MAKING SENSE OF FAMILY COMMUNICATION ABOUT AND AT THE END OF LIFE: FAMILY COMMUNICATION AROUND END-OF-LIFE PLANNING AND DECISION MAKING

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ABSTRACT

Families faced with end-of-life (EOL) decisions on behalf of a family member are charged with honoring a care recipient's wishes, which may or may not be clear to them. The process of decision making is challenging for surrogate decision makers and their families, and it often results in suboptimal decisions that fail to meet the best interests of the patients, cause stress for family members, and burden the legal and medical systems. Effective family communication, something that legal representatives, medical professionals, and social workers are often in positions to influence, can enhance the quality of EOL care planning and decisions. To this end, we first establish the significance of the family, an interdependent system, for decisions oriented around individual autonomy and independence. We then explore theory and research in family communication that can offer insight into family interaction about EOL preferences and decisions. Communication theory and research provide insight into how individuals and family members communicatively navigate multiple goals in conversations about EOL preferences and manage privacy and disclosure, deal with uncertainty, and negotiate contradictions in the planning and decision-making processes. We advance recommendations for practice associated with each area of research and theory.

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I. INTRODUCTION

In making end-of-life (EOL) decisions, ethical standards in legal and medical communities emphasize the care recipient's autonomy and independence. In the case that a care recipient is unable to voice his or her EOL care preferences, surrogates are asked to express "substituted judgment" and, when preferences are unknown, act in the "best interests" of the individual.[1] Although the formal emphasis in legal and medical communities lies on individual autonomy, EOL planning and decision making occur within interdependent familial relationships. Individuals making decisions about EOL care preferences commonly consider the implications for their family members when planning, and families become a part of the decision-making process when decisions must be made.[2] For example, individuals identify concerns about being a burden to family members as a factor in their individual preferences[3] and consider the feelings and experiences of their family members in advance care planning.[4] When decisions must be made, surrogate decision makers typically are family members, most often spouses, children, or grandchildren.[5] Additionally, surrogate decision makers often are not the only family members involved in the decision-making process. Multiple family members may discuss the decision, and decision makers may consider their

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1. Alexis M. Torke et al., *A Conceptual Model of the Role of Communication in Surrogate Decision Making for Hospitalized Adults*, PATIENT EDUC. & COUNS., Apr. 2012, at 54, 58; Gary S. Winzelberg et al., *Beyond Autonomy: Diversifying End-of-Life Decision-Making Approaches to Serve Patients and Families*, 53 J. AM. GERIATRICS SOC'Y 1046, 1047 (2005).

2. Anita Ho, *Relational Autonomy or Undue Pressure? Family's Role in Medical Decision Making*, 22 SCANDINAVIAN J. CARING SCI. 128, 130 (2008). In work on ethics and the role of the family in EOL decision making, the concepts of relational autonomy (recognizing patients as social beings influenced by others) and relational identity (understanding the self in relationship to others) capture the intersection of relationships with autonomous action and recognize the ways in which relational concerns may be an important component of an individual's personal agency. Jonathan M. Breslin, *Autonomy and the Role of the Family in Making Decisions at the End of Life*, 16 J. CLINICAL ETHICS 11, 15–18 (2005).

3. Karen Steinhauser et al., *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, 284 JAMA 2476, 2479 (2000); Amanda J. Young & Keri L. Rodriguez, *The Role of Narrative in Discussing End-of-Life Care: Eliciting Values and Goals from Text, Context, and Subtext*, 19 HEALTH COMM. 49, 55 (2006) (explaining that individuals consider the pros and cons of treatment decisions "in terms of not only their impact on the individual but also on family and society").

4. Jane Seymour et al., *Planning for the End of Life: The Views of Older People About Advance Care Statements*, 59 SOC. SCI. & MED. 57, 62 (2004).

5. Deborah Carr & Dmitri Khodyakov, *Health Care Proxies: Whom Do Young Adults Choose and Why?*, 48 J. HEALTH & SOC. BEHAV. 180, 182 (2007); Maria J. Silveira et al., *Advance Directives and Outcomes of Surrogate Decision Making Before Death*, 362 NEW ENG. J. MED. 1211, 1216 tbl. 2 (2010).

input an important part of the process.[6] To honor and facilitate individual autonomy, then, practitioners must understand and acknowledge family interdependence.

Two important assumptions about families and decision making offer a framework for understanding family communication involved with EOL care planning and decisions. First, *families are an interdependent system*.[7] The family system is comprised of interdependent individuals, and as a whole it develops patterns of interaction that can influence individual outcomes. In an interdependent system, the behaviors of or changes in one part of the system affect other parts of the system. Recognizing the family as an interdependent system necessitates attention to more than the surrogate decision maker in order to understand what effective planning and decision-making conversations might look like in practice. Overall family functioning (i.e., the degree to which the family system as a whole effectively engages in collective decision making and coordinated activity), for example, predicts the likelihood of individuals discussing EOL preferences with other family members.[8] Additionally, the family is an *open system* that interacts with its environment. The health care system, legal system, and larger cultural context all shape the experiences of the family when managing EOL issues. Surrogate decision makers and other family members, for example, must interact with and navigate complex hospital systems in order to obtain and share information necessary for sound health care decisions.[9]

Second, *decision making is a communicative process*. Very rarely do individuals make important decisions without consulting relevant others about the decision. Richard Street posits that medical decision making is fundamentally a communication process, given the nature of the information sharing and uncertainty management that takes place during the process.[10] Research demonstrates that EOL planning and decision making are inherently

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6. Elizabeth K. Vig et al., *Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making*, 54 J. AM. GERIATRICS SOC'Y 1688, 1691–92 (2006); Jennifer E. Ohs et al., *Holding On and Letting Go: Making Sense of End-of-Life Care Decisions in Families*, 80 S. COMM. J. 353, 354 (2015) [hereinafter *Holding On and Letting Go*].

7. Janet B. Bavelas & Lynn Segal, *Family Systems Theory: Background and Implications*, 32 J. COMM. 99, 100, 103 (1982); Gail Whitchurch & Larry L. Constantine, *Systems Theory*, *in* SOURCEBOOK OF FAMILY THEORIES AND METHODS 325, 332 (P.G. Boss et al. eds., 1993).

8. Kathrin Boerner et al., *Family Relationships and Advance Care Planning: Do Supportive and Critical Relations Encourage or Hinder Planning?*, 68 J. GERONTOLOGY SERIES B: PSYCHOL. SCI. & SOC. SCI. 246, 250–51 (2013).

9. *See* Jennifer J. Bute et al., *Surrogate Decision Makers and Proxy Ownership: Challenges of Privacy Management in Health Care Decision Making*, 30 HEALTH COMM. 799, 800 (2015).

10. Richard L. Street, *Aiding Medical Decision Making: A Communication Perspective*, 27 MED. DECISION MAKING 550, 551 (2007).

communicative as well.[11] Particularly in the case of medical EOL planning and decisions, people draw upon communication and experiences with relevant others to gather information, manage areas of uncertainty, and consult regarding the decision. The family is a central part of these communicative processes.[12]

Thus, despite the legal focus on individual autonomy, family members play an important role in advance care planning and EOL decision-making processes, and family communication about EOL preferences and decisions has significant consequences for individuals at the end of life and for their families. This essay explores the ways in which communication theory and research can help practitioners better understand important family communication processes relevant to EOL planning and decision making, including, but not limited to, interaction with surrogate decision makers, who are most often family members. Communication theory and research provides insight into how individuals and family members communicatively navigate multiple goals in conversations about EOL preferences and manage privacy and disclosure, cope with uncertainty, and negotiate contradictions in the planning and decision-making processes. Drawing on this knowledge, practitioners can foster more effective family interaction around EOL decisions and account for the role of family in the process of decision making.

II. FAMILIES AND EOL PLANNING AND DECISION MAKING

Advance care planning encompasses both formal documentation (e.g., living will, durable power of attorney for health care) and informal conversations with family members and medical care providers.[13] Despite the value of having an advance care directive (ACD) in place, many Americans have not created a formal advance care plan.[14] Additionally, individuals do not

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11. Allison M. Scott, *Communication About End-of-Life Health Decisions*, *in* COMMUNICATION YEARBOOK 38 243, 265 (Elisia L. Cohen ed., 2014).

12. Individuals express a preference for including family members in EOL planning conversations and are much more likely to have discussed their EOL preferences with family members than with physicians. Stephen C. Hines et al., *Dialysis Patients' Preference for Family-Based Advance Care Planning*, 130 ANNALS INTERNAL MED. 825, 826 (1999); Boaz Kahana et al., *The Personal and Social Context of Planning for End-of-Life Care*, 52 J. AM. GERIATRICS SOC'Y 1163, 1167 (2004).

13. Susan Bauer-Wu et al., *Communication and Planning at the End-of-Life: A Survey of Women with Advanced Stage Breast Cancer*, 2 J. COMM. HEALTHCARE 371, 373 (2009).

14. A large panel survey of 7,946 community-dwelling adults in the United States found that only 26.3% of "respondents . . . had an advance directive" in place. Jaya K. Rao et al., *Completion of Advance Directives Among U.S. Consumers*, 46 AM. J. PREVENTIVE MED. 65, 68 (2014). Advance directive completion varied by income level and race and ethnicity (with advance directives more common among white, higher income individuals). *Id.* Work focused on racial and ethnic differences in advance care planning suggests that beliefs about God and his control over death partially explain the Black-White gap and beliefs that illness negatively affects

always talk about their EOL preferences with their designated surrogates or the other members of their personal social network, who likely will be a part of the decision-making experience.[15] This is sometimes true even if individuals do have an ACD in place.[16] There are a variety of reasons for this, including discomfort in talking about death, uncertainty about what their preferences actually are, and a desire to protect loved ones.[17] The quality of family relationships also affects the likelihood of having informal discussions with a family member and the appointment of a family member as a legal surrogate.[18] General experiences of emotional support from a spouse, for example, increase the odds that married parents will engage in advance care planning.[19] In contrast, poor relationships offer one reason that explains why individuals do not engage in discussions with family and friends about EOL preferences.[20]

Family communication should be encouraged as an important component of EOL planning.[21] Individuals sometimes perceive conversations to be unnecessary, trusting that family members will know what they would want without having to talk about it.[22] However, even when ACDs are in place, surrogates often report uncertainty or lack of knowledge when in the position of making a decision on behalf of another.[23] Informal discussions with surrogates about EOL preferences in combination with ACDs may give surrogates greater clarity and specificity in their understanding of older adults' preferences.[24] It is not uncommon for elderly Americans at the end of life to

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family partially accounts for the Hispanic-White gap. Deborah Carr, *Racial Differences in End-of-life Planning: Why Don't Blacks and Latinos Prepare for the Inevitable?*, 63 OMEGA 1, 15 (2011).

15. Faith P. Hopp, *Preferences for Surrogate Decision Makers, Informal Communication, and Advance Directives Among Community-Dwelling Elders: Results from a National Study*, 40 GERONTOLOGIST 449, 453 (2000).

16. *Id.*

17. Adam D. Schickedanz et al., *A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers*, 57 J. AM. GERIATRIC SOC'Y 31, 35–36 (2009).

18. Boerner et al., *supra* note 8, at 253; Deborah Carr et al., *End-of-Life Planning in a Family Context: Does Relationship Quality Affect Whether (and with Whom) Older Adults Plan?*, 68 J. GERONTOLOGY SERIES B: PSYCHOL. SCI. & SOC. SCI. 586, 591 (2013).

19. *See* Boerner et al., *supra* note 8, at 253.

20. *See* Carr et al., *supra* note 18.

21. Stephen C. Hines, *Coping with Uncertainties in Advance Care Planning*, 51 J. COMM. 498, 508 (2001); *see also* Sharla Wells-Di Gregorio, *Family End-of-Life Decision Making*, *in* DECISION MAKING NEAR THE END OF LIFE 252 (James L. Werth, Jr. & Dean Blevins eds., 2008).

22. Rao et al., *supra* note 14.

23. Ruth P. Lopez & A. J. Guarino, *Uncertainty and Decision Making for Residents with Dementia*, 20 CLINICAL NURSING RES. 228, 230 (2011).

24. Betty S. Black et al., *Surrogate Decision Makers' Understanding of Dementia Patients' Prior Wishes for End-of-Life Care*, 21 J. AGING & HEALTH 627, 646 (2009); *see also* Vig et al., *supra* note 6, at 1691 ("Advance care planning discussions, with a focus on eliciting care

lose decision-making capacity and require a surrogate to make decisions for them.[25] When a decision must be made by a surrogate in such situations, understanding a loved one's EOL preferences for care can decrease the likelihood of inaccurate care decisions by surrogates.

In addition to increasing the likelihood that an individual's EOL wishes will be followed, understanding a loved one's preferences also may mitigate the emotional burden created by an EOL decision. Decisions at the end of life are emotionally difficult, and surrogates report that making treatment decisions can have a long-lasting, negative emotional impact for them.[26] Feelings of guilt, resentment, and/or doubt can linger long after a decision has been made. Family decision making is more difficult in contexts where wishes are unclear,[27] and having an ACD in place can alleviate the negative emotional consequences of surrogate decision making.[28]

Although one family member may be the formally-appointed decision maker, multiple family members often participate in decision-making conversations, taking on various informal roles within the family system.[29] Some families may expect consensus in the decision, and individuals at the end of life and/or their family members may want multiple family members included in the decision-making process.[30] This can lead to challenges in effectively communicating and coordinating decision making both among family members and between family members and medical professionals.

The participation of multiple family members in decision making also creates the potential for family disagreement around EOL decisions. Family disagreement about EOL decisions relates to reduced elder-proxy accuracy regarding EOL preferences[31] and predicts a greater likelihood of requesting

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preferences in specific illness scenarios, have been proposed as the best way to prepare for substituted judgment and to protect patient autonomy.").

25. Silveira et al., *supra* note 5, at 1216.

26. Julia W. Buckey & Olga Molina, *Honoring Patient Care Preferences: Surrogates Speak*, 65 OMEGA 257, 267 (2012); David Wendler & Annette Rid, *Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others*, 154 ANNALS INTERNAL MED. 336, 344 (2011).

27. Jill R. Quinn et al., *Family Members' Informal Roles in End-of-Life Decision Making in Adult Intensive Care Units*, 21 AM. J. CRITICAL CARE 43, 47–48 (2012).

28. Virginia P. Tilden et al., *Family Decision-Making to Withdraw Life-Sustaining Treatments from Hospitalized Patients*, 50 NURSING RES. 105, 113 (2001); *see also* Wendler & Rid, *supra* note 26, at 343.

29. Quinn et al., *supra* note 27, at 44.

30. Marya J. Cohen et al., *Exploring Attitudes Toward Advance Care Directives in Two Diverse Settings*, 13 J. PALLIATIVE MED. 1427, 1431 (2010).

31. Susan M. Parks et al., *Family Factors in End-of-Life Decision-Making: Family Conflict and Proxy Relationship*, 14 J. PALLIATIVE MED. 179, 179 (2011).

"aggressive treatment for patients."[32] Despite legal enforceability, simply having an ACD in place does not mitigate family conflict over EOL decisions.[33] Informal conversations with family members may impact the agreement among family members about what to do in situations requiring implementation of a person's EOL care wishes. Indeed, conversations with multiple family members about EOL preferences (as opposed to just talking with the surrogate decision maker) could help to alleviate conflict when decisions must be made at the end of life.

The importance of family for both planning and decision making offers a practical imperative to better understand family communication processes in these contexts. Communication theory and research offer direction for how one may encourage helpful conversations within the family and improve interaction between the family and health care providers regarding EOL care.

III. ATTENDING TO MULTIPLE GOALS IN EOL PLANNING CONVERSATIONS

Encouraging conversations about EOL preferences before a decision must be made has a number of positive outcomes. Informal conversations among family and friends may offer an important step in the process of developing EOL preferences and a prelude to conversations with physicians and/or the creation of formal documents.[34] Conversations with loved ones become a source of information that individuals draw on when asked to provide substitute judgment[35] and contribute to surrogates' confidence that they are honoring the wishes of their loved ones.[36] Research suggests that it is not enough, however, to simply ask whether or not a conversation has taken place or how frequently EOL preferences have been discussed. The number of conversations individuals have had with their surrogates, for example, does not predict surrogates' understanding of specific preferences or agreement on

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32. Lorraine Winter & Susan M. Parks, *Family Discord and Proxy Decision Makers' End-of-Life Treatment Decisions*, 11 J. PALLIATIVE MED. 1109, 1109 (2008).

33. *See* Betty J. Kramer et al., *Predictors of Family Conflict at the End of Life: The Experience of Spouses and Adult Children of Persons with Lung Cancer*, 50 GERONTOLOGIST 215, 223 (2009).

34. *See* Peter Clarke et al., *Information Seeking and Compliance in Planning for Critical Care: Community-Based Health Outreach to Seniors About Advance Directives*, 18 HEALTH COMM. 1, 3 (2005) ("In situations in which patients have lost their ability to communicate, a properly executed advance directive can assist family and medical providers in striking a balance between aggressive procedures and protection of a quality of life that honors the patient's preferences."); Rebecca L. Sudore et al., *Engagement in Multiple Steps of the Advance Care Planning Process: A Descriptive Study of Diverse Older Adults*, 56 J. AM. GERIATRIC SOC'Y 1006, 1011 (2008) (noting that "facilitating family discussions may be one of the most important targets of [advance care plan] interventions").

35. *See* Vig et al., *supra* note 6, at 1691.

36. Buckey & Molina, *supra* note 26, at 268.

treatment choices.[37] To address this issue, we must attend to the *content* of EOL planning conversations in the family and identify features that characterize high-quality conversations. Allison Scott proposes applying multiple goals theories to illuminate important dimensions of family discourse about EOL preferences.[38]

Multiple goals theories offer a theoretical frame for understanding the goals that people have in EOL conversations and how they discursively accomplish those goals as they talk about EOL preferences with spouses, parents, adult children, and other members of their personal network. These perspectives assume that human interaction is purposeful and that individuals' goals affect their message production choices.[39] Individuals in any conversation may have more than one goal at work, shaping interactional choices.[40] These can include task goals (related to the primary purpose of the conversation), identity goals (related to impression formation and management), and relational goals (related to creating or sustaining desired relational understandings).[41] At times, multiple goals might be in conflict with one another, and more sophisticated messages adroitly meet the needs of multiple goals simultaneously.[42]

Multiple goals are likely present in complex situations like EOL planning conversations.[43] The task goals of EOL conversations (e.g., identifying and explaining EOL preferences) are challenging in and of themselves, as individuals may not completely understand their preferences and may find it uncomfortable to talk about EOL topics. To add to the difficulty, however, planners and their family members also must attend to identity and relational goals encountered in the conversation. Identity goals can include efforts to honor individual autonomy (e.g., respecting individual choices in EOL decisions), efforts to demonstrate approval or acceptance of the other person (e.g., avoiding criticism of others' choices), and/or addressing one's own

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37. Stephen C. Hines et al., *Improving Advance Care Planning by Accommodating Family Preferences*, 4 J. PALLIATIVE MED. 481, 485–86 (2001).

38. Scott, *supra* note 11, at 254–55.

39. John P. Caughlin, *Goals Theory of Personal Relationships: Conceptual Integration and Program Overview*, 27 J. SOC. & PERS. RELATIONSHIPS 824, 825–26 (2010); Steven R. Wilson, *Communication Theory and the Concept of "Goal," in* EXPLAINING COMMUNICATION: CONTEMPORARY THEORIES AND EXEMPLARS *passim* (B.B. Whaley & W. Samter eds., 2007).

40. Caughlin, *supra* note 39, at 826.

41. *Id.* at 827.

42. *Id.* at 828, 831.

43. Allison M. Scott & John P. Caughlin, *Enacted Goal Attention in Family Conversations About End-of-Life Health Decisions*, 81 COMM. MONOGRAPHS 261, 279–80 (2014) [hereinafter *Enacted Goal Attention*]; Allison M. Scott & John P. Caughlin, *Managing Multiple Goals in Family Discourse About End-of-Life Health Decisions*, 34 RES. ON AGING 670, 674 (2012) [hereinafter *Managing Multiple Goals*].

identity concerns (e.g., not appearing inappropriate or intrusive).[44] Relational goals encompass efforts to affirm the importance of the relationship (e.g., demonstrating commitment to the other and/or loving care)[45] and negotiate relational roles (e.g., managing role reversals, such as an adult child taking responsibility for a parent in older age). The challenge of managing multiple goals is exacerbated when multiple goals are in conflict with one another, which is likely given the complexity of EOL decision conversations.[46] A family member, for example, may struggle with how to talk about death and other pragmatic issues related to EOL preferences (task goal) while ensuring that a loved one knows how much he or she values and cares for the relationship (relational goal). The desire to honor an individual's independence and autonomy in a conversation about his or her EOL preferences (identity goal) may be experienced as a conflict with the goal of ensuring good decisions (task goal).

In a study analyzing the discourse of parents and adult children discussing EOL preferences, Allison Scott and John Caughlin identified features of talk that family members used to attend to task, relational, and identity goals.[47] Conversations that included descriptions of a variety of factors that might affect EOL preferences and elaborated on decision-making criteria demonstrated more sophisticated, task-focused messages.[48] In contrast, in lower quality conversations, individuals avoided the topic or failed to elaborate on or explain their perspectives, keeping details to a minimum.[49] Both the desire for approval or acceptance and the desire for autonomy were identity goals present in the conversations.[50] In some conversations, behaviors like criticism or rejection of the other person's preferences undermined these identity goals.[51] In contrast, in other conversations individuals explicitly expressed approval or recognized the threats to autonomy and validated the importance of the individuals' perspectives.[52] Discourse that attended to relational goals in more sophisticated ways confirmed the importance and value of the relationship.[53] Scott and Caughlin found that better quality conversations attended to multiple goals in the interaction.[54] They also

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44. *See Enacted Goal Attention*, *supra* note 43, at 264; *see also Managing Multiple Goals*, *supra* note 43, at 680.

45. *Enacted Goal Attention*, *supra* note 43, at 264.

46. *See* Caughlin, *supra* note 39, at 828.

47. *See generally Managing Multiple Goals*, *supra* note 43.

48. *See id.* at 678.

49. *See id.* at 679.

50. *Id.* at 680.

51. *Id.* at 681.

52. *Managing Multiple Goals*, *supra* note 43, at 680.

53. *Id.* at 682.

54. *Id.* at 686.

observed that the ways in which individuals addressed relational or identity goals sometimes had consequences for the task goal as well, and these effects could be positive (e.g., respecting autonomy created opportunities for sharing preferences) as well as negative (e.g., focusing on agreement and relational closeness to the neglect of individual elaboration and clarity of individual preferences).[55]

Additional research by Scott and Caughlin examined conversations between adult children and parents about EOL decisions and demonstrated that attention to both relational and identity goals contributed to individuals' satisfaction with the conversations.[56] Furthermore, attention to relational goals predicted hopefulness at the end of the conversation, and attention to all three types of goals predicted more positive relational outcomes.[57]

Applying a multiple goals perspective points to several recommendations for helping individuals think about how to approach conversations with loved ones about their own or others' EOL preferences. These can be useful for health care practitioners, social workers, and community outreach coordinators who are working to encourage effective advance care planning with patients or in the community.

A.   Recognize the Multiple Goals Individuals Will Face

In terms of the task goal, when planners provide an understanding of the values underlying their positions and acknowledge factors that may change their preferences, surrogate decision makers and family members are more likely to have a mature understanding of the planner's desires.[58] Additionally, when encouraging and helping individuals to approach conversations about their own or others' EOL preferences, it is important to recognize goals that go beyond the task of clearly communicating or accurately understanding one's preferences. Relational goals, like emphasizing the value of the relationship,[59] reflect challenges in how to talk about decisions that may require letting go of a loved one. Specific communicative behaviors, like statements of relationship affirmation or expressions of love and recognition of expected sorrow, can help to honor the relationship while talking about the end of life.

Attending to identity goals, like recognizing and legitimating individual autonomy, protecting dignity, and affirming the individual,[60] fits with the larger ethos of individual choice in EOL planning and creates a supportive context for talking about difficult topics. Facework strategies offer one

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55. *Id.* at 683–85.

56. *See generally Enacted Goal Attention*, *supra* note 43.

57. *Id.* at 274, 278.

58. *See id.* at 263.

59. *See id.* at 264.

60. *Id.*

example of specific communicative behaviors that attend to identity needs while pursuing a sensitive topic of conversation.[61] For example, an adult child initiating a conversation about a parent's EOL care preferences constitutes a threat to the parent's face in that the parent is inherently framed as vulnerable.[62] Facework strategies, such as the use of questions, hedges and qualifiers, statements that recognize the sensitivity of the topic and the importance of independence, emphasis on collaboration (e.g., use of "we" and "us"), and expressions of concern for the individual and a desire for him or her to have good experiences, can minimize threats to face and enhance the productivity of conversations.[63] Multiple different conversational moves might be included across a conversation to respect identity needs. Individuals, however, should be encouraged to consider communication strategies to mitigate identity threats that fit within their family's normative expectations for good communication behaviors.[64] Problematic family relationships may create different types of challenges for goal-directed communication in advance care planning. Individuals, for example, are more likely to avoid discussing EOL preferences when their children are frequently critical in interactions.[65] Helping older adults plan how to protect their own identity goals while having necessary interactions may mitigate the barriers created by critical children.

B.   Consider How to Navigate Goal Conflict

In addition to recognizing the diversity of goals that individuals will have in advance care planning conversations, it is also helpful to consider the complexity of these goals and the potential for goal conflict. People can benefit from recognizing that messages may be consequential for multiple goals simultaneously. Failing to meet identity and relationship goals may undermine the accomplishment of instrumental goals in the conversation. Adult children talking with parents, for example, need to find a way to talk about death while simultaneously acknowledging the value and importance of the relationship to their lives. Successfully accomplishing both goals may be important for both them and their parents. At the same time, it is also important to recognize that pursuing some goals in a conversation may undermine other goals, even when both goals are worthy endeavors for effective EOL planning. Most specifically, attending to relational or identity goals can interfere with task goals. If too much effort is focused on relational affirmation, for example, individuals may

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61. Margaret J. Pitts et al., *Politeness Strategies in Imagined Conversation Openers About Eldercare*, 33 J. LANGUAGE & SOC. PSYCHOL. 29, 30 (2012).

62. *See id.* at 41.

63. *See id.* at 36–38.

64. Caughlin, *supra* note 39, at 831.

65. Carr et al., *supra* note 18, at 589.

fail to talk about the important topics that should be discussed for effective EOL planning.[66] Practitioners working with individuals to encourage family conversations about EOL plans need to recognize the complexity of the content of these conversations and help individuals prepare to address multiple goals in EOL conversations with family members.

IV. MANAGING PRIVACY AND DISCLOSURE IN EOL PLANNING AND DECISION MAKING

Appropriately sharing information is a key element of effective communication for both EOL planning and EOL decision making. As a part of EOL planning, surrogate decision makers need to know patients' preferences in order to make decisions consistent with their wishes. The completion of an ACD often provides a formal statement of EOL preferences.[67] However, older adults with ACD documents do not always discuss those documents with their physicians, designated surrogate, or other members of their personal networks.[68] Additionally, ACD documents may not contain sufficient detail to clarify specific decisions that must be made,[69] and EOL preferences may change over time.[70] Given this, advance care planning should be treated as an ongoing conversation among family members and medical care providers, and managing disclosure effectively is an important part of this dialogue.[71] At the end of life, both surrogates (and other family members) and medical care providers need to share information about the individual's current health and future prognosis when decisions must be made, and information disclosure constitutes an important component of effective communication during EOL decision making.[72] Family member uncertainty, frustration, and resentment increase when family members perceive that medical professionals are not providing desired information.[73]

Both family members and practitioners experience competing pulls between the need to disclose information for the benefit of the patient, family, and/or clinicians and discomfort with disclosure for personal, familial, or legal

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66. Caughlin, *supra* note 39, at 839–40.

67. Thomas J. Prendergast, *Advance Care Planning: Pitfalls, Progress, Promise*, CRITICAL CARE MED., Feb. 2001, at N34, N34 (Supp. 2001).

68. *See* Bute et al., *supra* note 9, at 805.

69. Debra A. Kossman, *Prevalence, Views, and Impact of Advance Directives Among Older Adults*, J. GERONTOLOGICAL NURSING, July 2014, at 44, 44.

70. Bauer-Wu et al., *supra* note 13, at 381.

71. *Id. See also* Wells-Di Gregorio, *supra* note 21, at 254.

72. *See generally* Torke et al., *supra* note 1.

73. *See* Steven Radwany et al., *End-of-Life Decision Making and Emotional Burden: Placing Family Meetings in Context*, 26 AM. J. HOSPICE & PALLIATIVE MED. 376, 382 (2009). *See also generally* Ursula K. Braun et al., *Voices of African American, Caucasian, and Hispanic Surrogates on the Burdens of End-f-Life Decision Making*, J. GEN. INTERNAL MED. 267 (2008).

reasons.[74] Communication Privacy Management theory (CPM) offers insight into how family members and medical care providers manage tensions between disclosure and privacy in EOL planning and decision-making interactions.

According to CPM, metaphorical boundaries exist around information, like EOL preferences or health information, and individuals and families actively manage those boundaries as they experience tension between the need to share information and the desire to maintain privacy.[75] Beliefs about who owns information also shape understanding of who has the right to control access to information.[76] Boundaries around information vary in terms of permeability, with information more easily shared across more permeable boundaries.[77] When information is shared, linkages are created and others become co-owners of the information or stakeholders within the shared boundary.[78]

Privacy rules shape privacy management processes, offering guidelines for coordinating privacy boundaries and regulating to whom disclosure occurs.[79] Access rules provide guidelines for who is granted access to private information (disclosure), and protection rules offer guidelines for restricting access to information (avoidance or ambiguity).[80] Ownership rules guide expectations about the degree of freedom co-owners have to determine how private information is managed once it is shared.[81] These rules help to construct the privacy boundary system and control information flow.[82] According to CPM, cultural values, gender, motivations, context, and perceived risk–reward ratios all influence rules about disclosure or avoidance as individuals and families coordinate boundaries.[83] Within the family, patterns develop around boundaries and rules for disclosure.[84] These family privacy orientations shape expectations for the flow of private information both within the family (internally) and between the family and the environment

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74. *See* Bute et al., *supra* note 9, at 801; *see also* Torke et al., *supra* note 1, at 55–56.

75. Sandra Petronio, BOUNDARIES OF PRIVACY: DIALECTICS OF DISCLOSURE 21 (State Univ. of NY Press 2002) [hereinafter BOUNDARIES OF PRIVACY]; Sandra Petronio, *Communication Privacy Management Theory: What Do We Know About Family Privacy Regulation?*, 2 J. FAM. THEORY & REV. 175, 180 (2010) [hereinafter *Family Privacy Regulation*].

76. Sandra Petronio & Wesley T. Durham, *Communication Privacy Management Theory: Significance for Interpersonal Communication*, in ENGAGING THEORIES IN INTERPERSONAL COMMUNICATION 335, 337 (2d ed. 2015).

77. *Id.* at 341.

78. *Id.* at 338.

79. *Family Privacy Regulation*, *supra* note 75, at 179.

80. *Id.* at 179–80.

81. *Id.* at 181.

82. *Id.* at 178.

83. BOUNDARIES OF PRIVACY, *supra* note 75, at 38–39.

84. *Id.* at 151.

(externally).[85] Based upon a family's internal privacy orientation, some information might be shared by all family members whereas other information may be shared only within family subsystems.[86] For example, an individual may choose to share EOL preferences only with his or her spouse and perceive that to be information that is not to be shared with children. A family's external privacy orientation determines the permeability of the boundary with those outside the family.[87] Some families have a relatively impermeable boundary, expecting that private information will not be shared with anyone outside the family.[88] Boundary turbulence occurs when individuals experience rule violations or when there are conflicting perspectives about what the rules should be.[89]

Individuals may be selective about creating linkages within their boundary system, allowing only certain others access to private information. In talking about EOL options, older adults may have differing preferences about whom they disclose to and vary in their disclosure to and vary in their degree of ambiguity within that disclosure. For example, while an adult child might be in a legal position to make an EOL treatment decision on behalf of a parent, the parent may not have felt compelled to discuss his or her private health background and care wishes in detail with the child. In families with relatively impermeable EOL preference boundaries, access to information about EOL preferences might be tightly controlled and rarely, if ever, discussed. In addition, ambiguity may be used within disclosures to sustain a more impermeable boundary while disclosing.[90] Family members may discuss EOL issues, for example, but do so with relatively little elaboration or detail.[91]

When EOL decisions must be made, CPM offers insight into how health care workers, surrogates, and other family members negotiate information disclosure as well. Jennifer Bute and colleagues interviewed surrogate decision makers about how they and other family members navigated boundaries around health information as they both provided private information to and

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85. *Id. See also* Mary Claire Serewicz & Daniel J. Canary, *Assessments of Disclosure From the In-Laws: Links Among Disclosure Topics, Family Privacy Orientations, and Relational Quality*, 25 J. SOC. & PERS. REL. 333, 336 (2008); Mary Claire Serewicz et al., *Family Privacy Orientation, Relational Maintenance, and Family Satisfaction in Young Adults' Family Relationships*, 7 J. FAM. COMM. 123, 124 (2007).

86. BOUNDARIES OF PRIVACY, *supra* note 75, at 153.

87. Serewicz & Canary, *supra* note 85.

88. *Id.*

89. BOUNDARIES OF PRIVACY, *supra* note 75, at 12.

90. *Family Privacy Regulation*, *supra* note 75, at 56.

91. Betty S. Black et al., *Surrogate Decision Makers' Understanding of Dementia Patients' Prior Wishes for End-of-Life Care*, 21 J. AGING & HEALTH 627, 629 (2009). *See also Managing Multiple Goals*, *supra* note 43, at 687.

sought information from health care professionals.[92] They suggest that surrogate decision makers serve as proxy owners of information and must make decisions regarding disclosure that fit with their understanding of the access and protection rules they think the patient would want them to follow.[93] Surrogate decision makers reported that clinicians sometimes created a relatively impermeable boundary around a patient's information and did not always treat them as owners of the information with a right to access.[94] This resulted in a variety of challenges around disclosure management, including incomplete and delayed information, that undermined their ability to engage in sound decision making on behalf of their loved one.[95] In part, legal expectations regarding privacy (e.g., the Health Insurance Portability and Privacy Act (HIPAA)) shape where and how medical professionals might draw the boundaries for ownership of information.[96] Other aspects of the context, like hospital structures and policies, also affected family members' ability to get information as needed.[97] They had to repeat disclosures to multiple different people, and surrogates who did not know the patient's treatment preferences also experienced anxiety around expectations that they disclose information that had not been shared with them.[98] The variety of clinicians that surrogate decision makers interacted with also created challenges both for obtaining and providing information.[99]

The demands of surrogate decision making require some degree of co-ownership over private information. Given its focus on ownership and boundaries, CPM offers a framework for thinking about how family members and medical professionals navigate the tension between disclosure and privacy in EOL planning and decision making.

A.   *Understand the Privacy Rules Governing Disclosure*

Attending to family privacy orientations and to ownership rules can help practitioners identify potential difficulties in coordinating effective disclosure. Families develop specific patterns and expectations for disclosure, and understanding a family's typical pattern for managing private information as well as an individual's beliefs about ownership and boundary permeability can help practitioners understand how family members are likely to approach disclosure about EOL preferences and decisions. In families with relatively

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92. *See generally* Bute et al., *supra* note 9.
93. *Id.*
94. *Id.* at 803.
95. *Id.* at 804.
96. *Id.* at 801, 805.
97. Bute et al., *supra* note 9, at 806.
98. *Id.* at 805.
99. *Id.*

permeable internal boundaries, for example, disclosure might be more likely, and multiple family members may be informed about EOL preferences and involved in the decision-making process. In families with less permeable internal boundaries, however, family members may not have information that they need for good decision making. Families with relatively permeable internal privacy orientations may expect multiple different family members to be participants in disclosure, but some clinicians may find this difficult or frustrating given expectations for a single, official decision maker or spokesperson.[100] During EOL planning, physicians may be in a position to encourage disclosure to family members if it becomes clear that individuals do not perceive EOL preferences to be information that should be co-owned with surrogate decision makers.[101]

B.   *Mitigate Boundary Turbulence*

One of the most common sites of boundary turbulence is in the linkages that form between family members and medical care providers when EOL decisions must be made.[102] When family members are frustrated with the communication of health care workers, that frustration often revolves around a desire for greater information than provided.[103] Surrogate decision makers perceive health-related information to belong to them,[104] but health care workers may not have the same definition of ownership. Additionally, there may also be boundary conflicts around access rules, with family members casting a wider net of inclusion than medical personnel. Medical systems may create unnecessarily extensive control around information due to legal concerns (e.g., HIPAA) that cause difficulties for surrogates.[105]

V. COPING WITH UNCERTAINTY IN EOL DECISION MAKING

Making a decision on behalf of someone at the end of life is an emotional and stressful experience, representing one of the most emotionally challenging decisions a family member will ever face.[106] Family members are often required to make a consequential decision amidst uncertain circumstances, which produces anxiety.[107] To manage the anxiety and uncertainty associated with EOL decisions, decision makers might consult with family members,

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    100. *Id.* at 807.
    101. *See* Braun et al., *supra* note 73, at 271.
    102. *See* Bute et al., *supra* note 9, at 804.
    103. *See id.* at 804–05; Radwany et al., *supra* note 73, at 379.
    104. Bute et al., *supra* note 9, at 803.
    105. *Id.* at 805–06.
    106. Buckey & Molina, *supra* note 26 (noting that the decision-making responsibility at the end of life "constitutes a heavy duty"); Tilden et al., *supra* note 28, at 106.
    107. Braun et al., *supra* note 73, at 268.

close friends, and medical professionals, as well as social workers and religious or spiritual guides, as relevant to the family. Although family members may vary in the degree of information they desire about a given situation,[108] gathering insight, support, and information during the process of an EOL decision has important consequences for the quality of the decision. In particular, the communication between a physician and a surrogate decision maker is of great importance when managing uncertainty in EOL decisions. To varying extents, however, physicians also experience uncertainty surrounding prognoses, which is expressed to patients both verbally and nonverbally, and it can influence patients.[109] In the context of EOL decisions on behalf of a patient, how families and physicians manage uncertainty and uncertainty-related anxiety is essential for promoting quality EOL decisions.

Theory associated with information and uncertainty management provides a productive framework for understanding how decision makers manage EOL decisions on behalf of a person at the end of life. Growing from a body of theories addressing communication and uncertainty, Problematic Integration theory (PI) offers a lens through which to understand quality decision-making processes associated with the end of life.[110]

PI recognizes that individuals hold probabilistic and evaluative orientations to their experiences.[111] Probabilistic orientations refer to appraisal of the likelihood of a particular association.[112] For example, when making a treatment decision on behalf of a loved one, a person may tap into a *probabilistic orientation* to the decision when considering the *likelihood* the treatment will extend a loved one's life. On the other hand, an *evaluative orientation* involves an assessment of *value or desirability*.[113] In the case of an EOL decision, a person might evaluate a treatment on the basis of whether extending the life of a loved one is desirable if that person's quality of life would be severely damaged. PI contends that probabilistic and evaluative orientations are integrated through sense-making processes and reciprocally

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108. Terri R. Fried & John O'Leary, *Using the Experience of Bereaved Caregivers to Inform Patient- and Caregiver-Centered Advance Care Planning*, 23 J. GEN. INTERNAL MED. 1602, 1605–06 (2008).

109. Geoffrey H. Gordon et al., *Physician Expressions of Uncertainty During Patient Encounters*, 40 PATIENT EDUC. & COUNS. 59, 62 (2000); Jane Ogden et al., *Doctors Expressions of Uncertainty and Patient Confidence*, 48 PATIENT EDUC. & COUNS. 171, 175–76 (2002); Ming Tai-Seale et al., *Expressing Uncertainty in Clinical Interactions Between Physicians and Older Patients: What Matters?*, 86 PATIENT EDUC. & COUNS. 322, 327 (2012).

110. *See generally* Austin S. Babrow, *Communication and Problematic Integration: Understanding Diverging Probability and Value, Ambiguity, Ambivalence, and Impossibility*, 2 COMM. THEORY 95 (1992).

111. Austin S. Babrow, *Uncertainty, Value, Communication and Problematic Integration*, 51 J. COMM. 553, 554 (2001).

112. *Id.* at 556.

113. *See id.* at 554.

related; appraisals of likelihood can impact evaluations of value and vice versa.[114] Furthermore, integration is often problematic and dilemmas arise in sense-making attempts.[115] Communication is the primary means by which "integrative dilemmas" are uncovered and managed.[116]

PI is ideally suited to fostering greater understanding of communication associated with EOL decisions. "Patients, their families, and health care providers experience EOL decisions as a complex interweaving of various manifestations of PI. These experiences intertwine with communication in ways that lead to difficulties and often inadequacies in EOL decision making."[117] In our research applying PI to EOL care decisions, we identified three main areas of uncertainty and anxiety for families making EOL decisions.[118] Management of each of these areas of uncertainty has important consequences for EOL decisions.

First, family members in the position of making decisions on behalf of a loved one experience uncertainty as to *how* they come to know whether a loved one is at the end of life,[119] a form of *epistemological uncertainty*.[120] Physicians play an important role in helping decision makers manage epistemological uncertainty. When physicians are ambiguous in their communication with family members about the condition of a loved one, decision makers' uncertainty and anxiety can be heightened.[121] Similarly, if different physicians offer conflicting opinions regarding the prognosis of a family member, decision makers may experience an increase in anxiety related to epistemological uncertainty.[122]

Second, family members also reported uncertainty around determining who serves as the decision maker.[123] This can be an area of divergence in families making an EOL decision.[124] Regardless of whether someone is a formally-designated decision maker, families often experience uncertainty and subsequently engage in conflict about who is responsible for an EOL decision,

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114. *Id.*

115. Austin S. Babrow, *Problematic Integration Theory*, *in* ENCYCLOPEDIA OF COMMUNICATION THEORY 800–01 (Stephen Littlejohn & Karen Foss eds., 2009).

116. *Id.* at 1101–02.

117. Stephen C. Hines et al., *Communication and Problematic Integration in End-of-Life Decisions: Dialysis Decisions Among the Elderly*, 9 HEALTH COMM. 199, 203 (1997).

118. Jennifer E. Ohs et al., Address at the National Communication Association Annual Convention Symposium: Problematic Integration and Family Communication about End-of-Life Decisions (Nov. 12, 2016) (on file with author).

119. *Id.*

120. Babrow, *supra* note 111, at 558–60.

121. Ohs et al., *supra* note 118.

122. *Id.*

123. *Id.*

124. *Id.*

as well as who has the right to participate in the discussion.[125] Although sometimes family members seek consensus for decision making,[126] in other situations, family members do not want to take on responsibility for the decision, while other times more than one individual wants to take responsibility for the decision and conflict ensues.[127]

A final area of uncertainty, which has the potential of resulting in familial conflict, is what a patient at the end of life would choose to do in a given EOL situation.[128] The primary criteria for EOL decision making, given the present legal and medical system in the United States, involves using substitute judgment on behalf of a person at the end of life.[129] When an ACD is not in place, family members manage uncertainty by drawing upon past experiences and conversations with a loved one—often those that were not directly related to the decision situation.[130] People construct a narrative of the EOL decision that helps them manage uncertainty and create a "good" death for a loved one.[131] This happens regardless of whether an ACD is in place.[132] Clearly, having a legally enforceable ACD has important implications for decision making. However, ACDs do not necessarily provide guidance for the specific decisions that must be made, particularly when a family member's wishes cannot be followed because of the decision circumstances. For example, a loved one might express a desire to die in the home, but attempting to move a loved one from the hospital to his or her home may not be possible without risking loss of life in transit. Given the uncertainty inherent in EOL decisions, families must come together to integrate their orientations to the decision situation in order to manage their uncertainty about a loved one's wishes and make a sound decision.

The experience of uncertainty creates anxiety and stress when decisions must be made at the end of life, and family members use communication within the family and with health care providers to reduce uncertainty about whether or not they are doing the right thing. Several recommendations for practice emerge from the application of PI to EOL decision making.

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125. Hsiu-Fang Hsieh et al., *Contradictions and Communication Strategies During End-of-Life Decision Making in the Intensive Care Unit*, 21 J. CRITICAL CARE 294, 299 (2006).

126. Cohen et al., *supra* note 30, at 1430.

127. Hsieh et al., *supra* note 125, at 302.

128. *Id.* at 296.

129. Torke et al., *supra* note 1.

130. Ohs et al., *supra* note 118.

131. Torke et al., *supra* note 1.

132. *Id.*

A.   *Attend to Epistemological Uncertainty*

When physicians attend to a decision maker's epistemological uncertainty, anxiety may be lessened. For example, communicating directly about a loved one's impending death may offer a decision maker permission to make decisions that honor the patient's EOL wishes, as opposed to making decisions that might extend the patient's life. If the end of life is not immediate, letting family members know that whether the loved one is close to death is still uncertain will help them to make decisions accordingly. Not attending to a decision maker's epistemological uncertainty has consequences for how the family makes decisions. If a decision maker is asked, for example, whether he or she would like to put a loved one on a ventilator, and the decision maker is not sure if the loved one's end of life is imminent regardless of the decision, the decision maker cannot honor the loved one's EOL wishes. Necessarily, epistemological uncertainty should be dealt with before EOL care decisions should be made.

B.   *Honor the Responsibility of the Surrogate Decision Maker*

An ACD formally designating a surrogate decision maker can ease the uncertainty associated with who is in the legal position to make a decision. During the process of decision making on behalf of someone at the end of life when a formal surrogate has been named, medical professionals, social workers, and legal representatives are in a position of encouraging surrogates to honor their responsibility as the decision maker.[133] However, formal surrogates seek input from multiple family members and friends during the decision-making process, as they recognize that their decisions impact other family members as well.[134] Practitioners can support decision makers by encouraging them to consult with other family members, while also emphasizing to the family unit the surrogate's role in making final decisions. Having a formal decision surrogate in place does not mitigate conflict about who is permitted to be a part of the decision and ultimately, what decision to make.[135] The costs associated with such conflicts are great, placing a burden on the legal system.[136] Thus, especially in situations when tension and potential conflict are surfacing in families regarding EOL decisions on behalf

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133. *Surrogate Decision Makers*, ENCYCLOPEDIA OF HEALTH COMMUNICATION (2014) ("[S]urrogates . . . should have regular communication with the health care team.").

134. *See* Cohen et al., *supra* note 30, at 1430.

135. Quinn et al., *supra* note 27, at 49–50.

136. Wendy H. Sheinberg, *Informed Counsel, Informed Consent: They Go Together Like a Horse and Carriage*, 45 S.D. L. REV. 567, 575–76 (2000) (noting that many types of parties have standing in court when conflicts arise, including "health care providers, guardians and those who hold earlier appointments as committees or conservators, family members close friends . . . and the commissioners of health, mental health, mental retardation and developmental disabilities").

of a family member, care must be taken to help families navigate the uncertainty associated with *who* should be in the position of making final decisions before discussing EOL decision options.

C.   Guide Families to Integrate Areas of Divergence Through Communication that Minimizes Ambiguity

The uncertainty and anxiety faced by families making an EOL decision require family members to attempt to integrate areas of divergence in their orientations to the decision in order for optimal decisions to be made. PI asserts that communication is the primary means by which problematic integration occurs.[137] Communication with medical professionals plays a vital role in helping families manage divergent orientations to an EOL decision.[138] Specifically, medical professionals influence probabilistic orientations in ways that can help or interfere with families' transformation of divergent PI experiences associated with EOL decisions. Physicians who communicate ambiguously about a family member's prognosis and condition can hinder sense-making processes associated with related EOL decisions, leaving family members more uncertain and anxious. Such ambiguity can impede quality PI that can assist families in making quality decisions on behalf of a loved one. Alternately, communicating directly with families in ways that assist them with PI can help family members orient to medical situations as sites of EOL decisions, allowing decision makers to shift their orientations to the decision situation in ways that can assist with PI and produce sound decisions.

VI. NEGOTIATING CONTRADICTIONS IN EOL PLANNING AND DECISION MAKING

Conversations about EOL care planning and decision making in families compel family members to construct the meaning of death in a given situation.[139] This process is challenging for families, particularly in the United States, given cultural taboos surrounding death that give way to avoidance of talking about or planning for the end of life. Family members facing EOL decisions also must make sense of the decision itself and the meaning that it has for them.[140] This sense making occurs in part through interaction both

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137. Babrow, *supra* note 115, at 802.

138. Ohs et al., *supra* note 118.

139. *See* Sarah Forbes et al., *End-of-Life Decision Making for Nursing Home Residents with Dementia*, 32 J. NURSING SCHOLARSHIP 251, 254–255 (2000) (describing that family members are often torn between whether EOL was a "tragedy versus blessing, accepted versus forbidden and acknowledged versus unacknowledged"); *see also* Hsieh et al., *supra* note 125, at 296 (noting that contradictions arise during clinician-family conferences when individuals assign different meanings to death).

140. Hsieh et al., *supra* note 125, at 297.

within the family and between family members and health care workers. Given the complex nature of the meaning making associated with death that occurs in the process of EOL planning and decision making in families, Relational Dialectics Theory (RDT) is informative for understanding discourse in these situations.[141]

RDT considers discourse as "a system of meaning . . . that cohere[s] around a given object of meaning."[142] Meaning is constructed not only from individual utterances but also chains of discourse that might occur, for example, within families' interactional histories as well as larger cultural discourses (e.g., sociocultural rhetoric about death and dying, medical and legal discourses).[143] For example, public discourse surrounding the "death panels" associated with the Affordable Care Act can intersect with informal family conversations about the end of life, as well as during decision-making processes about EOL care, to create meanings. The discourse of EOL decision making and planning, then, can be seen as producing the meaning associated with the end of life. Meanings of death that are constructed during EOL care planning will necessarily impact care decisions at the end of life.

In addition to drawing attention to the interconnectedness of various influential discourses on EOL care planning and decisions, RDT posits that *discursive tensions*, the interplay of opposites in relational and cultural discourses, produce meaning.[144] When people communicate, they draw upon various systems of meaning, which are sometimes in opposition.[145] For example, in the context of EOL planning, an adult child might initiate a conversation with an aging parent about his or her EOL care wishes, tapping into a system of meaning that purports that with age, the end of life is nearing. The parent may respond to the adult child by indicating that EOL care is not a concern, given the parent is in good health, tapping into a system of meaning that suggests that chronological age alone does not signal the end of life. Competing discourses, or discursive tensions, such as these are inevitable and necessary for constructing meaning. Communication strategies for managing these contradictions may privilege one tension over the other (e.g., choosing to ignore one side of the opposition, switching back and forth between

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141. Jennifer E. Ohs & April R. Trees, CONTEMPORARY CASE STUDIES IN HEALTH COMMUNICATION: THEORETICAL AND APPLIED APPROACHES 233 (Maria Brann ed., 2d ed. 2015).

142. Leslie A. Baxter, VOICING RELATIONSHIPS: A DIALOGIC PERSPECTIVE 2 (2011).

143. Leslie A. Baxter & Kristen M. Norwood, *Relational Dialectics Theory: Navigating Meaning from Competing Discourses*, *in* ENGAGING THEORIES IN INTERPERSONAL COMMUNICATION 279, 281 (Dawn O. Braithwaite & Paul Schrodt eds., 2d ed. 2015).

144. Leslie A. Baxter & Kristen M. Norwood, *Relational Dialectics Theory: Crafting Meaning from Competing Discourses*, *in* ENGAGING THEORIES IN INTERPERSONAL COMMUNICATION 349, 351 (Dawn O. Braithwaite & Paul Schrodt eds., 2d ed. 2015).

145. *Id.* at 349.

discourses).[146] Alternatively, they may privilege both at the same time through neutralization (i.e., drawing on elements of both in interaction) or transformation (i.e., reframing so that the competing discourses no longer contradict).[147] How people manage competing discourses has important implications for interactional outcomes. For example, how the parent and adult child manage their discursive tensions around the meanings of age and health influences whether the parent's EOL care wishes are communicated clearly to the adult child, who in the future may be charged with making an EOL care decision on behalf of the parent.

The overarching discursive tension that families experience when faced with making a medical decision on behalf of a family member at the end of life involves "holding on" versus "letting go."[148] When a family member is at the end of life, families recognize the need to let go of that family member, but simultaneously desire to hang on to their loved one's life.[149] Often, the desire to extend a family member's life through medical intervention stands in contradiction to the family member's EOL care wishes, either articulated formally or perceived by the family.[150] Families must communicatively manage the tension between their wishes and the patient's wishes in interaction within the family and with clinicians. Furthermore, family members must make sense of death as a likely outcome. A study of family and clinician interaction in intensive care unit family meetings, for example, observed discursive tensions between making sense of death as a burden or a benefit and making sense of the decision as killing a loved one versus letting him or her die.[151] As families make sense of the decision itself, holding on to a family member at the end of life is framed as an emotional, as opposed to rational, response to an EOL situation.[152] The dialectic tension of emotionality versus rationality emerges in family discourse about who should make a decision on behalf of a loved one at the end of life. Family members who are perceived as emotional might be excluded from decision-making processes, in favor of those who are perceived as having the ability to make a decision objectively. Management of dialectical tensions associated with who makes final EOL decisions might provide criteria when uncertainty exists with regard to who should make decisions. Additionally, understanding that families must negotiate the discursive tension between holding on and letting go lends insight into practice.

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146. *Id.* at 353.
147. *Id.* at 354–55.
148. *Holding On and Letting Go*, *supra* note 6.
149. *Id.*
150. *Id.*; *see also* Hsieh et al., *supra* note 125, at 298.
151. *See* Hsieh et al., *supra* note 125, at 296.
152. *See Holding On and Letting Go*, *supra* note 6, at 360.

A.   *Acknowledge the Experience of Contradictions in Family Sense Making*

As families engage in conversations about EOL planning and decision making, they experience discursive contradictions that must be managed. RDT suggests that it is rarely beneficial to avoid or deny the existence of one side of the contradiction.[153] Focusing on autonomy, for example, to the exclusion of interdependence in talking about EOL preferences fails to help EOL planners and their family members make sense of how to attend to these competing pulls within their decision-making processes. Family discourse is the means through which families manage dialectic tensions associated with EOL care decisions and ultimately let go of a family member at the end of life. Recognizing that families experience discursive tensions regarding their desires and a loved one's wishes for EOL care treatments can clarify EOL decision situations for decision makers. Particularly in situations that are highly uncertain and obfuscated by emotions, understanding the discursive tensions that families face and naming them can help decision makers manage tensions in ways that promote quality decisions associated with the end of life. Avoiding or negating the contradictions that emerge in discourse, on the other hand, is unlikely to effectively help family members cope with the complexity of the decision that they face.

B.   *Respect Divergent Perspectives, but Aim to Transform Discursive Contradictions*

As families struggle with meaning making and negotiating discursive contradictions, a dominant discourse might be honored while others are marginalized. Alternately, families might reconstruct competing discourses in such a way that new meaning can be created in the family. For example, a family faced with a decision whether to remove life support may face conflict stemming from the discursive tensions associated with honoring the loved one's wishes not to be kept alive artificially versus the family's desire not to "kill" their loved one. Encouraging family members to acknowledge the contrasting discourses associated with the discursive tension is important in helping them to manage the tension. Subsequently, families can begin to transform the tension. Framing the removal of life support as a means to give a loved one dignity and independence at the end of life can help families transform the meaning associated with their decision. In order to help families consider ways to transform discursive contradictions, medical care providers can use information seeking to promote discussion and help family members

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153. *See* Baxter & Norwood, *supra* note 144, at 358 ("[I]t is not fruitful to ask whether the presence or absence of discursive oppositions correlates with any variety of possible relationships outcomes . . . . [D]iscursive tensions are inherent in the meaning-making enterprise.").

make sense of a decision when families are struggling with sense making.[154] Asking questions of family members can help family members clarify their meanings, recognize their experiences, and lead to aesthetic moments in which competing discourses are no longer framed as oppositional.[155] The sensitive nature of EOL decisions for families requires communicating respect for divergent discourses. However, fostering discussion that allows families to reconstruct the meaning associated with competing discourses can give new meaning to their decisions and will lay the foundation for optimal decisions and healing for family members.

VII. CONCLUSION

Legally enforceable advance care plans are essential for directing EOL decisions. However, simply having an ACD in place is not enough to guarantee proxy accuracy in honoring the wishes of a person at the end of life or to avert family conflict regarding the interpretation and application of ACD, both of which can have costly repercussions for families and burden the medical and legal systems.[156] In order for advance care plans to effectively guide EOL care decisions, sound family communication processes are vital during EOL planning and decision making. Research indicates that interactive interventions are most effective in increasing ACD completion rates and that informal discussions should accompany formal planning.[157] Identifying ways to encourage and facilitate skillful family communication about directives is important for citizens to fully realize the value that comes from completing advance care planning. To facilitate family discussions regarding EOL care, professionals working with older adults must consider each family's established patterns of disclosure and problem solving that impact a surrogate's ability to make a decision on behalf of a person at the end of life.[158] Practitioners and families should also recognize that experiences of uncertainty impact sense making associated with EOL decisions. Effective management of uncertainty can be facilitated through interactions with medical professionals,

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154. *See* Hsieh et al., *supra* note 125, at 302.

155. *See* Baxter & Norwood, *supra* note 144, at 355.

156. Thomas R. Defanti, *Changing the Cultural View and Coverage of End-of-Life Care*, 27 AM. J. HOSPICE & PALLIATIVE MED. 365, 367 (2010); Tilden et al., *supra* note 28, at 106 ("Even with written advance directives, which are notoriously non-specific or unavailable [citation omitted] the family's responsibility constitutes a heavy duty."); Lorraine Winter & Susan M. Parks, *Family Discord and Proxy Decision Makers' End-of-Life Treatment Decisions*, 11 J. PALLIATIVE MED. 1109, 1109 (2008) ("Disagreement about an incapacitated relative's care . . . is a common feature of [EOL] decision making and may have a number of undesirable consequences for both patients and families.").

157. Maria-Isabel Tamayo-Velázquez et al., *Interventions to Promote the Use of Advance Directives: An Overview of Systematic Reviews*, 80 PATIENT EDUC. & COUNS. 10, 17 (2010).

158. Boerner et al., *supra* note 8, at 255.

and it can enhance EOL decision making in families. Finally, as family members face inevitable discursive tensions associated with the desire to hold on to a family member at the end of life when they simultaneously face the necessity to let go, families and practitioners can benefit from clarifying dialectic tensions in light of the needs of families and their loved ones at the end of life in ways that promote a good death and healing in the family. Although autonomy in EOL planning and decision making is a legal and ethical imperative, the interdependence of family members cannot be ignored. Shaping planning processes in ways that honor autonomy but also recognize and respect the role of family communication in interpreting and applying the wishes of those at the end of life is necessary for enhancing medical and legal practices for those at the end of life.