Family Communication at the End of Life

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ABSTRACT

This article presents a brief review examining what research has been conducted exploring family communication at the end of life (EOL) and suggestions for future research at the end-of-life context. Future research areas include: 1) the role of culture, 2) family member role and relational climate, 3) ethical considerations in regard to methodological choices, 4) the role of emotional and cognitive development on EOL communication, 5) EOL backstage communication, 6) death circumstances, and 7) the use of interdisciplinary research teams.

The end of life creates a context where dying individuals search for meaning in their lives (McQuellon & Cowan, 2000). The search for meaning is accompanied by a prioritization of relationships (Carstensen, Isaacowitz, & Charles, 1999); specifically, familial relationships (Keeley & Yingling, 2007). It is only through communication that those with a terminal illness (hereafter referred to as the Dying) and their family members can come together to participate to find greater meaning about life, death, and their relationships (Generous & Keeley, 2014; Keeley, 2007; Keeley, Generous, & Baldwin, 2014). End-of-life (EOL) communication with the Dying and family members leads to better care and well-being at the end of life for the Dying, as well it provides stress relief and support for families in three important ways (Bernacki & Block, 2014). First, it leads to timelier referrals into hospice, resulting in a better quality of life with less pain and suffering for the Dying and provides important social support and direction for families. Second, it leads to care that is more consistent with the preferences of the Dying. Third, it reduces the use of unnecessary and nonhelpful medical intervention near death.

In addition, EOL communication has the potential to have a tremendous impact on the familial relationships (biological, legal, or chosen families) (Keeley et al., 2014; Keeley & Yingling, 2007). Specifically, the terminal time (which is a framing of time from the moment of a terminal diagnosis and the actual moment of death) that is created by the illness, increases the urgency for the Dying and family members to tie up loose ends in their relationships and it gives individuals permission to make time in their busy lives to focus on the relationship with their dying loved one through their participation in final conversations (FCs) (Keeley & Yingling, 2007). Final conversations are all communication (verbal and nonverbal) that occur from the moment of a terminal diagnosis and the moment of death between the Dying and their family members (Keeley, 2007). Final conversations gives the Dying the opportunity to help their family members move forward after the death by providing advice, direction and permission to move on, as well as creating a sense of closure and completion of the relationship (Keeley & Yingling, 2007). Unmistakably, EOL communication has a tremendous impact on families, so it is helpful to review what we have learned thus far about EOL communication in the family and to begin the discussion as to where we should go with future research endeavors.

My career for the past 16 years has been focused solely on family communication at the end of life. My co-authors and I have learned a lot about communication at the EOL and we have shared
our findings with academic audiences through the publication of 27 articles and book chapters/encyclopedia entries and 24 national and international conference presentations. From the beginning, I have also felt passionately that this information must be translated for and shared with the general public, so I wrote a book with my coauthor (with a different life experience regarding Final Conversations) for the popular press (Keeley & Yingling, 2007), and combined we have given over 50 workshops on the topic of FCs to lay audiences, and I have also given numerous talks to palliative care specialists for invited, medical and palliative care “Grand Rounds” presentations.

Specifically, my program of research incorporates four major phases. Phase one of my FCs research qualitatively explored adult FCs through the use of interviews. One of the issues that I realized about EOL communication is that most of these conversations take place in private, so individuals do not have any examples about what EOL communication looks like or how to successfully accomplish FCs. The FCs themes, in order of prominence within the qualitative data, include: love (Keeley, 2004a), individual and relational identity (Keeley & Koenig Kellas, 2005); religious/spiritual messages (Keeley, 2004b, 2009); everyday talk, and difficult relationship talk (Keeley, 2007).

The family EOL communication included both verbal and nonverbal messages (Keeley, 2007; Manusov & Keeley, 2015). Our investigation highlighted the importance of including analysis of nonverbal communication, because some illnesses rob individuals of their speech; as death nears the importance of nonverbal communication increases (Foster & Keeley, 2015; Manusov & Keeley, 2015). Overall, our findings revealed that communication at the end of life is as important and necessary for the family members (Keeley, 2007) as it is for those that are dying (Kubler-Ross, 1969, 1997; Wittenberg-Lyles, Goldsmith, Sanchez-Reilly, & Ragan, 2010).

Some of the individuals who shared their FCs with me in Phase one had been young children and/or adolescents when they had their FCs with a parent that had died years and even decades previous to their interview with me. The fact that they still vividly remembered their FCs led me to explore children/adolescents FCs. In Phase two, I talked with children/adolescents (5–18 years of age) within a limited time frame of the death (e.g., between 3 months and 3 years of the death) and asked them to describe their FCs. I found that children/adolescents and adults shared similar FCs in four out of five areas, but with different levels of importance (Keeley et al., 2014). Specifically, the themes that emerged, in order of prominence, include: everyday talk (Keeley & Baldwin, 2012); love, identity, and religious/spiritual messages. The one area that did not cross over into children/adolescent’s FCs was the theme of “difficult relationship talk” and we concluded that children/adolescents might not have the verbal and/or cognitive maturity to identify and discuss these types of messages (Keeley et al., 2014).

In addition, children/adolescents also gave us their best advice about how parents should communicate with them at the EOL, which focused on three issues: honesty, timeliness, confirmation of the child/adolescents identity and their relationship with the Dying family member (Keeley & Generous, 2013). Children/adolescents want to know the truth and if they don’t get it from their parents, they become very “adroit at continual eavesdropping, reading parental nonverbal cues, and pretending to sleep” while adults talk about the diagnosis (Galvin, 2015, p. 41). Children/adolescents want to be informed about their own treatment options and health status (Wolfe, Friebert, & Hilden, 2002), and most want to be included in the EOL communication when it involves any of their family members (Keeley & Generous, 2013).

The similarity in findings in Phase one (adults) and Phase two (children/adolescents) led me to want to find out if my qualitative/descriptive findings could be supported for a larger, more generalizable population. Phase three developed and tested the FC Scale to see if the themes discovered were generalizable to a wider population. The findings validated the previous qualitative results (four out of the five themes were found), and one new theme was identified in the study. The five factors identified in Phase three include: (1) messages of spirituality and religion, (2) expressions of love, (3) proactive difficult relationship talk, (4) everyday communication, and (5) instrumental talk (Generous & Keeley, 2014).
The last theme that was found, instrumental talk (which is talk about the illness, impending death, and funeral wishes), did not emerge from the qualitative data, but items were added to the scale during its development because of previous research on EOL communication and palliative care research regarding the need of the Dying to talk about their illness and dying (Wittenberg-Lyles et al., 2010; Wittenberg-Lyles, Goldsmith, Ferrell, & Ragan, 2012). We clearly found that family members do indeed talk about issues revolving around their terminal illness, their EOL decisions, and even their funerals. The fact that this theme did not emerge during the previous qualitative interviews suggests that these messages are not the most memorable or meaningful FCs for the family members, but clearly are important to the Dying.

Talk about the illness, death, decision making at the EOL, and/or funeral plans may be important for the Dying during the final weeks but are often uncomfortable for family members (Pecchioni & White, 2015). It is evident that Dying individuals and their family members often have different goals for their EOL communication. If the EOL communication is perceived to be positive and focused on relational, identity and task goals, then both parties are satisfied with their EOL communication, however, if their perception is that these goals are not being accomplished, then their EOL communication is perceived to be associated with hurt feelings and the participants are left with the desire to distance themselves from the relationship, therefore in these instances, family members may avoid and/or cease EOL communication (Scott & Caughlin, 2014).

One area that I had not heard about very much during my research were the challenges that people faced with their family members regarding FCs and what topics were avoided. Phase three allowed me to directly question people on these areas. Ellis (2000) found that that the death journey is a shared endeavor that must be negotiated between the Dying and their family members. The idea of a negotiation suggests that there are some inherent tensions that occur within EOL communication. Keeley and Generous (2015) found three dialectical tensions in EOL communication: acceptance-denial, openness-closedness, and expression-concealment of emotion.

First, people cannot begin to have open and honest conversations if the Dying, or one of the members of the family, does not accept the impending death (Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011). Failure to accept a terminal diagnosis is especially difficult if it is a child in the family that has been given a terminal diagnosis (Galvin, 2015). Children are often not allowed to talk about death and dying because of cultural norms, protectiveness, as well as parents’ fear of facing the truth (Black, 1998). Second, what is talked about and in what depth things are talked about are greatly dependent upon how open or closed family conversations have traditionally been in the family (Koerner & Fitzpatrick, 2002), as well as how much openness is allowed revolving around the topic of death and dying. Many family members simply do not want to know about the severity of the illness or the life expectancy because they believe that it robs everyone of hope (Cherlin, Fried, P Brigham, Schuman-Green, Johnson-Hurzelr, & Bradley, 2005).

Some family members often adopt a “context of painful pretense” (which is using energy trying to act positive in the face of the impending death) as a way to protect others in the family that are unwilling or unable to openly talk about the impending death (Bluebond-Langer & Nordquist Schwallie, 2008, p. 166). In some instances, there is mutual pretense occurring between the Dying and various family members, whereby the parties assume that individuals don’t want to talk about the difficult truth, and they act to protect one another and avoid the conversations thereby creating multiple layers of denial and avoidance (Goldsmith, Wittenberg-Lyles, Ragan, & Nussbaum, 2011).

A sad truth is that by not having open and honest EOL communication, many family members are left with regret and a more challenging grief recovery process (Beale, Baile, & Aaron, 2005; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). Third, even within a family there are wide variations of acceptance about whether or not emotions may be revealed or if they need to be concealed from each other. Some families have norms that revolve around individuals not becoming upset and controlling emotions and protecting others from strong and/or negative emotions (Bluebond-Langer, 1996). These patterns are often created long before the illness but often dysfunctionally continue until it is too late (Bluebond-Langer, 1996). The best FCs are the ones where
family members are accepting of the diagnosis, are open, honest, and accepting of each other’s thoughts and feelings, and are tolerant of the myriad of emotions that are experienced at the end of life (Bluebond-Langner, Belasco, & DeMesquita Wander, 2010; Keeley & Generous, 2015; Keeley & Yingling, 2007; McQuellon & Cowan, 2000).

Generous and Keeley (2015) identified a number of topics that are generally avoided at the end of life and are supported by other research. These topics include: negative relationship characteristics (i.e., why rehash old issues at this point in time) (King & Quill, 2006); death and dying (i.e., too depressing and cultural taboos about this topic) (Ko, Roh, & Higgins, 2013); postdeath arrangements (i.e., it would bring the conversation back to death and dying) (Pecchionini & White, 2015); and personal information (i.e., do not want to worry the Dying person with anything negative) (Kubler-Ross, 1997).

Furthermore, individuals often avoid these topics at the EOL because they want to emotionally protect the Dying person and/or themselves from the topic (Bluebond-Langner & Nordquist Schwallie, 2008), or family members and/or the Dying may simply not be ready to handle the truth (Caughlin et al., 2011). Perhaps the participants recognize that there are clear relational differences on the topic and no one’s opinion is going to change at this late point in time (Keeley & Yingling, 2007). Last, if the FCs are occurring closer to the actual death, then family members believe that the condition of the Dying has deteriorated to the point where no significant verbal communication can take place and instead the nonverbal communication becomes the focus (Manusov & Keeley, 2015).

I am currently working on Phase four of FCs where we are revising the scale and fixing the methodological issue revolving around identity and looking at additional issues looking at the impact of participating in FCs on a variety of outcomes. In addition, past research suggests that culture makes a difference at end of life (Ko et al., 2013; Kubler-Ross, 1969; McQuellon & Cowan, 2000; Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008), but the question still exists as to how different cultural views about death and dying impact FCs? Thus, we are looking more closely at cultural impact on end-of-life communication. The complicated issue of culture is a good place to start discussing where we as family communication researchers need to go next in our exploration of EOL communication within the family.

The following sections of this manuscript address potential future directions within the field of EOL communication and family studies, including: 1) the role of culture, 2) family member role and relational climate, 3) ethical considerations regarding methodological approaches to studying EOL communication, 4) the role of emotional and cognitive development on EOL communication, 5) EOL backstage communication, 6) death circumstances, as well as 7) the use of interdisciplinary research teams.

**Family, culture, and EOL communication**

Cultural expectations and beliefs lends itself to a number of questions regarding family EOL communication, such as: who is included in the EOL conversations? What are the topics that can be talked about? Where do the EOL conversations occur (at home, in a hospital, in hospice)? And when do they occur (i.e., as soon as the diagnosis is given, as the person begins to show signs of deterioration, only as the death appears to be imminent, or not at all) (Keeley, in press). All cultures attribute specific meanings and significance to death and dying, which impact the “who,” “where,” and “when” of EOL communication. In addition, these are influenced by the family’s religious and philosophical belief systems (Aiken, 2001).

For instance, there are a few differences already noted in research regarding culture and family EOL communication. Specifically, Caucasian American families often sterilize and remove dying from sight with most deaths still occurring primarily in hospitals (Ragan et al., 2008). African Americans families are less likely to make advance care directives because they believe that they will be denied help and comfort from medical professionals and suffer premature and/or painful
deaths (Bullock, 2011). Hispanic American families believe that talk about death and dying should only be done within the family (Kreling, Selsky, Perret-Gentil, Huerta, & Mandelblatt, 2010). Asian American families believe that talk about death brings misfortune upon the family and therefore it is considered a taboo topic (Yick & Gupta, 2002). Undoubtedly, cultural differences impact EOL communication in many as yet unknown additional ways that occur within the family.

These issues impact family EOL communication highlighting important issues that continue to need investigation. For instance, how does culture impact individuals’ and families’ decision making and communication regarding advance care directives and end-of-life wishes (Pecchioni & White, 2015)? Are family members allowed to express one’s feelings at the EOL or are they pressured to remain silent due to their family and cultural norms (Ragan et al., 2008)? At what age are children socialized and/or included in the EOL communication (Galvin, 2015)? What is the importance of talking about the afterlife and spiritual beliefs on EOL communication within the family (Lobar, Youngblut, & Brooten, 2006)?

If the impending death is acknowledged and talked about among family members and not with outsiders, how does it impact all of the other factors concerning EOL (i.e., use of Hospice, EOL decision making, postdeath bereavement, etc.) (Bullock, 2011). These questions (and so many others) will be challenging to answer because it is extremely difficult to get family members of different cultures to participate in studies if the researcher is not a member of the culture (Generous & Keeley, 2015; Keeley, 2007; Keeley et al., 2014), but with the rapidly changing population, these under-studied populations must be reached.

**Family member role and relational climate**

Research within the family has begun exploring EOL communication between spouses/significant others; between parents and children/adolescents, between siblings, grandparents and their grandchildren, and chosen family members (close friends viewed as family) (Generous & Keeley, 2014; Keeley, 2007; Keeley et al., 2014). But much more research needs to be completed. Other familial relationships such as extended familial relationships (e.g., aunts, uncles, and cousins) should also be explored regarding their EOL communication (Galvin, 2015). It is important to note however, that most of this past research has focused on the Dying person’s perspective (Wittenberg-Lyles et al., 2010), as opposed to the family member(s). Furthermore, most of these EOL studies have taken more of a medical and/or psychological perspective, as opposed to a family communication viewpoint (Adolescent and Young Adult Oncology Progress Review Group, 2006; Howk & Wasilewski-Masker, 2011). Each of these familial dyads have unique perspectives about their EOL communication with their Dying loved one, and they also have communication concerns and challenges that must be dealt with within the family. For instance, siblings are often caught in the midst of stressors including anxiety, change, fear (Galvin, 2015), as well as dealing with unmet needs and invisibility (Wilkins & Woodgate, 2005) while their parents deal with the terminal illness and all that it brings with it on a daily basis. What is more, most volunteers for research are usually skewed to the more positive end of coping and dealing with EOL (Keeley, 2007), there needs to be rigorous effort made to reach the participants that have had more negative experiences in their familial communication at the EOL in order to understand the complexity of the EOL issues.

It is important to stress that while family relationship type might influence EOL communication, the relational climate is also necessary to consider. EOL communication, and specifically FCs, is often reserved for close, intimate others (Keeley, 2007). We found that the relational climate between the Living and the Dying (i.e., characterized by perceptions of relational closeness) significantly predicts the frequency of retrospectively recalled FCs (see Generous & Keeley, 2014). Consequently, researchers seeking to understand the role of family relationship type on EOL communication must also consider the contextual nuances of the relational climate (e.g., closeness, satisfaction, commitment, control mutuality, etc.).
Ethical considerations in regard to methodological choices

Ethical considerations are always of concern when researching sensitive, painful and private topics and this is never more evident than when dealing with the end of life. Death and dying comes with suffering, fear, and the unknown (Keeley & Yingling, 2007) and these research participants must always be in the forefront of researchers’ concerns (Wittenberg-Lyles et al., 2010). Our task is to be sure to not do any harm to the participants, to not to add to their stress and heartache while they are dealing with imminent threat of the death of a family member (Ragan et al., 2008). Thus, some of methodological considerations include the choice between conducting retrospective interviews (Keeley, 2007; Keeley et al., 2014) and interviewing participants in the midst of the death journey. I chose to favor the side of privacy and respecting the solemn moment of the FCs.

It was my experience that participants were better able to focus on the communication after they had time for reflection and had dealt with their grief. In addition, while some researchers have respectfully videotaped EOL communication among patients and palliative care specialists in hospitals and hospice organizations (Wittenberg-Lyles et al., 2012), it is a more delicate task when trying to capture EOL communication among family members—especially when it may be the only conversation the Dying and the family member have before the death. Survey and open-ended questions are also good options when exploring EOL communication; the challenge remains to get enough participants to complete them, which individuals are usually more open to the task when they are not under the stress of the death journey.

Impact of child development on EOL communication: Children 5–12 versus adolescents 12–18

Children (5–12 years of age) and adolescents (12–18 years of age) experience death differently from adults and from each other because of differences in their cognitive, emotional, and communicative development (Aiken, 2001; Yingling, 2004). For instance, children 5 years old and younger do not understand the conclusiveness of death and have trouble accepting its finality. Children aged five to nine begin to understand that death is not reversible, but see it in simplistic ways looking for brief answers about death. Children ten to adolescence begin to convey a more accurate view of death and understand that death is inevitable, irreversible, and can happen to anybody and at any time; yet, they still struggle when communicating about death. Adolescents contemplate the nature of death and turn to dependable and trusted individuals for answers about death and afterlife. These developmental differences do impact how children/adolescents participate in EOL communication (Keeley & Yingling, 2007), but more exploration of all ages is needed. Additional areas of exploration include: more in-depth exploration regarding how children and adolescents communicate about death among themselves, their friends, different members of their family, as well as their EOL communication with the Dying. A terminal illness, and eventually the death of a family member, brings tremendous stress on family members that must be dealt with in unique ways to deal with the end-of-life journey for each age group (Maguire, 2012); therefore, looking at the ways that communication helps and hinders that process for different age groups would be extremely beneficial.

EOL “backstage” communication

After conducting over 150 interviews and collecting hundreds of surveys about FCs, I have come to realize that there are also numerous EOL “backstage” conversations going on in the family. These conversations are occurring among adult children as they observe and/or participate in their parents’ death journeys. Family EOL communication can also bring up “old issues” among the adult siblings such as: familial cohesiveness, adaptability, conflict, decision making, and satisfaction, which should be more thoroughly explored as to how they impact the family during their end of life (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2009). Backstage conversations are also going on among children/adolescents without parents being aware of them because the children/adolescents...
are trying to gain more information and voice during the EOL process, but are doing so in a way that protects their parents (Galvin, 2015).

**EOL communication based on death circumstances**

More research needs to be conducted to examine the nature of the conversations (before, during, and after the death) that transpire within families based on how the death occurred (e.g., long-term illness, sudden death through an accident, unexpected health crisis, drug-overdose, or suicide). It is believed that the circumstances of the death may impact the types, amount, and nature of the communication that occurs within the family at the EOL (Aiken, 2001), yet much more needs to be researched for conclusive answers.

**Interdisciplinary teams**

One last suggestion involves the use of interdisciplinary teams. The fastest way to move forward in our understanding about family EOL communication is to involve interdisciplinary teams (Wittenberg-Lyles et al., 2010, 2012). Until we begin sharing our knowledge, combining our insights and strengths, gaining access to hard to reach populations, as well as come together for gaining grants, we will be stuck in in our “own lanes” instead of conducting research on the national and international “highways” of scholarship. Palliative care scholarship is now coming from medical, sociological, psychological, communication, and family studies. We all have a lot of expertise and knowledge to share with one another for greater understanding about the end-of-life journey.

**Conclusion**

I expect to be conducting this research for at least another decade, and I welcome my fellow family communication researchers to join me in this area of scholarship. It is challenging, uplifting, fulfilling, and it is practically relevant to everyone. Participants have also repeatedly told me how therapeutic it is to share their end-of-life stories. Participants welcomed the opportunity to finally talk about death, dying, and their EOL communication. It is a relief for individuals to finally share their stories and the experience also reignites memories of their FCs. We do make a difference when we try to understand, improve, and teach family members how to have more effective communication at the EOL, as well as those that must communicate with them such as health professionals, clergy, and social workers. We also must translate this research into ways that everyone can understand and publish/present where they can read/hear the information to improve their FCs and their end-of-life experiences.

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