End-of-life communication, comfort, and engagement among middle-aged and older individuals with families in the United States

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Abstract

Objective: Drawing from the family communication patterns theory and family life cycle theory, this study examined predictors for middle-aged (40 to 59 years old) and older (60 to 79 years old) individuals' comfort level and actual patterns in communication about their EoL wishes with their families, specifically with their spouse and child(ren).

Background: Communicating about end-of-life (EoL) wishes is not easy for many, even though scholars recommend clarifying and communicating EoL wishes with family members well before one is near death (Nakajima, 2012). People are not always well educated or informed about their EoL care options and wishes (Silveira, et al., 2000), do not always know what an AD entails, how an AD works (Kapp, 1999), or how to communicate effectively about advance care planning (Bernerd et al., 2020). The discussion of one's EoL wishes is beneficial, not only for improving the overall care and well-being of a patient, but also for their family and caretakers (e.g., Keeley, 2017).

Method: A total of 189 married individuals between the ages of 40 and 80 with one or more child(ren) participated in a survey that examined the clarity of their EoL wishes, knowledge of their EoL issues, health status, and the two dimensions of their family communication environment.

Conclusion: The current study indicates that an open family communication climate, knowledge of EoL issues, clarity of EoL wishes, and age are strong predictors for individuals' engagement in EoL communication among their family.

Key words: EoL Communication, EoL Knowledge, Clarity of EoL wishes, Family Communication Patterns Theory, Family Life Cycle

1. Introduction

According to Rao and colleagues (2014), one in four adults in the United States prepares an advance-care directive (AD). A Pew Research Study has also reported that 26% have ADs, and that 15% to 22% of seriously ill elderly patients have their preferences on treatments included in their medical records (Pew Research Center 2006). Even when patients have prepared an AD, if its presence is not communicated with anyone and not included in the patients' medical records, it can be disregarded when patients are admitted to the hospital (Emanuel & Emanuel 1989; SUPPORT 1995).

In 1991, the US Congress passed the Patient Self-Determination Act (PSDA). This legislation requires healthcare facilities (e.g., hospitals, nursing homes, and hospice providers) to provide information on ADs to adult patients at the time of admission to hospital. More recently, the new Medicare billing codes updated in 2016 permitted physicians to bill for the time spent communicating about end-of-life (EoL) treatment preferences with patients. Even with these policies, EoL communication is not common among patients, physicians, and the family members who take care of them.

For the AD to work as intended, patients need to discuss their healthcare preferences and EoL wishes with their families. If patients themselves fail to inform their family about their EoL wishes, the family members of terminally ill patients often face difficult EoL medical treatment decisions without input from the patient. This can lead to family members experiencing significant stress, anxiety, and depression (Pocard et al. 2001; Nakajima 2012; Wiegard et al. 2008). This research fills a gap in the literature by exploring the associations among relevant family members, individual variables, and older individuals' comfort and engagement in communicating EoL issues using quantitative methods.

1.1 Positive outcomes resulting from EoL communication

Previous research has indicated that effective family communication about end-of-life (EoL) wishes is associated with a patient's better overall patient outcomes, such as higher self-esteem, feelings of more control, fewer negative feelings, fewer psychological and physical complaints (Mesters et al. 1997), and emotional acceptance of the end of life. (Lepore & Helgeson 1998). Open communication about EoL issues is associated with positive outcomes such as enhanced ability to cope with fatal diseases (Gotcher 1993), higher levels of family support (Mesters et al. 1997), higher levels of empathy and intimacy among family members (Porter et al. 2005), emotional acceptance (Generous & Keeley 2014; Lepore & Helgeson 1998), caregivers not feeling overburdened (Fried et al, 2005), and better care of the patient at the end of their life (Bernacki & Block 2014).

Keeley (2017) summarized many benefits of effective EoL communication. This communication means "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" (p. 1). Keeley (2017) added that with effective EoL communication, a patient is more likely to have EoL wishes fulfilled and is less likely to have unnecessary or unwanted medical intervention near the EoL. Bernack and Block (2014) underscored

the importance of family members communicating about EoL decisions. Such communication can help relieve a patient's stress and result in better overall care and well-being at the end of life.

Most studies have focused on intra-family EoL communication involving a terminally ill family member rather than focusing on intra-family EoL communication prior to a family member being diagnosed with a terminal illness. Nakajima (2012) specifically recommends that families determine EoL healthcare preferences while everyone is healthy, since one never knows when a family member will be in a situation in which an AD is needed. An AD makes it easier for family members and doctors to ensure that the terminally ill family member's medical treatment preferences are carried out.

Scholars have examined the final conversations between dying individuals and their family members. Common themes are relational talks, emotional affirmations, daily conversations, spirituality, expressions of love, and instrumental talks (Generous & Keeley 2014; Keeley 2007). The last category—instrumental talk regarding EoL issues—was the least examined theme. Instrumental talk about EoL issues refers to a person's EoL decisions, care preferences, and wishes after their death such as funerals. Keeley (2016) reported that instrumental talk (or talk about care preferrences and EoL decisions and wishes) might not be considered as memorable or meaningful for family members. This study focusses on the middle-aged and older people's comfort and engagement in instrumental EoL communication.

1.2 The challenges of EoL communication

Even though scholars agree that EoL communication is essential, it is uncomfortable for many to address EoL issues. Terminally ill patients, their caregivers, family members, and even healthcare professionals are sometimes hesitant to have a discussion about EoL. Numerous studies have discussed the diverse challenges of EoL communication among the various parties involved (Larson & Tobin 2000; Galushko et al. 2012; Thompson 2011; Russel 2018). Physicians and healthcare providers do not always communicate their EoL prognosis for various reasons, such as the fear of causing discomfort, their lack of training in communicating bad news, their lack of knowledge of AD laws, medical-legal concerns, and the anticipation of a disagreement with the patient or the family about what treatment or lack of treatment should be pursued (Morrison 1998; Russel 2018).

At times, family members fail to accept a terminal diagnosis or the impending death of a family member, and it them becomes difficult to have open and honest conversations about EoL issues (Caughlin et al 2011; Cherlin et al 2005). Moreover, it has been reported that some of the ADs may not be honored by physicians, who fear that they may be sued by family members who may disagree with the treatment or the lack of a treatment decisions made by them (Hines et al. 1997; Swanson & McCrary 1996).

Some families may avoid EoL conversations to protect their members from painful interactions (Goldsmith et al. 2011; Pecchoini & White 2015). In an interview study among stage III or IV lung cancer patients and caregivers, the majority (over 65%) of the families in a study reported experiencing communication problems characterized by silence and avoidance, as well as an undercurrent of optimism (Zhang & Siminoff 2003). Physicians or other healthcare practitioners are often blamed for failed or ineffective EoL

conversations (Amati & Hannawa 2015). Even a terminally ill patient may be at fault in terms of the lack of EoL conversations. In this regard, they may choose to discourage or avoid EoL conversations because they may feel embarrassed, feel a sense of stigma of welcoming death, and confusion along with a fear of death and dying (Greene & Adelman 1996; Jarrett & Payne 1995). It thus becomes crucial for patients or healthy aging individuals to be aware of their EoL healthcare preferences and wishes; accordingly, they should legally document them, and communicate them to family members, caregivers, and their designated healthcare agents.

1.3 EoL knowledge and clarity of wishes

People are not always well educated or informed about their EoL care options and wishes (Silveira et al. 2000) and do not always know what an AD entails or how an AD works (Kapp 1999). Even though they do know, they may not know how to communicate effectively about advance care planning (Bernerd et al. 2020). Professional care givers, such as physicians, have different degrees of knowledge of EoL procedures, which then impacts how effectively they can communicate about EoL planning with their patients (Russel 2018).

In the United States, Congress passed the Patient Self-Determination Act (PSDA) in 1991, which was an amendment to the Omnibus Budget Reconciliation Act of 1990. This legislation required healthcare institutions to provide information on ADs to adult patients at the time of admission to the hospital. ADs are "a varied set of witnessed instructions that provide information outlining the medical measures a person would or would not want to be used to prolong life when that individual is no longer capable of expressing his or her wishes" (Barkar1999 as cited in Kane et al. 2005, p. 51).

An AD can have two key elements: a living will and the appointment of a healthcare agent. A living will is a general statement that states, "Do not resuscitate"/"Do not attempt resuscitation" (DNR/DNAR), or it can include specific healthcare treatment information regarrding an individual's desire for pain relief, hydration, feeding, use of ventilators, or cardiopulmonary resuscitation (CPR). The other key element is the desgination of a healthcare proxy agent. A healthcare agent is an individual who will communicate the terminally ill person's wishes to healthcare providers when the patient is unable to speak for themselves.

In 2015, a report from the committee of the Institute of Medicine (IOC) claimed that the traditional approaches of people completing ADs and designating a healthcare power of attorney has failed, suggesting instead to consider advance care planning (ACP). The IOM (2015) claimed that ACP is essential to improving EoL care, and that we should view ACP as a recurring discussion about someone's goals, values, belief system, and ultimately, treatment preferences.

In order for patients to have meaningful conversations about their ACP, patients should be aware of their own EoL wishes regarding the EoL treatments and be able to communicate their values and preferences. Together with the complexity and uncertainty surrounding medical treatment, processes, and decision-making, ACP communication can be challenging or even ineffective (Bernard et al. 2020; Hines 2001). Bernard et al. (2020) examined the patient-reported barriers to engage with ACP and identified that a lack

of knowledge about EoL issues and ACP, being too young (or perceiving it as not the right time), and concerns about family dynamics as patient-reported barriers to engage with ACP.

1.4 Family life cycle approach

Everyone is born into a family, regardless of its type. As people age, they go through various cognitive and affective stages, from childhood to retirement as members of a family, and these stages are associated with certain responsibilities and tasks in family life (Carter & McGoldrick 1989; McColfrick & Carter 2003). According to the family life cycle approach, there are various stages of development in the family, including the childless family, family with young children, family with adolescent children, family with children leaving the home, and family in later life (Carter & McGoldrick 1989; McColfrick & Carter 2003). Although there are differences in how people progress through these stages, one's age is a key factor when considering one's life cycle, especially when it comes to examination of communication within the family. Individuals with a family - specifically a spouse and one or more children - may experience these various stages in later life involving children leaving their home.

Besides age, various other factors can characterize the family life cycle, such as a person's health status or the experience of a death in the family. The death of a family member can place a great amount of stress on the individual and the family unit, thus altering how family communication may occur (Berge et al. 2012; Carter & McGoldrick 1989; McGoldrick & Carter 2003). In the current study, these life cycle factors—age, health status, and experience of the death of an immediate family member—are expected to impact people's comfort and engagement in discussing EoL plans.

1.5 Family communication environment

The family communication environment is also predicted to impact comfort and engagement in EoL communication. Each family has a pattern of communication that members of the family enjoy. Research on family communication has indicated that each family has a unique communication environment that varies in the degree of conversation orientation and conformity orientation (Koerner & Fitzpatrick 2002a/b; 2006a/b; Ritchie & Fitzpatrick 1990). Conversation orientation refers to the degree to which a family encourages an open communication climate in which all members take part in a variety of topics. Conformity orientation refers to the degree to which a family emphasizes the consistency of attitudes and beliefs among its members. These two types of orientations are not mutually exclusive; each family can manifest different degrees of the two orientations (Koerner & Fitzpatrick 2002a/b; 2006a/b; Ritchie & Fitzpatrick 1990).

Previous studies have reported that the family communication patterns theory is associated with various types of family processes, such as conflict resolution (Koerner & Fitzpatrick 1997; 2006a/b; Shearman & Dumlao 2008), family rituals (Baxter & Clark 1996), and parent-adolescent understanding (Sillars, Koerner & Fitzpatrick 2005). A meta-analysis of 56 studies concluded that family communication patterns can affect a wide

range of cognitive activities (e.g., informative processing of mass media, attitudes toward advertising, TV violence, and music videos); relational behavioral outcomes (e.g., family conflicts, expressiveness, aggression, concealing secrets, and self-disclosure); and psychosocial outcomes (e.g., relational satisfaction, closeness, commitment, perceived stress, and general well-being) (Schrodt et al. 2008).

Bernard and colleagues (2020) identified family dynamics as one of the barriers in individuals' engagement in ACP. Given the evidence regarding the family communication patterns theory, it is reasonable to predict that the individuals' comfort and willingness to communicate about their EoL wishes may be associated with the conversation and conformity orientation of their families. Additionally, it is logical to assume that characterstics of the family cycle (e.g., age, health status, experience of death in family, clarity, and knowledge of EoL issues) may impact one's willingness and comfort level when communicating about EoL wishes. Drawing from earlier literature on EoL communication as well as the family communication environment and the life cycle approach, the following hypothesis is proposed:

Family communication environment dimensions (i.e., conversation orientation and conformity orientation) and other family cycle factors, including age, health status, experience of death in the family, and clarity and knowledge of EoL issues, will predict the level of comfort and engagement in communicating about one's EoL wishes with one's family members.

2. Method

2.1 Participants

A total of 189 individuals (male = 98, 51.85%; female = 91, 48.15%) participated in the online survey study. The individuals in the United States who were 40 years or older, married, and had at least one child living were recruited through a Qualtrics Panel (Qualtrics XM n.d.). The participants' ages ranged from their 40s ($n = 50$, 26.45%); their 50s ($n = 45$, 23.81%); their 60s ($n = 49$, 25.93%); and finally, their 70s ($n = 45$, 23.81%). The average age of the participants was 58.56 years old, with a standard deviation of 11.03 years. The majority of participants (85.71%) were European American (excluding Hispanics), followed by Native American (3.17%), African American (2.12%), Hispanic American (2.12%), Asian American (2.12%), Multiracial (3.70%), and others (1.06%).

When asked about their health conditions, 51.32% of the participants reported that they were extremely healthy, 17.46% reported that they were moderately healthy, 21.16% reported that they were somewhat healthy, 7.41% reported their condition(s) as manageable; and 2.65% reported that they were not healthy at all. Among those who said they were not healthy, health issues of varying severities were reported, including hypertension, diabetes, depression, melanoma, vertigo, heart problems, congestive heart failure, cystic fibrosis, liver disease, and arthritis. Most participants (74.08%) reported that they had experienced a death in their immediate family, while the rest (25.93%) reported that they had not. Participants who had reported a death in their immediate family were

asked to list their relation to the deceased family member and the number of such deaths. Subsequently, 24.34% of the participants reported one loss, 32.80% reported two losses, 10.58% reported three losses, 4.76% reported four losses, and 1.5% reported five to seven losses.

2.2 Procedure

Eligible participants for this study were individuals who were 40 and older who were married and had a family (i.e., had a spouse and at least one child). Eligible participants who resided in the United States were recruited through a Qualtrics Panel (Qualtrics XM n.d.). These selection criteria were intended to recruit individuals who were likely to be in two of the later family cycle stages: families in later life, and families with children leaving home. A purposive sampling method was used, so that a roughly equal number of participants from the different age groups (in their 40s, 50s, 60s, and 70s) were included in the study.

After informed consent was obtained, the survey included Ritchie and Fitzpatrick's (1990) Revised Family Communication Patterns (RFCP) scale, questions about the participants' comfort level, actual engagement in EoL communication with their family, knowledge about EoL issues, and clarity about their own EoL wishes. Participants were also asked to answer other demographic questions such as their sex, race/ethnicity, family composition, and any previous experience of a death in the immediate family.

2.3 Measures

Family communication patterns. The survey included the five-point Likert scale items (1 = strongly disagree; 5 = strongly agree) of Ritchie and Fitzpatrick's (1990) Revised Family Communication Pattern (RFCP) instrument for their families, particularly, the participants, their spouse, and their child(ren). Sample question items for conversation orientation included statements such as "In our family, we often talk about our feelings and emotions," and "My parents often ask my opinion when the family is talking about something." Sample question items for conformity orientation included "In our home my parents usually have the last word," and "When I am at home, I am expected to obey my parents' rules." The RFCP instruments yielded reliability for conversation orientation (α =.85) and conformity orientation (α =.83).

Knowledge and clarity. The participants were asked how informed they were about a living will, a healthcare proxy, and the option of hospice care using the following self-reporting four-point Likert scale responses: "not at all familiar," "somewhat familiar," "moderately familiar," and "fully knowledgeable." Three items on how informed each participant felt about EoL issues were added up to calculate that person's level of knowledge on EoL issues and each participant's self-reported knowledge regarding EoL issues (α =.81).

The survey included questions about the participants' level of clarity about their own EoL wishes. Specifically, each participant was asked about their level of clarity concerning their wishes about their living will, their healthcare agent or proxy, and their level of clarity

with regard to a hypothetical situation of incapacitation. The participants' level of clarity as to their EoL wishes about medical care/treatment, wishes after death, and healthcare proxy were measured with the following four-point Likert scale response options: "not at all," "a little," "somewhat," and "very much." The three items on clarity of EoL wishes were added up to calculate a person's level of clarity regarding EoL wishes. Three questions directly measured the respondents' clarity of their EoL wishes with a reliability score of α =.78.

Comfort in EoL communication. The participants reported their level of comfort in communicating their EoL wishes. Six-item five-point semantic differential scale questions were used to measure each participant's level of comfort in communicating EoL issues using bipolar adjectives such as "uncomfortable-comfortable," "unpleasant-pleasant," "challenging-easy to do," "waste of time-rewarding," "uplifting-depressing," and "relaxing-awkward." These followed two statements: "Communicating about your EoL wishes with your spouses is..." and "Communicating about EoL wishes with your children is..." Each participant then rated their level of comfort in communicating about EoL issues with their spouses and child(ren) (six items). The participants' perceived level of comfort in communicating about EoL issues with their spouse and child(ren) produced a reliability score of α =.93, which was calculated with combined scores of six semantic differential items for spouse (α =.90) and six items for child(ren) (α =.92).

EoL communication. Each participant's self-report of their engagement in communicating about their EoL wishes was measured by six questions asking how much they had communicated about their EoL wishes on three different topics with their spouse and child(ren). The four-point Likert scale included "not at all," "a little," "occasionally," and "frequently" was used as response options. The questions included whether and how much each participant had communicated about: 1) their wishes regarding the EoL medical care with their spouse and child(ren); 2) their wishes after death, such as type of funeral, location of tombstones, etc.; and 3) their wishes regarding the hypothetical situations in which the participant was incapacitated. The three items involving communication with spouse were combined with the three items regarding communication with their child(ren), resulting in a total of six items that yielded a combined score of each participant's communication about their EoL wishes. The participant's report of their own communication about their three different end-of-life wishes - medical care, wishes after death, and wishes in the hypothetical case of incapacitation - were reliable with their spouse (α =.87), with their children (α =.89), and with a combined score of α =.82.

3. Results

3.1 EoL issues and participant characteristics

The participants of this study were divided into two groups: middle-aged (40 to 59 years old) and older (60 to 79 years old) individuals. There was a significant difference in the level of knowledge on EoL issues between the middle-aged group (M = 6.69, SD = 1.84)

and the older group (M = 7.76, SD = 1.76); t(187) = -3.080, p < .01. The current data indicated that females tended to have more EoL knowledge than males, but there were no significant gender differences in the knowledge of EoL issues between females (M = 7.60, SD = 1.73) and males (M = 7.11, SD = 1.92); t(187) = -1.845, p = .067.

In addition, there was a significant difference in the clarity of wishes between the middle-aged group (M = 7.69, SD = 2.01) and the older group (M = 8.35, SD = 1.55); t(187) = -2.511, p < .05. The older participants (60 to 79 years old) in this study are more likely to have knowledge of EoL issues and more likely to have clearer EoL wishes. There was no significant gender difference for the reported clarity on EoL wishes (females, M = 7.98, SD = 1.99, males, M = 8.05, SD = 1.78; t(187) = .233, p =.816).

Additional analysis involved the examination of the participants' responses to the questions about having a living will and healthcare proxy. These questions indicated how much EoL knowledge they had and how clear the individuals were about their EoL wishes. The chi-squared test results showed significant differences between the two age groups in the frequency of people having a living will [χ^2 (1, 189) = 12.6, p < .0001]. A little over one third (35.45%) of the participants (n = 67) reported that they had a living will, while the majority (64.6%, n = 122) reported that they did not. In contrast, 11.64% of the middle-aged participants (n = 22) reported having a living will, while 38.62% of the older participants (n = 73) reported having a living will. Older participants (60 to 79 years old) were more likely than middle-aged participants (40 to 59 years old) to have prepared a living will, although less than half of the participants in the older group reported having a living will. There was no significant gender difference, although more male participants (38.8%, n =38) had a living will than female participants (31.9%, n = 29).

The participants were asked if they had designated healthcare proxies or agents. In response, 46.56% (n = 88) of all the participants said they had appointed a healthcare proxy or agent, while 53.43% (n = 101) said they had not. Only 15.34% of the middle-aged participants (n = 29) reported having a healthcare proxy or agent, while 31.21% of the older participants (n = 59) reported having a designated healthcare agent or proxy. The chi-squared test results showed significant differences in the frequency of people having a healthcare proxy person by the two age groups [χ^2 (1, 189) = 19.74, p < .001]. There was no significant gender difference, although in the current data, more male participants (48%, n =48) reported having a designated healthy proxy than female participants (45.1%, n = 41).

3.2 Multiple regression analysis

EoL communication comfort. A simple linear regression was calculated to predict the participants' level of comfort in communicating their EoL issues using the following two dimensions of family communication patterns: conversation orientation and conformity orientation. The following significant regression equation was found: F(2, 176) = 8.479, p < .001 with R^2 = .093. Conversation orientation was a significant predictor of the participants' level of comfort when communicating about their EoL issues (β =.293, t =3.959, p < .001), but not conformity orientation (β = -.562, t =-0.994, p = .322). Conversation orientation was a significant predictor of the participants' perceived level of comfort in communicating about their EoL issues with their family members. The

following significant regression equation was found: $F(2, 183) = 20.843$, $p < .001$ with an $R^2 = .187$.

A multiple linear regression analysis was carried out to examine whether participants' comfort in communicating their EoL issues with family members could be explained by these two dimensions of family communication patterns (i.e., communication orientation and conformity orientation), knowledge of EoL issues, clarity of EoL wishes, age, gender, health status, and experience of death in the immediate family. The results of the regression indicated that the model explained 23% of variance, with $R^2 = .23$, and that the model was significant [$F(8, 167) = 5.926$, $p < 0.001$]. Furthermore, age ($\beta = .100$, $t = 2.527$, $p < .05$); clarity of EoL wishes ($\beta = .848$, $t = 3.135$, $p < .01$); and conversation orientation ($\beta = 1.566$, $t = 2.280$, $p < .05$) were significant predictors.

EoL communication engagement. A regression analysis using family communication pattern dimensions on the participants' engagement in EoL communication was analyzed. It was found that the conversation orientation was a significant positive predictor ($\beta = .594$, $t = 6.110$, $p < .001$), while the conformity orientation was a significant negative predictor ($\beta = -.199$, $t = -2.176$, $p < .05$) for the participants' communication about EoL issues with their families. The participants are more likely to engage in EoL communication with their family members when conversation orientation is high, even though conformity orientation is low in the family.

Table 1: Correlations among the parameters included in multiple regression for analyses

	1	2	3	4	5	6	7	8	9	10
1. Comfortable in EoL Communication (Comfort EOLC)	—									
2. Engagement in EoL Communication (Engage EOLC)	.388**	—								
3. Knowledge of End of Life Issues (Know EOLI)	.316**	.524**	—							
4. Clarity of EoL Wishes (Clarity of EOLW)	.377**	.548**	.525**	—						
5. FCPS - Communication Orientation (CO)	.105	.280**	.322**	.208**	—					
6. FCPS - Conformity Orientation (MO)	-.134	-.012	-.074	-.079	.261**	—				
7. Age	.296**	.353**	.252**	.194**	-.182*	-.119	—			
8. Sex[a]	-.010	.108	.134	-.017	.107	-.123	-.099	—		
9. Exposure to Death in Immediate Family (DIF)	.258**	.283**	.243**	.159*	.017	.079	.377**	-.023	—	
10. Health Status (HS)	.022	-.056	.075	.033	.156*	-.083	-.022	.192**	.045	—
Variables	1	2	3	4	5	6	7	8	9	10
M	3.39	2.71	7.35	8.02	3.18	2.60	58.56	0.48	1.50	4.07
SD	0.95	1.05	1.84	1.82	0.72	0.69	11.03	0.50	1.27	1.12
Range	1-5	1-4	3-12	3-12	1-5	1-5	40-79	0-1	0-7	1-5
α	.93	.82	.81	.71	.85	.83				

Note: *p < .05, **p < .01, ***p < .001.
[a]Sex: 0 = male, 1 = female

In addition, a multiple linear regression analysis that included various life cycle factors was carried out to examine whether a middle-aged or older individual's actual communication about EoL issues with family members could be explained by the two dimensions of family communication patterns – conversation orientation and conformity orientation. The analysis involved communication orientation and conformity orientation, knowledge of EoL issues, clarity of EoL wishes, age, gender, health status, and experience of death in the immediate family. The results of the regression indicated that the model explained 47.6% of variance, with $R^2 = .476$, and that the model was significant [$F(8, 183)$ = 19.882, $p < .001$]; age ($\beta = .020$, $t = 3.651$, $p < .001$), knowledge of EoL issues ($\beta = 0.98$, $t = 2.390$, $p < .05$), clarity of EoL wishes ($\beta = .194$, $t = 5.097$, $p < 0.001$), health status ($\beta = -.127$, $t = -2.389$, $p < .05$), and conversation orientation ($\beta = .268$, $t = 2.873$, $p < .05$) were significant predictors. A correlation table, including all the parameters in the regression analyses, is provided in Table 1, and the multiple regression analysis results on EoL communication comfort and engagement, is provided in Table 2.

Table 2: Regression analyses for EoL communication comfort and engagement among middle aged and older individuals

	EoL Communication Comfort					
	Model 1 (FCPS)			Model 2 (FCPT + EoL Clarity/Knowledge + Demography Variables)		
Variables	B	SE B	Std. β	B	SE B	Std. β
FCPS - Conversation Orientation	2.523	.637	.293***	1.566	.678	.182*
FCPS - Conformity Orientation	-.562	.566	-.074	-.057	.554	-.007
Knowledge of EoL Issues				.186	.286	.058
Clarity of EoL Wishes				.848	.269	.259**
Age				.100	.039	.188*
					.871	-.017
Sex				-.200	.377	-.006
					.908	.017
Health Status				-.029		
Experience of Deaths in Immediate Family				.213		
R^2	.093			.238		
R^2 (Adjusted)	.082			.200		
F (F for change)	8.479***			6.124***		

Note: p *< .05, ** p < .001, *** p < .0001

Table 2: Regression analyses for EoL communication comfort and engagement among middle aged and older individuals (continued)

| | Engagement in EoL Communication | | | | | |
| | Model 1 (FCPS) | | | Model 2 (FCPT + EoL Clarity/Knowledge + Demography Variables) | | |
Variables	B	SE B	Std. β	B	SE B	Std. β
FCPS - Conversation Orientation	.594	.097	.409***	.268	.093	.185**
FCPS - Conformity Orientation	-.199	0.92	-.146	-.066	.079	-.49
Knowledge of EoL Issues				.098	.041	.172*
Clarity of EoL Wishes				.194	.038	.335***
Age				0.20	.006 .123	.213***
Sex				.210	.053 .129	0.99
Health Status				-.127		-.135*
Experience of Deaths in Immediate Family				.236		.104
R²	.187			.476		
R² (Adjusted)	.178			.452		
F (F for change)	20.843***			19.882***		

Note: p *< .05, **, p < .001, *** p < .0001

4. Discussion

This study examined predictors for middle-aged (40 to 59 years old) and older (60 to 79 years old) individuals' comfort level and actual engagement in communication about their EoL wishes with their families, specifically with their spouse and child(ren). Older participants are more likely to have knowledge of EoL issues and also to have clear EoL wishes than middle-aged participants.

Additional analysis indicated that older individuals are more likely to have prepared a living will and have a designated healthcare proxy or agent. These results indicates that as people age, they are are more informed and clearer about their EoL wishes. However, less than half of the participants among the older participants have a living will or a healthcare proxy or agent, which is consistent with earlier reports on the lack of preparedness among older individuals (Pew Research Center 2006). Thus, the current results show that more work is needed to facilitate middle-aged and older individuals to be informed about EoL issues and to prompt them to think more about what their wishes are. As some scholars have advocated for EoL communication among younger populations (Zadeh, Pao & Wiener 2015), more work is needed to target younger and healthier populations to make them more informed and to prepared them to communicate about their own EoL issues.

In terms of the family communication environment, conversation orientation was positively associated with the perceived level of comfort in engaging in EoL communication, while conformity orientation was negatively associated with the perceived

level of comfort in engaging in EoL communication. This indicates that having a high-power distance within families makes individuals less comfortable and less likely to communicate about their EoL issues. Having a high power distance in the family, as indicated by conformity orientation is associated with greater discomfort in communicating about EoL issues among participants. It is possible that emphasis on conformity contradicts conversations about EoL wishes, indicating a show of weakness as a parent, and a reversal in the power distance between the parents and the children. Instead, valuing open communication and the exchange of information between family members in general can facilitate EoL communication for individuals in the 40 to 70 age range. Engaging in EoL communication may not be easy to accomplish for anyone, but this study indicates that an open family communication climate, knowledge of EoL issues, clarity of EoL wishes, and age are strong predictors for individuals' engagement in EoL communication among their families.

In a meta-analysis of the studies that used family communication patterns theories, Schrodt et al. (2008) showed that conversation orientation is 1) "a stronger predictor for psychosocial outcomes than conformity orientation," and 2) a strong predictor for "psychosocial outcomes than information processing and behavioral outcomes" (p. 17). Consistent with the claim made by Schrodt et al. (2008), conversation orientation is a strong predictor in this study. The middle-aged and older individuals' perceived sense of comfort in communicating about EoL issues (i.e., psychosocial outcomes) and actual engagement in EoL communication with family members (i.e., behavioral outcomes) were explained by the conversation orientation.

Both knowledge of EoL issues and clarity of EoL wishes were positively associated with the actual communication of EoL issues with family members, i.e., spouse(s) and child(ren). If middle-aged and older individuals are informed about EoL issues and are clearer about EoL issues, the likelihood of intra-family communication about EoL issues increases. In predicting comfort in communicating about EoL issues, age, conversation orientation, and clarity of EoL wishes were all significant predictors. EoL issues involve a lot of uncertainty, and thus tools to assist individuals in clarifying their EoL wishes can be valuable. In order to clarify one's EoL wishes, it may be useful to utilize tools such as Robert Wood Johnson's "Five Wishes" documents (Aging with Dignity.org, n.d.), Judy MacDonald Johnston's "Five Step Plan" for a good EoL (2013), and Akira Nakajima's (2012) "Write-in-Ending Note" or "Medical Treatment Intension Confirmation Sheet." Other accessible tools are the "Go Wish" card game (The Coda Alliance, n.d.) and the "Death over Dinner" workbook (https://deathoverdinner.org/), which more casually prompt conversations about death. These tools should not only prompt users to clarify EoL wishes, but also help them engage in communication about specific EoL wishes with family members.

In predicting actual communication of EoL wishes with families, age, knowledge of EoL issues, clarity of EoL wishes, health status, and conversation orientation were significant predictors. This indicates that as individuals get older, they know more about EoL issues and are clearer about their EoL wishes. This factor, coupled with an open conversation climate in a family, is associated with the likelihood of an individual's communicating about EoL issues with the family. The life cycle theory holds that families go through various stages, and in each stage, they face different challenges (McGoldrick &

Carter 2003). There were indeed significant differences between middle-aged and older individuals in terms of how informed they are and how clear they are about their EoL wishes. Age, or being older even within our current sample of 40 or older, was a significant predictor of how much individuals engaged in EoL conversations with their families. The current study examined two dimensions, yet there must be a more complex dynamic of the family communication environment that might affect families at different stages—specifically involving aging family members. It is possible that aging family members may face different issues, especially in relation to conformity orientation. Interestingly, health status was a negative predictor, while all other predictors were positive. When an individual starts to have health issues, it is possible that they are less inclined to talk about their EoL issues. This is additional evidence to support the idea that individuals should not wait until they are unhealthy to start thinking about EoL issues. Although people tend to wait until they have an immediate need to talk about EoL wishes with their families, they should be communicating about EoL issues before a health scare occurs.

4.1 Limitations and future research

The current study only included survey responses from individuals who were 40 years and older with a spouse and with at least one child. We may have missed some unique communication environments that we may observe by increasing the diversities of family types, such as same sex couples and unmarried cohabiting couples. With the small sample size of the current study, our ability to generalize our results is limited. While this research employed a survey method, future research may consider performing in-depth interviews in order to further understand what may lead to earlier conversations about EoL planning, awareness of particular communication tactics to deal with avoidance or reluctance, and the creation of incentives for people to talk about their EoL wishes.

As many doctors and scholars advocate, it is best if we do not wait until we get sick or incapacitated to work on our ADs (Hebb 2018; Nakajima 2012). Hebb (2018) states that death is inevitable and the discussion of EoL issues can be considered as one of life's most important conversations. Nakajima (2012) not only requests that members of society work on their ADs or ACPs when they are young and healthy, but he also challenges people to designate one day per year to reviewing any EoL wishes and documents. Further research on ways to foster an open communication environment on EoL wishes within the family, by using such tools as the "Five Wishes" or the "Go Wish" card game (Coda Alliance, n.d.), might function to facilitate earlier EoL conversations among families.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author, upon request.

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Information in German

Deutscher Titel

Kommunikation, Komfort und Beteiligung am Lebensende in Bezug auf Personen mittleren Alters und ältere Menschen mit Familien in den Vereinigten Staaten

Zusammenfassung

Fragestellung: Ausgehend von der Theorie der familiären Kommunikationsmuster und der Theorie des Familienlebenszyklus untersucht diese Studie Prädiktoren dafür, wie wohl sich Personen mittleren Alters (40 bis 59) sowie ältere Personen (60 bis 79 Jahre) fühlen, wenn sie ihre EoL-Wünsche mit ihren Angehörigen, insbesondere mit ihrem Ehepartner und ihren Kindern, besprechen, und wie intensiv sie dies tatsächlich tun.

Hintergrund: Die Kommunikation über die Wünsche für das Lebensende ist für viele nicht einfach, obwohl empfohlen wird, diese mit Familienmitgliedern schon vor dem Tod zu besprechen (Nakajima, 2012). Viele Menschen sind nicht gut informiert über ihre EoL-Pflegeoptionen und -wünsche (Silveira, et al., 2000), sie wissen nicht immer, was eine Patienten- bzw. Vorsorgeverfügung beinhaltet und wie sie funktioniert (Kapp, 1999) oder wie man effektiv über die Vorausplanung der Pflege spricht (Bernerd et al., 2020). Die Besprechung der eigenen EoL-Wünsche ist nicht nur für die Gesamtversorgung und das Wohlbefinden der Patienten von Vorteil, sondern auch für deren Angehörige und Betreuer (z. B. Keeley, 2017).

Methode: Insgesamt 189 verheiratete Personen zwischen 40 und 80 Jahren mit einem oder mehreren Kind(ern) nahmen an einer Umfrage teil, in der die Klarheit ihrer EoL-Wünsche, das Wissen über ihre EoL-Themen, der Gesundheitszustand und die beiden Dimensionen ihrer familiären Kommunikationsumgebung erhoben wurden.

Schlussfolgerung: Die Studie zeigt, dass ein offenes Kommunikationsklima in der Familie, das Wissen über EoL-Themen, die Klarheit der EoL-Wünsche und das Alter einflussreiche Prädiktoren dafür sind, wie intensiv innerhalb der Familie über EoL-Themen gesprochen wird.

Schlagwörter: EoL-Kommunikation, EoL-Wissen, Klarheit der EoL-Wünsche, Theorie der familiären Kommunikationsmuster, Theorie des Familienlebenszyklus

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