committing ourselves to more than easing pain and suffering, more than sitting sadly by the bedside. We are dedicating ourselves to love in action—ready to receive as much to give, prepared to learn and even change and be changed, ready to ponder anew what we mean by dignity and honesty, and ready to ensure that the one we love will, in some mysterious ways, live until he or she dies, leaving us and the world better than when they entered it.*

(Doyle, 1994. p. 5).

Doyle (1994) highlights the accessibility, possibility and necessity of love that is often uniquely available at the end of life. In the final months, weeks and days before death, people often have the opportunity to experience a deepening of love, a resolution of feuds, and a forgiveness of past hurts (Doyle, 1994). How is this possible? These acts of love and resolution are achieved through communication. By turning toward death together through authentic conversation, people have the potential to “illuminate and enrich the very meaning of life for patients and caregivers alike as they enter the sacred moment of mortal time together” (McQuellon & Cowan, 2000, p. 318).

What is known specifically about communication at the end of life? Kubler-Ross’s ground-breaking work highlights the dying person’s need for communication

(1969; 1997). Most of the research about the end-of-life comes from a psychological or sociological perspective framework rather than a communicative one. A communication perspective focuses specifically on the verbal messages and nonverbal behaviors and their meaning to the interactants. A current project, which takes a communication perspective, is an ongoing study exploring “final conversations” (FC). FC includes all interactions (verbal and nonverbal) that a participant had with the loved one that was dying, between the point of a terminal diagnosis and the moment of death; and both individuals had to be aware that one was dying.

The impact of communication during the dying experience is profound for all participants involved. The majority of research on end-of-life communication focuses on the importance of communication from the dying person’s perspective (Aiken, 2001; Callanan & Kelley, 1992; Kubler-Ross, 1969; 1997); yet, family members also want to have the opportunity for final communication with dying loved ones (Gold, 1984). People want to achieve closure in their relationships with dying intimates and often have concerns similar to those expressed by the dying person (Fieweger & Smilowitz, 1984). The nature and manifestation of verbal messages and nonverbal interactions remains unclear from the survivor’s perspective, as does their meaning. Therefore, I look at FC from the survivors’ perspective.

It is through communication that relationships often evolve and strengthen during the period of the terminal illness (Nussbaum, Pecchioni, Robinson, & Thompson, 2000). Time and again, relationships become more intimate because people are “confronting the past, speaking the unspeakable, acknowledging the difficult, and talking about death” (Nussbaum, et al., 2000, p. 44). Communication with a loved one at the end of life

presents an opportunity for survivors to “resolve issues, say important things, finish unfinished business, and share important moments” (Callanan & Kelley, 1992, p. 133) with those dying. In this way, connections are obtained through talking, sharing fears and thoughts, and through simple nonverbal acts such as touching and spending time with the dying loved one. One major and extremely important theme that emerged from the FC interviews is love.

Individuals have a fundamental need for unconditional love, “a love that affirms and supports people just as they are and does not demand that they make themselves different in any way” (May, 1983, p. 72). People seek out and want emotional connections but their requests for love are often missed (Gottman & DeClaire, 2001). However, communication at the end-of-life creates a situation in which unconditional love may be more readily exchanged between people because many of society’s barriers to love and intimacy such as loss of one’s identity, exposure, attack, and/or abandonment (Feldman, 1979) are removed by the impending death. Further, changes in individuals’ bodies (e.g., body chemistry, brain, effects of long-term pain) and perspectives (e.g., time has run out, there is nothing left to lose) that frequently accompany a terminal illness, often strip people of obstacles that may have previously impeded their expression and experience of love (Levine, 1984).

## Participants and Method

### *Participants and Procedures*

Forty retrospective interviews were completed in a private office (N = 40). The sample consisted of 35 female and 5 male participants: 34 White, 5 Hispanic, and 1 Black. Participants ranged in age from 21 to 85, with the average age being 47.

Participants identified the relationship that they had their FC with as their: spouse 9%, mother 26%, father 22%, sibling 3%, child 4%, grandparent 26%, close friend 5%, and other 5% (e.g. uncle, cousin, etc). The amount of time between the loved one's death and the FC interview ranged from 1 month to 27 years (57.5% of the interviews occurred within the recent past, 37.5 % past, and 5 % extreme past)<sup>1</sup>. A snowball sampling technique, (Lindlof, 1995) was used to recruit participants. Participants had to meet two criteria to participate in the study: they must have had a FC and also needed a clear memory of their FC interaction. To reduce the invasion of people's privacy and to reduce the possibility that anyone would feel pressure to participate, individuals made first contact<sup>2</sup> with the researcher about their interest in participating in the study.

Retrospective interviews were conducted, with the researcher utilizing a 10-minute focusing exercise<sup>3</sup> to help individuals' recall their FC. Retrospective interviews are valuable because they give participants some distance from strong emotions as well as time for people to reflect and assign meaning to the communication that occurred (Metts, Sprecher, & Cupach, 1991). Morse (2000) concurs that retrospective interviews are highly effective for recalling past experiences and cautions that there is often a resurgence of memories and emotions with the experience.

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<sup>1</sup> Breakdown re: the amount of time between the final conversation and their participation in the interview (7.5% = 1 year or less, 50% = 1.5 to 5 years, 12.5% people = 5.5 to 10 years, 15% = 10.5 to 15 years, 10% = 15.5 to 20 years, and 5% = 20 to 27 years).

<sup>2</sup> Participants contacted the researcher by phone after they had read a flyer or heard about the study from the researcher or someone else. Once the caller was given more information about the study the caller was asked if they would like to schedule a private interview.

<sup>3</sup> The focusing exercise consisted of a 10 minute free writing period. The aforementioned definition for FC was at the top of a page and then the words "I remember..." were typed out followed by blank (lined) pages. Participants were asked to write about their final conversation (or conversations) with their loved one without worrying about spelling or the legibility of their writing, and to not stop writing until they were finished or until the 10 minutes were completed. If at the end of the 10 minutes, the participant wanted some more time to complete their thoughts, they were given additional time.

Given the exploratory nature of the study, the interviews were conducted using a semi-structured focused format (Kvale, 1996; McCracken, 1988; Stewart & Cash, 2000) with 24 open-ended questions as the foundation. Additional questions were added as needed for clarification. Interviews were audio recorded and transcribed verbatim and resulted in 499 single-space pages of data. Interviews lasted an average of 90 minutes (range of 60 to 120 minutes). A six-step process was used during the actual interview, beginning with making the participant comfortable, completion of a 4 stage interview process (e.g., consent form, completion of a brief questionnaire, focusing exercise, and interview), and ending with a debriefing period. The interviewer strived to build a climate of rapport that cultivated an honest expression of emotions and “lived experiences” (Silverman, 2001).

#### *Data Analysis*

The transcripts were analyzed to describe the meaning of the participants’ experiences through an examination of recurring patterns (Creswell, 1998; Strauss & Corbin, 1990). Grounded theory was utilized to identify themes in FC (Glazer & Strauss, 1967). For the focus of this paper, only the messages pertaining to the themes of love in FC are discussed in this paper.

Emergent themes were identified utilizing open and axial coding (Spradley, 1979; Strauss & Corbin, 1990). Then utilizing the constant comparative method, the meanings of the participants’ statements were read numerous times to identify the important messages for each of the categories (Strauss & Corbin, 1990). To ensure that categories were not forced on the data, the researcher used the negative case analysis technique to look for other possible explanations for the research findings (Erlandson, Harris, Skipper,

& Allen, 1993; Miles & Huberman 1994). After the coding was completed, five participants were asked to review the findings to validate the researcher's interpretation of the participants' experiences (Creswell, 1998; Lincoln & Guba, 1985). All five participants confirmed that the themes and structures were consistent with their FC experiences in regard to the messages of love that they experienced.

### Results and Discussion

Messages of love are not surprising in a study examining communication at the end of life, but it is an important confirmation of a message that people would expect to experience during a FC. The findings reveal three themes of love. The first and most common theme found during the analysis was an affirmation of love. The second theme revolved around the importance of the communication of love as a bridge for reconciliation. The third theme that emerged focused on people's ability to express altruistic love through sacrificial caring for their dying loved one.

#### *Affirmation of Love*

Many people give and receive simple (but important) affirmations of love during their FC. This finding is consistent with reports by people that one of the most common benefits of sharing a loved one's end of life experiences was a strengthening of relationships or an increased sense of connection with others (Marrone, 1999). Thirty-nine out of the 40 participants (97%) stated that they told their loved one "I love you."<sup>4</sup>

Declarations of "I love you" were often repeated throughout brief conversations with their loved one verbally and nonverbally. The simple statement of "I love you" was often given while holding the dying loved one's hand, touching their face, or giving them

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<sup>4</sup> Note: In the one interview that did not directly address love, the participant indicated that love was clearly understood between him and his mother and did not need to be explicitly stated.

a kiss goodbye. Many of the participants talked about the eye contact that was shared, or the importance of simply spending as much time as possible with the dying person.

While this first category of love does not offer any new insight into communication at the end-of-life, this study does confirm the importance of communicating the simple but powerful message of love. A final message of love helped people to complete their relationship (Ellen) and inevitably aided their grieving process (Victoria).

### *Love and Reconciliation*

FC provides a last opportunity for reconciliation between the participants through the communication of love. Despite difficult relationships during their lives together, people often realize that they are faced with their last window of opportunity to verbally state their love for someone with whom they have had a difficult relationship. McQuellon and Cowan (2000, p. 317) state, that “caregivers who can turn toward the subject of death in an open, empathic manner with those who are facing it invite the possibility of healing conversation.” While only three of the participants of the FC project talked about their FC with a person with whom they had a difficult relationship, they are a very important part of the FC experience.

All three of these participants with troubled relationships stated that they would not have been able to let go of the anger or to really love anyone in the future if they had not had the opportunity to tell their mothers that they loved them. They revealed that it was only the imminent presence of death that gave each of them the opportunity to share this final message of love and forgiveness with their mothers.

The best example of a healing conversation that resulted from a communication about loving and being loved comes from Katherine<sup>\*5</sup>:

I would have to say it took me days to, uh, get myself ready to tell her that I love her ... it seemed like this huge thing...it had just so much emotional baggage with it...because she had never told me...[One night] she was ranting about how nobody loves her...And it just, it just laid itself out there...And I just said, "Mom, I love you dearly. And I appreciate everything you've done for me all of my life"...there was all this conflict between she and I...And so I cleaned that up.

Later Katherine\* went on to tell the interviewer that her mother finally did tell her that she loved her. Perhaps more importantly, Katherine\* realized that her mother had a hard time accepting or recognizing love, but that upon reflection, her mother constantly gave to people as a way to try to demonstrate her love for others. Katherine learned from this interaction, that she was a lot like her mother and that she needed to forgive her mother and to open herself up to love, if she hoped for love in the future.

The other two participants (who shared the fact that they had had troubled relationships) finally told their mothers that they loved them just hours before their mothers' deaths. Both participants also talked about the importance of nonverbal communication, specifically holding hands with their dying loved one and spending a significant amount of time with them during their final days. Their mothers finally gave a positive response back to them by squeezing their hand. The participants also noted that their message of love was finally possible only after their loved one could no longer talk

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<sup>5</sup> \* Signifies the use of a pseudonym, the majority of names used in this manuscript are the participants real first names, used at their request.

or interrupt them. All three of these participants expressed the sentiment that their final message of love was a much needed release for themselves.

### *Altruistic Love*

Family members caring for and openly communicating with loved ones at the end of their life's journey must be "willing to be stretched in the effort to understand and hold an experience that is always painful and often incomprehensible (McQuellon & Cowan, 2000, p. 317). Acts of sacrificial caring are profound expressions of altruistic or unconditional love. Ten participants or 25% of the participants shared examples of sacrificial caring. These acts of love go beyond the simple statements of "I love you" that are the most common messages of love. In these interactions, these individuals fully shared in their loved one's death and through their actions and expressions of love, helped their loved one to die peacefully. For instance, Victoria, Cathy, and Ellen all told their husbands that they loved them, that they would always love them, but that they knew that they had to let them go despite their personal fears and needs.

Another element of altruistic love during final conversations focused on people doing things for their loved ones that were difficult or challenging for them, but comforting for their loved ones. For instance, Gloria talked about the cruel and comforting irony of feeding her 19 year-old son his first and last meal on this earth (some chilled peaches, which was his favorite meal). Lindsey rubbed her grandmother's feet with lotion as she told her that she loved her (and stated that she could not imagine rubbing anyone else's feet for any reason). Kasey would rub her sister's sciatic nerve (from her buttocks all the way down the back of her leg) for hours on end to help relieve

her sister's pain. All 10 of these participants talked of long hours spent caring for and focusing on the needs of their loved ones at the expense of their own needs.

In sum, declarations of love are clearly one of the most important final messages for surviving participants of FC. These messages of love often reconfirm a love that is already known. For others, love is a message that can finally be shared because the impending death tore down previous barriers and helped heal lifelong wounds. FC is also an opportunity for people to demonstrate altruistic love in the face of their own suffering. It appears that death may force people to let go of what is unimportant, resulting in a reprioritizing of what is communicated. Levine (1984, p. 243) was right when he stated, "when we let go of everything, only love remains."

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