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Closing the Gap: Embedding Advance Care Planning in a Latino Community by Using a Culturally Sensitive Dispute Systems Design Approach

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CLOSING THE GAP:
EMBEDDING ADVANCE CARE PLANNING
IN A LATINO COMMUNITY BY USING
A CULTURALLY SENSITIVE
DISPUTE SYSTEMS DESIGN APPROACH

JACQUELINE N. FONT-GUZMÁN, M.H.A., J.D., PH.D.*

"IT WAS A MIRROR OF A BAD DEATH, NOT A GOOD DEATH—HERE'S A GENTLEMAN WHO HAD BEEN ALONE IN AN OUTSIDE HOSPITAL AND NOW HE'S ALONE HERE" (MALE INTERN).[1]

INTRODUCTION

Dying is not merely biological; it is also a social process. Just as humans cannot have a good life in isolation, they cannot have a "good death" in isolation. This Article explores the factors that should be taken into account when designing a culturally sensitive dispute systems design (DSD) that incorporates conversations about end-of-life care in a community. Conflict practitioners and attorneys could actively participate in reducing end-of-life care inequalities in advance care planning (ACP) by moving DSD beyond the purview of health care and legal institutions and into the community.[2]

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 1. Mary-Jo DelVecchio Good et al., *Narrative Nuances on Good and Bad Deaths: Internists' Tales from High-Technology Work Places*, 58 Soc. Sci. & Med. 939, 944 (2004) (discussing good and bad deaths from an American physician's perspective).

 2. Many scholars have explored the need for conflict engagement skills in end-of-life care within institutions, but there is a lacuna regarding how conflict practitioners can take their skills into the community to enhance ACP. Conflict practitioners can positively impact end-of-life care in the institutional setting. *See generally* Debra Gerardi, *The Emerging Culture of Health Care: Improving End-of-Life Care Through Collaboration and Conflict Engagement Among Health*

ACP is usually described as an ongoing conversation in which an individual, their families, physicians, lawyers, and important people in their lives discuss their goals for end-of-life care taking into consideration their values, beliefs, fears, and hopes.[3] Dying is not always easy, but if you are poor, immigrant, black, or Latino, it can be grueling. Many studies have illustrated how if you fall in any of the aforementioned groups, you receive less quality end-of-life care[4] and are less likely than whites to have an ACP document.[5] For example, minority and certain cultural groups receive poorer quality of palliative care compared to whites in areas such as pain management and effective communication regarding treatment.[6]

The field of conflict engagement can contribute to reduce end-of-life care disparity by adopting a DSD approach that facilitates the integration of ACP within a community. For purposes of this Article, community is defined as "existing or potential networks of individuals and groups that either share or have the potential to share common concerns and goals."[7] In tandem, the common concerns and goals shared by individuals and/or networks are defined as those that are related to increasing ACP and enhancing end-of-life care.

Care Professionals, 23 OHIO ST. J. ON DISP. RESOL. 105 (2007); Karl A. Slaikeu, *Designing Dispute Resolution Systems in Health Care Industry*, 5 NEGOTIATION J. 395 (1989); NANCY NEVELOFF DUBLER & CAROL B. LIEBMAN, BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS (Rev. and Expanded ed. 2011); Richard C. Boothman et al., *A Better Approach to Medical Malpractice Claims? The University of Michigan Experience*, 2 J. HEALTH & LIFE SCI. L. 125 (2009).

3. INST. OF MED. OF THE NATIONAL ACADEMIES, DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE 120 (2015); *see also* Peter A. Singer et al., *Bioethics for Clinicians: 6. Advance Care Planning*, 155 CAN. MED. ASS'N J. 1689, 1689–90 (1996) (defining ACP and discussing its importance); Barbara J. Messinger-Rapport et al., *Advance Care Planning: Beyond the Living Will*, 76 CLEV. CLINIC J. MED. 276, 277 (2009) (discussing the importance of listening when introducing ACP).

4. Lisa C. Welch et al., *End-of-Life Care in Black and White: Race Matters for Medical Care of Dying Patients and Their Families*, 53 J. AM. GERIATRIC SOC. 1145, 1150–51 (2005) (discussing research supporting that racial discrimination in end-of-life care is present and that African-Americans are more likely to report that communication-related care with physicians is either lacking, or problematic). *See generally* BRIAN D. SMEDLEY ET AL., UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE (2002).

5. Jacqueline N. Font-Guzmán, *Moving 'Beyond Neutrality' and Cross-Cultural Training: Using World Café Dialogue to Address End-of-Life Care Inequalities*, 21 PEACE & CONFLICT STUD. 49, 51–52 (2014) (discussing health inequalities and the dying patient)*; see also* Howard B. Degenholtz et al., *Persistence of Racial Disparities in Advance Care Plan Documents Among Nursing Home Residents*, 50 J. AM. GERIATRIC SOC. 378, 378 (2002) (discussing research supporting that minority groups are less likely to have ACP documented); INST. OF MED., *supra* note 3, at 150–51 (sharing research supporting that certain groups of populations (e.g., blacks, Hispanics, and Asians) are less likely than whites to plan their goals for end-of-life care). For a discussion of the social construction of the race and the term 'Latino,' see *infra* section C.VII and notes 116–18.

6. Kimberly S. Johnson, *Racial and Ethnic Disparities in Palliative Care*, 16 J. PALLIATIVE MED. 1329, 1330 (2013) (discussing factors contributing to disparities in palliative care).

7. Jason Mills et al., *Building Community Capacity for End of Life: An Investigation of Community Capacity and Its Implications for Health-Promoting Palliative Care in the Australian Capital Territory*, 25 CRITICAL PUB. HEALTH 218, 219 (2015) (defining community).

I. Discussion of ACP Challenges

Patients in the United States and their families struggle with having conversations about their goals for end-of-life care. These conversations, especially if people do not have the skill set and a safe space to have them, can be arduous. The presence of a structure that reinforces disparate treatment and dismisses end-of-life care conversations heightens the barriers to planning for care towards end-of-life. For example, unconscious racial biases that lead to discrimination are more prevalent when communicating with patients that are deemed to be "different."[8] Another structural obstacle for advancing ACP equality is the fact that the percentage of minority students matriculated in U.S. medical schools is significantly lower when compared with whites.[9] The scarcity of minority physicians throughout the health care system may serve as a potential barrier to culturally sensitive ACP.[10] Likewise, there is an inadequate structural support for effective clinician-patient communication and ACP. Some examples include limited clinician training on how to engage in difficult conversations, a historical lack of insurance payment for ACP related activities, and legal requirements that serve as barriers to complete advance directives.[11]

The Patient Self-Determination Act of 1990 (PSDA) was an attempt to remedy the dearth of ACP in the United States. The PSDA mandates that every federally funded hospital, home health agency, skilled nursing facility, health maintenance organization, and hospice in the United States needs to provide patients with the opportunity to fill out an advance directive.[12] An advance directive consists of two documents: 1) a living will (a legal document indicating the medical treatments an individual wishes to refuse or receive if they are unable to express decisions for themselves) and, 2) a

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8. *See generally* Janice A. Sabine et al., *Physicians' Implicit and Explicit Attitudes About Race by MD Race, Ethnicity, and Gender*, 20 J. Health Care Poor & Underserved 896 (2009) (discussing research supporting evidence of unconscious biases among physicians).

9. Association of American Medical Colleges, Diversity in Medical Education: Facts & Figures (2012) (providing statistics on students who matriculate in U.S. medical schools).

10. Johnson, *supra* note 6, at 1330 (discussing factors contributing to disparities in palliative care); *see also* D. J. Reese, *Programmatic Barriers to Providing Culturally Competent End-of-Life Care*, 21 Am. J. Hosp. Palliative Care 357, 358 (2004).

11. Inst. of Med., *supra* note 3, at 117, 126; *see also* Centers for Medicare & Medicaid Services, Dept. of Health & Human Services, 80 Fed. Reg. 41685 (proposed August 15, 2015) (to be codified at 42 C.F.R. pts. 405, 410, 411, 414, 425, 495), https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-16875.pdf; Centers for Medicare and Medicaid Services, Dept. of Health & Human Services, 80 Fed. Reg. 70885 (November 16, 2015) (to be codified at 42 C.F.R. pts. 405, 410, 411, 414, 425, 495), https://s3.amazonaws.com/public-inspection.federal register.gov/2015-28005.pdf (stating that effective January 1, 2016, Medicare will reimburse physicians and other eligible medical personnel for having voluntary discussions about end-of-life care with Medicare beneficiaries and their families during a "Welcome to Medicare" visit which may occur within the first twelve months of enrollment).

12. Patient Self-Determination Act, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388, 155, 204 (1990).

durable power of attorney (a legal document that designates an agent to make health care decisions if patient is incapacitated).[13]

II.   RESULT OF THE LEGAL APPROACH TO ACP

Not surprisingly, the legal approach of focusing on filling out specific documents rather than on having conversations with patients about their goals of care has failed miserably.[14] First, it should not come as a surprise that law and the documents it produces are not as universal, objective, and neutral as they may seem. Legal structures and documents reflect the dominant cultural values that may not be consistent with those of certain societal groups.[15] Furthermore, historically, the law has refused to incorporate peoples' voices into its "official discourse" [e.g., statutes, forms, jurisprudence, and testimony].[16] In essence, peoples' stories and cultural values are dismissed, especially if they do not belong to the dominant cultural group.

The lack of universality and absence of minority voices in the legal discourse is illustrated through PSDA's emphasis on self-determination. At the core of the PSDA is the assumption that 'self-determination' is a patient's individual right to exercise autonomy over end-of-life care and that choices are selected based on rational cognition assessments.[17] This approach of decision-making through legal forms and rationality originates from economic theories that focus on individuals as the main decision-makers and reflect the biases of Western cultures that do not necessarily recognize the influence of family members and social networks on the decision-maker.[18] Contrast the PSDA's focus on autonomy and self-determination with the following expression of an elderly Korean-American: "Giving control to my family is the right thing. It is what I personally prefer and is my expression of autonomy."[19]

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13.   Deborah Carr, *Racial Differences in End-of-Life Planning: Why Don't Blacks and Latinos Prepare for the Inevitable?*, 63 OMEGA 1, 2 (2011) (discussing the PSDA).

14.   INST. OF MED., *supra* note 3, at 117; *see also* Stacy M. Fisher et al., *Advance Directive Discussions: Lost in Translation or Lost Opportunities?*, 15 J. PALLIATIVE MED. 86 (2012); Theresa S. Drought & Barbara A. Koenig, *"Choice" in End-of-Life Decision Making: Researching Fact or Fiction?*, 42 GERONTOLOGIST 114 (2002).

15.   *See generally* JULIE MACFARLANE, THE NEW LAWYER: HOW SETTLEMENT IS TRANSFORMING THE PRACTICE OF LAW 183 (2008) (discussing how legal principles are not culturally blind).

16.   *See generally* JOHN M. CONLEY & WILLIAM M. O'BARR, RULES VERSUS RELATIONSHIPS: THE ETHNOGRAPHY OF LEGAL DISCOURSE 176 (1990) (discussing the legal system's unwillingness to include its constituencies' voices).

17.   Madelyn Hsiao-Rei Hicks & Mabel Sau-Ching Lam, *Decision-Making Within the Social Course of Dementia: Accounts by Chinese-American Caregivers*, 23 CULTURE, MED. & PSYCHIATRY 415, 416–18 (1999) (discussing decision-making in cross-cultural settings).

18.   *Id.* at 418.

19.   Geyla Frank et al., *A Discourse of Relationships in Bioethics: Patient Autonomy and End of Life Decision Making Among Elderly Korean Americans*, 12 MED. ANTHROPOLOGY Q. 403, 415 (1998) (discussing the difference between a discourse of relationships and one of individual rights).

Legal documents and forms are subject to multiple interpretations. As legal documents, advance directives do not stand alone, they "always refer back to an 'originary person.'"[20] The power of legal documents and the truth they claim to produce is incomplete."[21] Rather than certainty, legal documents create fear and apprehension because people are unsure as to how they may be interpreted in the future. A series of studies on how ACP is implemented reflect that the end-of-life care that patients receive is frequently inconsistent with their living wills.[22] Likewise, bereaved persons often perceive that physicians disregard the advance directives of their family members.[23] In my opinion, statutes and legal forms also serve as instruments to avoid difficult conversations by dehumanizing conflict and reducing it to a process that needs to be followed instead of a real life issue that needs to be grappled with. It is easier to check a box on a form as to what treatment a patient wishes to refuse than asking a patient, "what frightens you the most about your illness"?

Furthermore, physicians have been unwilling and/or do not have the adequate skills to partner with their patients to plan in advance for their end-of-life goals of care.[24] For the most part, physicians use an ACP document as an end in itself (i.e., check a box) and miss out on the opportunity of having meaningful conversations with their patients and family to provide guidance on setting goals for end-of-life care.[25] An ACP document in many ways discourages dialogue to the extent that it takes a dualistic framework that focuses on either the procedures the patient wishes to have done or those that they wish to refuse. Thus, it could be argued that ACP documents focus on biological death and treatment options, not on the social implications of dying.

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20. Tobias Kelly, *Documented Lives: Fear and the Uncertainties of Law During the Second Palestinian Intifada*, 12 J. Royal Anthropology Inst. 89, 92 (2006) (discussing the inherent unstableness of legal identity documents).

21. Susan Bibler Coutin et al., *In the Mirror: The Legitimation Work of Globalization*, 27 L. & Soc. Inquiry 801, 823 (2002) (discussing the impact of legal documents on individuals).

22. Inst. of Med., *supra* note 3, at 132–33 (discussing a series of empirical studies supporting the discrepancy between a patient's ACP and the care delivered).

23. *See* Sylvia McSkimming et al., *The Experience of Life-Threatening Illness: Patients' and Their Loved Ones' Perspectives*, 2 J. Palliative Med. 173, 180 (1999) (discussing major themes that surfaced regarding concerns of bereaved family members of patients regarding their care at end-of-life).

24. David C. Leven, *Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action*, 58 N.Y.L. Sch. L. Rev. 403, 408 (2013–14) (advocating for the need for palliative care laws to protect patients); Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 JAMA 1665, 1665 (2008) (citing studies that support that physicians and patients avoid conversations about death).

25. Ray D. Madoff, *Autonomy and End of Life Decision Making: Reflections of a Lawyer and a Daughter*, 53 Buff. L. Rev. 963, 969 (2005) (noting how medical professionals approach the decision making process in health care).

III.   Impact of the Legal Approach on Latinos

For the Latino population residing in the United States, the disparity in ACP worsens when compared to whites.[26] There is a lack of ACP among Latinos across socio-economic groups and health care settings.[27] Although there have been some recent attempts to translate advance directive templates and culturally sensitive material to Spanish, few Latinos complete advance directives.[28] For example, Latinos are less likely than whites to complete living wills and durable power of attorneys.[29] Furthermore, when compared with hospitalized Caucasians, Latino patients are less likely to report having conversations about advance directives.[30] A language barrier does not fully account for this disparity, but lack of effective communication with a health care professional and low rates of health literacy were likely barriers.[31]

The disconnect for some Latinos between cultural norms and the legal structures seems to influence their lack of ACP. Overall, Latinos and Hispanics seem to favor a family-centered decision-making process that is inconsistent with the decision-making process assumptions embedded in the PSDA.[32] Latinos also seem to have a low level of comfort with communicating a "bad" prognosis to a family member because it is deemed as cruel and the role of supporting a terminally ill or grave patient requires that the family member be protected from knowing the seriousness of their medical

26. *See* Irene A. Gutheil & Janna C. Heyman, *"They Don't Want to Hear Us": Hispanic Elders and Adult Children Speak About End-of-Life-Planning*, 2 J. Soc. Work in End-of-Life & Palliative Care 55, 57 (2006) (presenting a literature review on ethnicity and end-of-life planning).

27. Inst. of Med., *supra* note 3, at 154; *see also* Kathryn A. Frahm et al., *Racial Disparities in End-of-Life Planning and Services for Deceased Nursing Home Residents*, 13 J. Am. Med. Dir. Ass'n 819e7, 819e9 (2012) (discussing research results showing that Latinos in nursing homes are less likely to have advance directives documents in their files).

28. Amy S. Kelley et al., *Opiniones: End-of-Life Care Preferences and Planning of Older Latinos*, 58 J. Am. Geriatrics Soc. 1109–10 (2010) (discussing how the majority of older Latinos in this study do not document their end-of-life care preferences).

29. Jung Kwak & William E. Haley, *Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups*, 45 Gerontologist 634, 636 (2005) (discussing literature review of ACP among different racial groups); *see also* Degenholtz et al., *supra* note 5, at 378; Dan K. Kiely et al., *Racial and State Differences in the Designation of Advance Directives in Nursing Home Residents*, 49 J. Am. Geriatrics Soc. 1346, 1348 (2001). *See generally* G. Paul Eleazer et al., *The Relationship Between Ethnicity and Advance Directives in a Frail Older Population*, 44 J. Am. Geriatrics Soc. 938 (1996).

30. Fisher et al., *supra* note 14, at 86 (noting research evidencing that Latinos are less likely than Caucasians to complete advance directives).

31. *Id.* at 86; *see also* Kelley et al., *supra* note 28, at 1109.

32. *Id.* at 1114 (discussing older Latinos' preferences for end-of-life care); *see also* H. Russell Searight & Jennifer Gafford, *Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians*, 71 Am. Fam. Physician 515, 516–17 (2005) (discussing the manner in which cultural background influences the manner in which patients make decisions about end-of-life care); Inst. of Med., *supra* note 3, at 154.

condition.[33] Clearly, the legal emphasis on "truth telling" and autonomy is at odds with the cultural norms of some Latinos regarding end-of-life care for those they love. In its seminal report, the Institute of Medicine recommended that when addressing ACP issues, the focus should be on understanding cultural differences, identifying best practices for specific cultural groups, and developing measurable standards of effective communication that are culturally appropriate.[34]

Latinos in the United States rarely engage in ACP despite the fact that evidence shows that conversations about future health care choices reduce emotional and physical burdens on patients, caregivers, health care professionals, and family members.[35] Empirical studies suggest that individuals who partake in ACP are more likely to have their goals of care honored, are referred to hospice care earlier, and receive less aggressive treatment, which is associated with better quality of care towards the end-of-life.[36] Lawyers and conflict interveners can contribute to reduce end-of-life health care disparity (thus improving the quality of care) by designing dispute systems that facilitate the integration of ACP within a community and overcome the challenges of treating death as an isolated event.

IV.   WHY TAKE ACP TO THE COMMUNITY?

One of the many challenges in ACP is that in the United States dying is seen as a personal event isolated from the community. In spite of the fact that in 1997 the Institute of Medicine issued a report advocating the importance of embedding ACP within the community, dying continues to be treated, for the most part, as a personal event.[37] Steve Conway, a social scientist focusing on health inequality, argues that, "Individualism has colonized death."[38] By taking a personal stance, dying becomes a "personal problem" rather than an opportunity to engage with family and the community to change attitudes that perpetuate health care inequalities; clinical skills take priority over educating and training the community to achieve

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33. Searight & Gafford, *supra* note 32, at 517 (discussing cultural norms to communicating bad news across different cultural groups).

34. INST. OF MED., *supra* note 3, at 190 (noting lack of clinician's communication skills); INST. OF MED., APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE 250–51 (1997) (discussing how culture influences the communication and decision-making process in end-of-life).

35. Karen M. Detering et al., *The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial*, 340 BRIT. MED. J. 847, 847 (2010) (summarizing the results of their empirical research).

36. Wright et al., *supra* note 24, at 1668 (discussing the results of a study exploring whether end-of-life conversations between physicians and patients result in less aggressive interventions).

37. INST. OF MED., *supra* note 34, at 117, 270 (recommending public discussions about the community's responsibility to those approaching death); *see also* Irya Byock et al., *Improving End-of-Life Experience and Care in the Community: A Conceptual Framework*, 22 J. PAIN & SYMPTOM MGMT. 759, 760 (2001).

38. Steve Conway, *The Changing Face of Death: Implications for Public Health*, 17 CRITICAL PUB. HEALTH 195, 196 (2007).

much needed support and structural change.[39] The family unit, especially among Latinos as previously discussed, is at the core of an individual's community. Both the family and the individual need support from the community at large in setting adequate structures for effective ACP. Family in this context could also be neighbors who provide support and have "become" family. A culturally sensitive DSD can and must account for this type of support.

Looking at ACP as a family and community activity at the intersection with conflict is compelling because making sense of death and conflicts that arise during end-of-life care are contextual. As Allan Kellehear, a distinguished medical and public health sociologist, reminds us, a "good death has always been a reflection of the good life and these moral ascriptions have no meaning outside the social context of the dying person as citizen and the networks that underpin the social identity and experience."[40] Individuals' realities cannot be separated from the worlds they live in because their worlds influence their choices.[41] The process of making meaning of a good death takes place through an interaction between the individual, their families, and their communities.[42] Individuals are constantly negotiating, renegotiating, creating, recreating, and adapting to their circumstances, and this dynamic takes place within their families and their communities. Individuals and the groups to which they belong are part of larger systems that are interconnected. Therefore, making ACP decisions in isolation does not improve quality of care to the extent that individuals' subjective experiences are ignored and resources within the community are not taken into consideration. Inserting ACP within a Latino community that supports the individual and his/her family allows society to share the responsibility of caring for their members in a compassionate way.

V. THE SOCIAL CONSTRUCTION OF DEATH AND THE DYING EXPERIENCE

Although death and life are universal experiences, they do not have universal meanings; their meanings are socially constructed. The meaning people assign to experiences is a result of their interrelationship with the

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39. ALLAN KELLEHEAR, COMPASSIONATE CITIES: PUBLIC HEALTH AND END-OF-LIFE CARE 9 (2005).

40. *Id.* at 14.

41. Kay A. Lopez & Danny G. Willis, *Descriptive Versus Interpretative Phenomenology: Their Contributions to Nursing Knowledge*, 14 QUALITATIVE HEALTH RES. 726, 729 (2004) (discussing Heidegger's central tenet on how the individual's relationship with the world influences how a person experiences every day). *See generally* MARTIN HEIDEGGER, BEING AND TIME (1962).

42. For a discussion of the definition of a "good death," see Emily A. Meier et al., *Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue*, 24 AM. J. GERIATRIC PSYCHIATRY 261 (2016). This study conducted a literature search in all peer-reviewed articles/reports published in English that defined a "good death." The results identified themes of a good death with the top three being: preferences for dying process (94% reports); pain free death (81%), and emotional well-being (64%). This study also stresses the importance of having conversations with all stakeholders from the patient's point of view.

world.[43] This meaning is not only revealed or influenced by social factors; social actors also construct it.[44] However, the individual construction of meaning by social actors is relational in nature. As Vered Amit and Noel Dyck have pointed out, "Individuality, as a form of social enactment, is fundamentally and necessarily relational."[45] As a result, the relationship with death is not homogenous across cultures or within members of the same culture.[46] For example, studies reflect that among many Caribbean nations it is not uncommon for the dead and the living to have ongoing relationships.[47] Like the protagonist of *Pedro Páramo*, the dead continue to exist through living human beings and communicating with them through ghosts as mediums is their episteme.[48] For these individuals, "death is an instant without end."[49] Biological death does not obliterate social relationships. By taking a communal approach to ACP, setting goals for end-of-life care may be normalized in culturally supportive environments.[50]

The experiences of death, dying, living, and grief are too complex to be seen exclusively through the lens of legal documents and medical prognosis.[51] A system that embeds ACP within a community by taking into consideration the individual's autonomy and cultural values in unison with the collective expectation of end-of-life care can improve quality of life. For example, Byock's conceptual framework takes into account the individual's values (e.g., religious) and emotional needs (e.g., grief), as well as the community's values (e.g., fears and hopes), environmental needs (e.g., transportation), and support (e.g., community organizations), to improve the quality of life. All of the aforementioned concerns should be part of an effective ACP process.[52] Since conflicts are contextual, one can only address these conflicts effectively if one understands the context in which they are taking

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43. Ronald S. Valle & Mark King, Existential-Phenomenological Alternative for Psychology 8 (1978).

44. Gerard Delanty & Piet Strydom, Philosophies of Social Science: The Classic and Contemporary Readings 373 (2003).

45. Vered Amit & Noel Dyck, Claiming Individuality: The Cultural Politics of Distinction 9 (2006).

46. *See generally* Arthur Kleinman, Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry (1980).

47. Sandra L. Lobar et al., *Cross-Cultural Beliefs, Ceremonies, and Rituals Surrounding Death of a Loved One*, 32 Pediatric Nursing 44, 44 (2006) (discussing Latino rituals surrounding death).

48. *See* Juan Rulfo, Pedro Páramo (1955).

49. Carlos Fuentes, En Esto Creo 167 (2002).

50. Inst. of Med., *supra* note 3, at 160 (summarizing important aspects of effective communication when delivering a bad prognosis to patients and families); Inst. of Med., *supra* note 3, at 190 (recommending the development of standards for end-of-life communication and ACP).

51. Byock et al., *supra* note 37, at 759–60 (discussing reasons for studying the experience of end-of-life care through a community lens).

52. *Id.* at 761–62 (discussing the conceptual framework for whole community quality improvement).

place.[53] In ACP, the individual's family and community are an essential part of the context in which conversations about goals of care are discussed.

VI.   What is DSD?

DSD stands for dispute systems design and is "the intentional creation of a process to prevent or manage recurrent disputes within a system."[54] The DSD as originally developed by Ury, Brett, and Goldberg in their groundbreaking book, *Getting Disputes Resolved: Designing Systems to the Cost of Conflict*, presented three approaches to resolving a dispute: 1) reconciling interests, 2) determining who is right, and 3) determining who is more powerful.[55] Interests are needs and desires; they underlie positions and are usually identified by asking: what is more important?[56] Rights are determined by relying on an independent standard that is perceived as fair and legitimate (e.g., a statute).[57] Finally, exercising power usually takes two forms: acts of aggression (e.g., sabotage or physical attack) and withholding benefits.[58] The authors argue that organizations usually use power to solve disputes, and by ignoring interests they miss out on the opportunity of achieving resolution at lower cost, less strain in the relationship, and greater satisfaction with the results.[59]

I agree with the authors that using power as a mechanism to solve disputes may ignore creative and effective methods of solving disputes. However, I disagree with the limited conceptualization of seeing the exercise of power as exclusively "power over" through aggressions and withholding of benefits. For example, research suggests that informational power plays a key role in the lack of advance directives among African-Americans, Hispanics, and Korean-Americans; whites tend to be more knowledgeable about advance directives than the aforementioned groups.[60] This is problematic because the lack of informational power does not allow minorities and certain groups to seek out available end-of-life care services.

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53. Coby J. Anderson & Linda L. D'Antonio, *A Participatory Approach to Understanding Conflict in Health Care*, 21(4) Georgia St. Univ. L. Rev. 817, 823–25 (2004) (discussing how different worldviews and perceptions within professional groups in an institution influences their unique needs); Debra Gerardi, *The Culture of Health Care: How Professional and Organizational Cultures Impact Conflict Management*, 21(4) Georgia St. Univ. L. Rev. 857, 862 (2005) (affirming the importance of understanding the context in which conflict occurs in health care to effectively manage it).

54. Nancy H. Rogers et al., Designing Systems and Processes for Managing Disputes 3–4 (2013) (defining DSD).

55. William L. Ury et al., Getting Disputes Resolved: Designing Systems to Cut the Costs of Conflict 4–8 (1988) (discussing ways of resolving disputes in a system).

56. *Id.*

57. *Id.*

58. *Id.* at 7–8.

59. *Id.* at 15.

60. Kwak & Haley, *supra* note 29, at 635 (discussing several empirical studies on ACP knowledge and racial and ethnic diversity).

In a series of focus groups that included caregivers from eight ethnic-specific populations, the Hispanic caregivers reported, "information about needed support services was 'out there somewhere,' but did not know how to access it."[61] In relation to power, the goal would be to have a culturally sensitive DSD around ACP that supports moving beyond the coercive use of "power over" and towards a "power with" approach that guides conflict into productive channels.[62]

The idea behind an effective DSD, according to Ury, Brett, and Goldberg, is that stakeholders should be able to choose from an array of processes (e.g., negotiation, mediation, or arbitration) depending on the type of dispute they wish to solve.[63] An effective conflict management system needs to prevent disputes from arising, when possible; resolve disputes that emerge (i.e., emotional healing, reconcile competing interests, determine rights, test power dynamics); and prevent unresolved disputes from escalating in an unproductive manner.[64]

Costantino and Sickles Merchant build on Ury and his colleagues' work by adding the following tenets: 1) the designer is not the expert, rather the ultimate responsibility lies with the stakeholders; 2) the system considers larger systemic conflict management issues, such as the responses of individuals and the organization and how it fits among the organizational mission; 3) the system considers organizational dynamics and; 4) the system incorporates certain tools, such as facilitation, consensus building, and training in communication, to prevent disputes and not rely so heavily on solving the conflict.[65]

Overall, DSD scholars and practitioners agree that to have an effective and efficient system the following must be present: 1) multiple processes available to address rights-based and interest-based conflicts; 2) flexibility to switch back and forth between rights-based and interest-based conflicts; 3) high stakeholders involvement; 4) participation that is voluntary, confidential, transparent, accountable, and facilitated by a third party neutral; 5) training and education of stakeholders on how the system works, and 6)

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61. Andrew E. Schlarlach et al., *Cultural Attitudes and Caregiver Service Use: Lessons from Focus Groups with Racially and Ethnically Diverse Family Caregivers*, 47(1/2) J. of Gerontological Soc. Work 133, 145 (2006) (discussing the lack of knowledge as a service barrier to end-of-life care services).

62. Bernard Mayer, Staying With Conflict: A Strategic Approach to Ongoing Disputes 151–52 (2009) (discussing how to use power wisely in conflict escalation).

63. Stephanie Smith & Janet Martinez, *An Analytic System for Dispute System Design*, 14 Harv. Negot. L. Rev. 123, 129 (2009) (discussing the array of alternative dispute resolution processes in a dispute system).

64. *See* William L. Ury, *Conflict Resolution among the Bushmen: Lessons in Dispute Systems Design*, 11(4) Negot. J. 379, 380 (1995) (describing the main functions of an effective conflict management system).

65. Cathy A. Costantino & Christina Sickles Merchant, Designing Conflict Management Systems: A Guide to Creating Productive and Healthy Organizations 47–78 (1996) (describing the authors' conflict management system).

fairness and justice.[66] Furthermore, in my opinion, the system must have the ability to address conflicts that arise as a result of holding different cultural values.

VII.   Why is DSD a Good Framework to Embed ACP in the Community?

Taking a DSD approach to ACP in a community could serve as an effective way to engage with and preempt conflicts related to setting goals of care because its postulates are grounded on predicting the occurrence of reiterated disputes and creating a systematic way of addressing them.[67] Using Smith and Martinez's analytic framework for developing and designing a DSD, this section explores advantages and challenges of using such a model to support ACP in a community and address conflicts that happen by failing to set goals of care for the end-of-life.[68] The analytic framework emphasizes five elements: 1) goals; 2) processes and structure; 3) stakeholders; 4) resources; and 5) success.[69]

A.   Goals

Goals should include a clear identification of the types of conflicts the system seeks to address and accomplishments sought.[70] DSD provides a sound framework to move the community towards ACP in a structured manner that tends to prevent, resolve, or productively engage with conflicts that usually take place during end-of-life care and may prove helpful for conflicts that do not have a solution.[71] A DSD approach may also serve as an excellent framework to increase community members' awareness of available resources and may connect its members in novel ways.[72]

Separating dying and the loss that comes from it has communal and institutional consequences that, if unattended, will most likely lead to disagreement and uncertainty as to how the patient's medical needs should be managed. When people are not supported in ACP, conflict during end-of-

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66. Smith & Martinez, *supra* note 63, at 128–29 (discussing how to assess the quality of dispute system designs); *see also* Andrea Kupfer Schneider & Natalie C. Fleury, *There's No Place Like Home: Applying Dispute System Design Theory to Create a Foreclosure Mediation System*, 11(2) Nev. L. J. 368, 376–77 (2011) (discussing dispute system design principles and theories).

67. Slaikeu, *supra* note 2, at 395 (discussing the postulates of DSD).

68. Smith & Martinez, *supra* note 63, at 129–33 (discussing a framework for analyzing a DSD).

69. *Id.* at 133 (presenting a graphic summary of a framework for analyzing a DSD).

70. *Id.* at 129 (defining the elements of goals for a system).

71. Mayer, *supra* note 62, at 11–15 (discussing how to support people to engage constructively with an ongoing conflict that has no solution in sight); *see also* Charity Scott, *Ethics Consultations and Conflict Engagement in Health Care*, 15 Cardozo J. of Conflict Resol. 363, 381–82 (2014) (adopting Mayer's definition of conflict engagement and recognizing that in health care there are some conflicts that may not have a solution but they may be transformed into opportunities to improve the patient's care and wellbeing).

72. Kellehear, *supra* note 39, at 118 (describing what is community development).

life decision-making is almost guaranteed. Conflicts during end-of-life care usually fall under one (or more) of the following categories: 1) conflict among family members (including patient with family); 2) conflict between patient or family members and a health care professional; and 3) conflict among the team of health care providers.[73] Many of these conflicts are a result of miscommunications,[74] avoiding difficult conversations about goals of care for end-of-life,[75] lack of clarity about the patient's wishes,[76] treatment disagreements,[77] and clashes of worldviews (or realities) among stakeholders.[78]

At the heart of many of the end-of-life care conflicts is the tension between autonomy and interdependence. In the United States, the ethical principal of autonomy lies at the core of bioethical decisions and ACP.[79] The principle of autonomy dictates that when an ethical decision is made, medical professionals must "respect the views, choices, and actions of others."[80] This means that patient autonomy is at the center of the decision-making process and priority needs to be given to the choices that the patient makes based on his individual values. Unfortunately, privileging individual autonomy creates tension by ignoring the patient's interdependence and connectivity with other people.[81] Privileging autonomy has also proven to

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73. Gerardi, *supra* note 2, at 105 (identifying types of conflicts around end-of-life care).

74. Carol Liebman*, Introduction to the Symposium Issue on Alternative Dispute Resolution Strategies in End-of-Life Decisions*, 23(1) Ohio St. J. on Disp. Resol. 1, 8–9 (2007) (discussing why health care institutions are an incubator for miscommunications and why these problems are heightened by other factors such as distrust, uncertainty, and complexity).

75. *Id.* at 9 (discussing physician's lack of training in communication and their conflict avoidance behavior); *see also* David C. Leven, *Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action*, 58 N.Y.L. Sch. L. Rev. 403, 408 (2013–14) (noting that lack of timely conversations between patient and physician about ACP is detrimental to patient's care).

76. Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34(2) The Hastings Ctr. Rep. 30, 37 (2004) (discussing research showing physician's lack of exploration as to patient's preferences and the use of vague language in their communication with patients).

77. Michael D. Fetters et al., *Conflict Resolution at the end of life*, 29(5) Crit. Care Med. 921, 921 (2001) (discussing tension between patient or family, and physician when there is disagreement as to the medical treatment requested).

78. *See* Searight & Gafford, *supra* note 32, at 515 (discussing the manner in which cultural background influences the manner in which patients make decisions about end-of-life care). "[W]orldview. . .is a conceptual scheme by which we consciously or unconsciously place or fit everything we believe and by which we interpret and judge reality" *quoted in* Ronald H. Nash, Worldviews in Conflict: Choosing Christianity in a World of Ideas 16 (1992).

79. Inst. of Med., *supra* note 3, at 124–25 (discussing ACP and the ethical principles of autonomy); *see also* Searight & Gafford, *supra* note 32, at 516 (discussing principlism and the value of autonomy).

80. Tom Beauchamp & James Childress, Principles of Biomedical Ethics 57 (5th ed. 2001).

81. Inst. of Med., *supra* note 3, at 125 (describing the consequence of privileging autonomy in the ACP process).

be culturally insensitive towards cultural groups that place more value in collective decision-making when making medical decisions.[82]

At the present time, people spend a significant amount of time in their community before they die.[83] Through increases in technology and advances in science, it is estimated that the average American male's health is deteriorating for five years prior to dying, and for an American female the average is eight years.[84] Therefore, bridging DSD with a community approach to ACP becomes extremely relevant and necessary.[85] Guidance, education, conflict engagement, counseling, support, and discernment take place in the community with the support of individuals such as religious leaders, financial planners, funeral home directors, medical personnel, lawyers, social workers, caregivers, family members, and colleagues at work, to name just a few. It clearly takes a village to die well.[86] As one can expect, this interdependency creates tension between the individual's autonomy and his or her need for community support.

In Bernard Mayer's recent book, he discusses the tension that people in conflict experience between their want to share their need for community and autonomy, and their need for independence and affiliation.[87] There are few scenarios in which the tension between community and autonomy are so intertwined as in ACP. One of the reasons for which individuals prepare a living will and/or a medical power of attorney is to retain control and autonomy over their medical decisions when they are no longer capable of doing so themselves.[88] However, individuals depend on their community members to have their end-of-life care goals honored. Only a culture that exceedingly values self-determination, individuality, and freedom would construct terms such as "managed death," "advanced directives," "living wills," "do not resuscitate orders," and "allowed natural death"—as if there

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82. Searight & Gafford, *supra* note 32, at 516 (discussing principlism and impact on non-Western cultures).

83. John Hardwig, *Going to Meet Death: The Art of Dying in the Early Part of the Twenty-First Century*, 39(4) Hastings Ctr. Rep. 37, 38 (2009) (noting that people nowadays have prolonged deaths as a result of technological and medical advancements).

84. *Id.*

85. For an example of a successful DSD approach and community engagement through "Cure Violence," see Rogers et al., *supra* note 54, at 20–22. Cure Violence is a health model that has been implemented in many cities throughout the world and is designed to reduce violence in communities.

86. For an exhibition by Colin Gray, award winning photographer, illustrating the idea that as people's health deteriorates they need community support see: https://www.goodlifedeathgrief.org.uk/content/it-takes-a-village/.

87. Bernard Mayer, The Conflict Paradox: Seven Dilemmas at the Core of Disputes 237–65 (2015) (discussing the tension between autonomy and community).

88. Joan M. Teno et al., *Association Between Advance Directives and Quality of End-of-Life Care: A National Study*, 55(2) J. Am. Geriatr. Soc. 189, 189 (2007) (discussing purpose of drafting advance directives).

were a choice. I propose that just as we cannot develop as humans in isolation,[89] we cannot have a "good death" in isolation.

B.   *Processes and Structures*

Although most of the DSD scholars focus primarily on systems aimed at resolving disputes within an organization, some system designers have been creating processes in other venues to seek justice and safety, change the *status quo*, achieve personal or public understanding, or move towards reconciliation.[90] DSDs that are taking a broader approach, and in which a resolution is not the main or only goal, may consider including other approaches, such as storytelling,[91] Reflective Structured Dialogues,[92] World Café Dialogues,[93] and Bioethics Mediation, as part of the design process.[94] These processes may also be useful in addressing conflicts that result as a clash of worldviews (as opposed to interests) that happen in the ACP process and disagreements over end-of-life care. Worldviews collide when people have a different sense of reality or truthfulness, logical reasoning, values, acquisition of knowledge, or what is the proper way to act.[95]

As an illustration of the types of processes and structures that may be useful in addressing the conflicts discussed above, consider the following case study:

Dr. John Smith, medical oncologist, returned from vacation and found that Juan Rodríguez, (his 70 year-old, Puerto Rican patient, with metastasized cancer and many other illnesses) was on a ventilator in the intensive

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89. MAYER, *supra* note 87, at 240 (defining community as an essential human need).

90. ROGERS ET AL., *supra* note 54, at 201–17 (discussing developing DSD that seek justice, safety, reconciliation, change, personal and public understanding, and other non-problem solving goals).

91. *Id.* at 213–14 (discussing the use of storytelling by Philippine war victims with the goals of public and personal understanding, and setting the stage for change).

92. This type of dialogue was developed by Public Conversations Project, and it aims to have individuals with opposing views get together and have a respectful dialogue to share experiences and listen to each other's perspective so they become comfortable with those in which they are in disagreement. *See* PUBLIC CONVERSATIONS PROJECT, http://www.publicconversations.org/our-method (last visited April 16, 2016).

93. Font-Guzmán, *supra* note 5, at 61–63 (discussing the use of World Café Dialogue to unveil structural and cultural violence that drives the behaviors that maintain end-of-life care inequalities, especially among minorities, in acute health care hospitals); *see* Font-Guzmán, *supra* note 5, at 61; *see also* JUANITA BROWN & DAVID ISAACS, THE WORLD CAFÉ: SHAPING OUR FUTURES THROUGH CONVERSATIONS THAT MATTER (2005) (defining the World Café dialogue as a conversational process that surfaces collective understanding, as opposed to problem solving, by surfacing peoples' deep assumptions through intimate exchanges and cross-pollination of ideas).

94. Bioethics mediation provides a problem-solving model that aims to achieve consensus on future care interventions within accepted ethical and legal standards. *See* DUBLER & LIEBMAN, *supra* note 2, at 14; *see also* Font-Guzmán, *supra* note 5, at 59–61 (discussing the bioethics mediation process).

95. JAYNE SEMINARE DOCHERTY, LEARNING LESSONS FROM WACO: WHEN THE PARTIES BRING THEIR GODS TO THE NEGOTIATION TABLE 50–51 (2001) (defining and indicating how to delineate someone's worldview).

care unit. Juan always had great pride in being self-sufficient, and within his family, topics like death and end-of-life care were never discussed. His wife, María Rodríguez, is a practicing Catholic from the Dominican Republic and, although she can communicate in English, she sometimes has difficulties with English and would rather have these difficult conversations in her native language, Spanish. María is frightened that Juan may die and has asked Dr. Smith to pursue all possible treatments available to keep him alive. She firmly believes that taking Juan off the ventilator would be the equivalent of murder and his soul will be "stuck" forever in limbo. Dr. Smith is complying with the request and has placed Juan on full code. Three of their five sons are in agreement with providing all available treatments; the other two are demanding that their father be taken off the ventilator because they are convinced that such treatment is futile and their father would have never wanted to live this way. Additionally, one of their sons and his wife are atheists who think that María is insane by talking about a "limbo," while another son believes that his father will not die until his prior lover tells him that she forgives him. However, María refuses to let "that woman" come near Juan's death bed. Based on previous conversations with Juan, Dr. Smith infers that his patient would most likely have never asked to be on a ventilator. Dr. Smith also sees that María is scared. Arguments among the family as to future treatment decisions for Juan are in crescendo, and some are threatening to go to court. The family is struggling financially, all the sons live out of state, and María is the sole caretaker. María has a full-time job that she may lose soon if she keeps on missing work. Juan has no advance directives or durable power of attorney and never shared with anyone his goals for his end-of-life care.[96]

Some of the points of tension and conflict in the above scenario could have been prevented or effectively managed if there was a better understanding of the meaning of a "good death" for Juan and if the stakeholders were informed about ACP. For example, if Juan knew the stress that failing to set goals for end-of-life care would have on his family and knew about the availability of ACP, he may have chosen to have a conversation that may have led to having an advance directive. Juan may have also have been able to identify that ACP was a way of exercising his desire to be self-sufficient, and this did not necessarily mean that he was losing his sense of belonging to his family community by raising a taboo topic. Juan's autonomy was not only threatened by his inaction, but also by his relationship with his wife and family customs that may not have allowed him to articulate his wishes and experience his emotions independently of his family

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96. The author has prepared this narrative, and it is an amalgam of actual cases that she has observed in end-of-life situations.

members.[97] As previously discussed, this is a classic example of the paradox between autonomy and community; you cannot have one without the other.

A conflict intervener could address the tension between community and autonomy by coaching disputants through their conflict while simultaneously creating a space that allows them to stay connected to who they are and how they are changing.[98] Applying Mayer's framework, conflict interveners need to focus on three challenges when working with stakeholders to address the autonomy-community tension: 1) support stakeholders need for autonomy as they reach out to the other party; 2) keep the stakeholders connected as they withdraw or escalate conflict; and 3) walk stakeholders through the different communities as they experience conflict.[99]

A conflict intervener can support Juan's autonomy by facilitating ACP with Juan (before he was put on a ventilator) or any of the other stakeholders to discuss their fears and hopes. Worldview differences may trigger conflicts for which there is no resolution. A conflict intervener may support Juan in having a conversation with María regarding his wishes for end-of-life care, being well aware that although this topic upsets her and they may not agree on the path to follow, it needs to be discussed. On many occasions, disputants may be in a conflict that has no resolution, and they may have to escalate conflict while remaining engaged with the issues that are important to them.[100] Escalation becomes a tool to stay with conflict in a constructive and effective way; the unacceptable alternative is to avoid dealing with an important issue. Other ways of partnering with Juan to support his autonomy are breaking down ACP by discussing the meaning of a "good life" which can be less threatening to his self-image of being self-sufficient than talking about death; eliciting from Juan his story about how his illness may have changed him and how he experiences his "new-self;" and naming the challenges of facing death for Juan and his family.[101]

A conflict intervener may also keep the stakeholders connected through their conflict by supporting the manner in which they discuss and frame ACP, keeping the channels of communication open, and allowing for escalation in a contained fashion through coaching.[102] For example, although María and her sons are in disagreement about what is the best treatment for Juan, it is important that they keep their channels of

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97. MAYER, *supra* note 87, at 245 (explaining that threats to autonomy include not having freedom to act and not being able to think or feel for oneself due to the influence that relationships have upon individuals).

98. *Id.* at 250.

99. *Id.* at 249 (identifying the challenges in addressing the autonomy-community paradox).

100. MAYER, *supra* note 62, at 10–11.

101. *See* MAYER, *supra* note 87, at 249–54 (discussing how to support disputants manage their fear of losing autonomy as they engage with those on the other side).

102. *Id.* at 256 (providing examples of how a conflict intervener can keep disputing parties connected through conflict).

communication open in a way that it challenges them and simultaneously allows them to retain their sense of autonomy.

A DSD approach can provide a space for the conflict intervener to support Juan, María, their sons, and Dr. Smith as they are being pulled toward different communities.[103] The DSD model could allow for a conflict intervener to explain the different expectations from all the communities that stakeholders belong to and how they are connected to each other. In the case at hand, María is a member of her family community and also her church community. These two communities may have different values and expectations as to how Juan's illness should be managed. Having this discussion may raise María's awareness, which in turn may allow her to strategize in a more effective way the choices she makes regarding Juan's treatment, her interactions with her sons, and discussions with her priest.

Education is another important component to prevent or stay constructively with conflicts that have no solution and that result from lack of ACP. The importance of community involvement to better understand the experience of death and the responsibilities of families and the community was recognized by the Institute of Medicine.[104] The report identified the need for public education programs that enhance understanding of end-of-life needs and the importance of ACP.[105] The Institute of Medicine's latest report on the topic of death and dying not only encourages public education on dying, but also takes it one step further and recommends that members of the community (e.g., civic leaders, community-based organizations, faith-based groups, and professional societies) actively interact with individuals to encourage ACP.[106]

Education may happen through processes such as World Café Dialogues or Reflective Structured Dialogues. For example, during 2015 and 2016, in collaboration with another colleague, I facilitated a series of World Café Dialogues throughout Omaha and Bellevue, Nebraska to explore what constitutes a "good death" in Nebraska, raise awareness on ACP, share perspectives and knowledge on dying and ACP, and hear narratives that Nebraskans wished to share.[107] These World Café Dialogues took place in different community settings (e.g., universities, health care institutions, and

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103. *Id.* at 257–59 (discussing strategies to support parties in conflict to deal with multiple communities and attachments).

104. INST. OF MED. *supra* note 34, at 270 (providing recommendations for future directions to improve end-of-life care).

105. *Id.* at 117 (summarizing important factors to consider in establishing a 'whole community' model for care at the end of life).

106. INST. OF MED. *supra* note 34, at 346, 370 (noting and recommending the importance for professionals and community leaders to publicly engage the community and educate them in ACP).

107. Research grant was awarded to author and Dr. Helen Stranton Chapple (the Center for Health Policy and Ethics at Creighton University) by Creighton's Haddix President's Faculty Research Fund to explore what constitutes a good death in Nebraska, medically, legally, and interpersonally.

senior centers in different communities) with the participation of patients, physicians, nurses, health care professionals, clergy and spiritual leaders from different congregations, and community members in general. In the scenario of María and Juan, all the stakeholders could have enhanced their understanding of ACP, shared and listened to other community members' experiences with ACP and living with life threatening illnesses, and identified available resources in the community.

Reflective Structured Dialogues could also be helpful in preventing, engaging with, or solving conflict to the extent it allows stakeholders to clarify their perspectives, share their emotions in a safe space, and discuss opposing positions in a way that heals as opposed to divides.[108] In our case study, Dr. Smith would have a space to share with María his concern about providing a treatment to Juan that may be too aggressive and not what Juan may have wished for. Likewise, through a Reflective Structure Dialogue, María could have a conversation with her atheist son and discuss their different points of view regarding life, death, and spirituality with the purpose of understanding each other. These worldview conversations can set up parties for success in any future problem-solving activity (e.g., negotiation, mediation) pertaining to Juan's treatment. Conversations related to worldviews are not usually part of a DSD that emphasizes solving conflicts because the assumption is that problem-solving takes place in an "uncontested given reality."[109] However, when stakeholders are not allowed to manage their clash of worldviews, they are unable to problem-solve and reach agreements based on rules, roles, and relationships because they are focused on "negotiating reality."[110]

If conflict cannot be prevented and stakeholders are in need of a resolution, having bioethical mediation available at health care institutions could be an alternative before taking the conflict to the legal system. As described before, bioethics mediation provides a problem-solving model that aims to achieve consensus on future care interventions within accepted ethical and legal standards.[111] In the case scenario of Juan and María, bioethics mediation could be helpful in having the family members realize the severity of Juan's illness and craft goals of care for Juan in collaboration with the health care providers.

These processes could be available in institutions throughout the community, such as churches, medical facilities (e.g., hospitals, hospices), se-

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108. Robert R. Stains, Jr., *Repairing the Breach: The Power of Dialogue to Heal Relationships and Communities*, 10(1) J. PUB. DELIBERATION, 1, 2–3 (2014) (discussing the benefits of reflective structured dialogues in general).

109. DOCHERTY, *supra* note 95, at 55 (explaining the relationship between worldviewing and conflict).

110. *Id.* at 53, 56.

111. DUBLER & LIEBMAN, *supra* note 2, at 14 (defining bioethics mediation); *see also* Font-Guzmán, *supra* note 5, at 59–61 (discussing the bioethics mediation process).

nior centers, intercultural centers, mediation centers, community colleges, and similar institutions.

C. *Stakeholders*

In the DSD field, stakeholders are defined as those individuals who have a stake in the end result because they are directly involved or affected by the conflict.[112] In an institution or organization, the boundaries and stakeholders are usually clearly defined (e.g., all employees of XYZ Corporation). However, identifying stakeholders and addressing their different goals and needs is more of a challenge when the DSD is being developed in a community or outside a traditional organization.[113] A possible way of addressing this challenge is by focusing on social networks (instead of institutions) and adopting a theoretical framework that sees networks as dynamic, unbounded, and socially constructed by its members.[114] The suggested theoretical framework would emphasize in-depth descriptions of the nature of individuals' relationships, how they maintain them, and their role in society.[115]

In the Juan and María scenario, one would start by recognizing that the term "Latino" is a social construct.[116] In other words, race[117] and ethnicity[118] are defined through social interactions that take place in a specific historical context. For example, a Puerto Rican seen as white in Puerto Rico is "re-classified" as black when he or she moves to the U.S. mainland.[119] Therefore, since the focus of the proposed dispute system is to embed ACP

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112. ROGERS ET AL., *supra* note 54, at 6 (discussing the importance of identifying stakeholders).

113. *Id.* at 22 (explaining how to asses a current situation in a community).

114. Rosemary Leonard et al., *Identifying changes in the support of networks of end-of-life carers using social network analysis,* 2013 BMJ SUPPORTIVE & PALLIATIVE CARE 1, 1–2 (discussing the use of social network analysis to identify a particular community).

115. *Id.* at 1.

116. *See* PETER WADE, RACE AND ETHNICITY IN LATIN AMERICA 12–14 (1997) (discussing that many scholars have stepped away from the biological concept of race and are seeing race as a social construct).

117. UNITED NATIONS EDUCATIONAL, SCIENTIFIC AND CULTURAL ORGANIZATION, THE RACE QUESTION, 791 (1950) http://unesdoc.unesco.org/Ulis/cgi-bin/ulis.pl?catno=128291&gp=0&lin=1 &ll=s, (UNESCO statement, based on the opinion of a group of experts in anthropology, genetics, sociology, and psychologists, asserting that "race is a biological myth and there is only one human species").

118. *See* RICHARD JENKINS, RETHINKING ETHNICITY: ARGUMENTS AND EXPLORATIONS 13–14 (2003) (discussing that although there is no consensus on the meaning of ethnicity, many scholars associate ethnicity with the inclusion in a group that share meaning within a shared structure that takes place through social interaction); s*ee also* JEROME M. LEVI & BARTHOLOMEW DEAN, AT THE RISK OF BEING HEARD: IDENTITY, INDIGENOUS RIGHTS, AND POSTCOLONIAL STATES, 5 (2003) (arguing that a group does not become an ethnic group by merely sharing meaning; they must also develop political solidarity and group consciousness, and this happens when the group perceives their minority status within the dominant group and decides to mobilize).

119. WADE, *supra* note 116, at 13.

in a Latino community, a "Latino" for purposes of who belongs to the "Latino" community would be those individuals who self-identify as "Latinos."

A conflict intervener could talk with María and ask her to name all the people and institutions that provide her with support and/or assist in the care for Juan. If the conflict intervener asks the same question to all the identifiable stakeholders in María's conflict (e.g., sons, medical care providers, extended family), he or she can establish the networks of care for Juan and see how they are linked with each other. By taking a social network approach to identifying stakeholders, the designer does not have to set arbitrary boundaries, and by focusing on social actors and their connections, the designer can explore the complexity and ambivalence of relationships.[120] A social network approach would also allow the active participation of members of the community such as priests, counselors or support groups who, although they are not technically stakeholders, may influence the direction of the process.

A DSD approach that integrates ACP in a community would have numerous stakeholders, influencers, and networks. A possible list of stakeholders and influencers in the scenario being discussed in this Article may include: health care institutions (e.g., hospices, hospitals, and nursing homes), health care professionals (e.g., nurses and physicians), lawyers, local public service agencies, churches, neighborhood associations, funeral homes, community colleges, civic associations, bereavement groups, local media, and universities in the community.[121]

D.   Resources

Finding resources to fund a DSD system outside of an organization is quite an endeavor. Resources are needed not only to develop the program, but also to sustain it by having adequate staffing and professionals capable of delivering high quality services.[122] Community engagement to improve ACP and end-of-life care could be potentially sponsored by health care institutions, a coalition of organizations, community-based organizations, churches, universities (through grants), and local governments, to name a few.[123] Given the increasing cost of end-of-life care and the lack of correlation between high cost of care and improved outcomes, there may be a

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120.   Leonard et al., *supra* note 114, at 1–2 (discussing how a third generation social networks approach is a good way of overcoming criticisms of other social network approaches).

121.   Byock et al., *supra* note 37, at 764 (discussing the components of community structures).

122.   Smith & Martinez, *supra* note 63, at 141 (discussing the need and struggle of a system to find the resources to support itself).

123.   Byock et al., *supra* note 37, at 764 (applying a conceptual framework to improving end-of-life care in a community).

potential increase in sources of funding for embedding ACP within the community in the near future.[124]

E. *Success*

Success needs to be measured by gathering data that can reliably assess aspects of ACP and end-of-life care.[125] Measuring success under this model could be done by surveying people before and after they go through a bioethics mediation or participate in a World Café Dialogue to see if they have increased their knowledge of ACP and resources available in the community; conducting structured and semi-structured interviews (e.g., after death interviews with family members and/or physicians); and reviewing medical charts to determine if there has been an increase in ACP completions.[126]

Taking the social network approach discussed above can also serve as a tool to measure success. The proposed social network approach has the advantage that it can assist in identifying stakeholders and can also serve to evaluate if the network is increasing in size and if community capacity is being enhanced.[127] In the case of Juan and María, a conflict intervener could facilitate a focus group and have María and everyone participating in Juan's care write their names on a large piece of paper and trace a line to other people and institutions in their network.[128] The strength of the relationship (weak, medium, or strong) can be measured by using colored markers. Participants in this networking mapping activity will end up with a visual image of their networks and the strengths among the different networks.

Qualitative analysis of the focus group discussion and quantitative analysis of the network maps using software for Social Network Analysis could be used to measure the strength of participants' ties within the network, trends in bridging activity, and identifying resources that are being used effectively.[129] The qualitative analysis could consist of having a discussion with the participants in the focus group of their observations regarding the network maps they created. Through a group discussion,

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124. Gerald W. Neuberg, *The Cost of End-of-Life Care: A New Efficiency Measure Falls Short of AHA/ACC Standards*, 2 Circ. Cardiovasc. Qual. Outcomes 127, 127 (2009) (discussing high costs of end-of-life-care).

125. Byock et al*., supra* note 37, at 762 (discussing an evidence-based model for improving end-of-life care in a community).

126. *Id.*; *see also* Bernard J. Hammes & Brenda L. Rooney, *Death and End-of-Life Planning in One Midwestern Community*, 158 Arch. Intern. Med. 383 (1998); Kellehear, *supra* note 39, at 133–36.

127. Leonard et al., *supra* note 114, at 2 (noting advantages of third generation social network theory).

128. *Id.* at 2–3 (the method discussed in the rest of this paragraph is following the design used to analyze the caring networks of patients who are terminally ill).

129. *Id.* at 4–5 (discussing qualitative analysis using a network mapping approach).

participants can flush out the nature of their network ties, the meaning of those ties, and changes in the strength or quality of their relationships to their network ties throughout time, to name just a few.[130] Some examples of quantitative analysis are turning the network maps prepared by participants into computerized network maps using NetDraw 2.117 within UCInet to measure aspects such as size of the networks (number of individuals), density of the network (number of ties divided by number of potential available ties to identify strength of relationships), and transitivity (reciprocity among three individuals in the network to identify if they are connecting in egalitarian and collaborative ways).[131]

X. ACP as part of a Complex Adaptive System

This Article frames ACP within a Complex Adaptive System (CAS) as it relates to health care and the community. A CAS is defined as a large number of independent actors (or agents) who are interconnected and through their interactions establish patterns of behaviors throughout the system that influence each other.[132] Through simple rules and actors' interactions, the system self-organizes and refines itself without the intervention or tendency of an individual agent.[133] Four key elements of a CAS model include: 1) agents with schemata (i.e., cognitive structures/worldviews); 2) self-organizing networks sustained by importing energy; 3) coevolution to the edge of chaos; and 4) recombination and system evolution.[134] How do these characteristics serve as a framework for a DSD that embeds ACP within a community? What are the implications for health care of viewing ACP as a CAS?

A. *Agents with schemata (i.e., cognitive structures/worldviews)*

In a CAS, there is not one single truth, and interaction among stockholders (also identified as agents and individuals) is unpredictable because their worldviews shape their behavior and relationships may be negatively affected by their different beliefs.[135] Different agents could have the same or different worldviews, and worldviews may evolve or remain static over

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130. *Id.*

131. *Id.* at 2 (discussing quantitative analysis using a network mapping approach).

132. Kevin J. Dooley, *A Complex Adaptive Systems Model of Organization Change,* 1 Nonlinear Dynamics, Psychol. and the Life of Sci. 69 (1997); *see also* P. E. Plsek & T. Greenhalgh, *Complexity Science: The Challenge of Complexity in Health Care,* 323 British Med. J. 625, 625 (2001).

133. Philip Anderson, *Complexity Theory and Organization Science*, 10 Organization Sci. 216, 221–22 (1999).

134. *Id.* at 219–20.

135. Cary A. Brown, *Reconceptualizing chronic pain as a complex adaptive system*, 8 E:CO 2, 5 (2006) (discussing relationships as central to understanding systems)*; see also* Anderson, *supra* note 133, at 219 (discussing impact of agent's schema on the system).

time.[136] ACP takes place through the interaction and interconnectivity with family and the community. An individual's end-of-life care choice as a result of ACP will be influenced by his/her beliefs (e.g., religious), the legal system, and the reimbursement system, to name just a few. Through the course of an illness these choices may change or become more entrenched as a result of interactions with other systems or individuals within the system. However, the constant flow of information and the presence of diverse worldviews in the system enhance new information, innovation, and self-organization.[137]

B.   *Self-organizing networks sustained by importing energy*

Agents within the system are connected to one another, and as a consequence, the behavior of an individual agent depends on the behavior of other agents in the system.[138] When a system is open to its environment, it imports new "energy" into the system, which moves it away from its equilibrium into chaos and reorganizes into a new structure. Living systems cannot be forced or directed to follow a linear path because unforeseen issues will arise. Therefore, the challenge is to figure out how much one should disturb the system to approximate the desired outcome.[139] ACP most certainly cannot be forced into a linear path. Therefore, careful planning will not necessarily lead to the anticipated outcome. Legal documents are only effective if they are used as a conduit to having a conversation and establishing relationships. Relationships are important for effective self-organization.[140] It is through personal connections and networking that self-organization takes place. A DSD may set the necessary conditions for relationships to flourish throughout the ACP process. Through the course of life and illness, different options or alternatives may be more or less appropriate. As discussed in this Article, a way of disturbing the system or importing energy may be escalating conflict in a productive manner to reach the "sweet spot" that results in a different decision-making process as to what is the meaning of life, what is the course of treatment to follow, or should a particular treatment be discontinued.

C.   *Coevolution to the edge of chaos*

"The edge of chaos is a condition, not a location. [. . .] The edge is not the abyss. It's the sweet spot for productive change."[141] CAS theories pre-

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136. *Id.*

137. *Id.* at 104, 174 (discussing impact of diverse worldviews on the system).

138. Anderson, *supra* note 133, at 219 (discussing impact of agent's schema on system).

139. Richard T. Pascale et al., Surfing The Edge of Chaos: The Laws Of Nature and the New Laws of Business 6 (2000).

140. M.L. Piven et al., *MDS Coordinator Relationships and Nursing Home Care Processes,* 28(3) Western J. of Nursing Res. 294, 296 (2006).

141. Pascale et al., *supra* note 139, at 61.

sume that the adaptation of the system is based on the efforts of the agents that compose the system to increase their payoffs.[142] What constitutes an increase in payoff will be constantly shifting and adapting because the payoff of a particular agent depends and is connected to the payoff of other agents in the system. Based on this assumption, the most effective systems are those that place themselves at the "edge of chaos" and can strike a healthy balance between flexibility and stability.[143] In other words, complex systems that maintain their *status quo* and only make slight changes in their behavior will not enhance their performance; constant equilibrium equals death.[144] In the topic at hand, if end-of-life care goals are not set or difficult conversations are avoided because there is no structure available to productively "disturb" the system, there is the potential for a terminally ill patient on a ventilator to not have his or her wishes of discontinuing treatment honored. By preserving the *status quo*, people are forcibly kept alive which may result in spending a significant amount of money on futile care.

D.   *Recombination and system evolution*

CAS models evolve through the "entry, exit, and, transformation" of actors within the system.[145] As a result of this dynamism, the links among agents may change in strength, interconnectedness, and function within the system.[146] The transformation of a CAS takes place within a "nested hierarchy" that contain other CASs.[147] In prior sections, I have illustrated how different CASs (e.g., family unit) are embedded within other CASs (e.g., religious groups), which in turn are nested in other CASs (e.g., hospital). Likewise the ACP experience is nested within different cultural systems, such as cultural sub-groups, economic status, and language. Seeing ACP as a CAS and experiencing the recombination of the system and its evolution can be overwhelming for an individual.[148] If one sees end-of-life care conversations as connected to other systems (e.g., family, physicians, religious community), managing and controlling these decisions becomes an enormous task. There is a sense of "empowered powerlessness," the paradox of feeling responsible for ACP and simultaneously powerless.[149]

The proposed approach of designing a culturally sensitive DSD that embeds ACP in the community aims at supporting individuals' needs to manage this paradox by taking incremental steps in their decision process and being receptive to modifying decisions as their health condition

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142. Anderson, *supra* note 133, at 223 (discussing coevolution at the edge of chaos).
143. *Id.* at 224 (discussing coevolution at the edge of chaos).
144. Pascale et al., *supra* note 139, at 19–21.
145. Anderson, *supra* note 133, at 220 (discussing recombination and systems evolution).
146. *Id.* at 220 (discussing recombination and systems evolution).
147. *Id.* at 225 (discussing recombination and systems evolution).
148. Emily Martin, Flexible Bodies: The Role of Immunity in American Culture from the Days of Polio to The Age of Aids 123 (1994).
149. *Id.*

changes. In a CAS, patients and their communities become aware of their environment and as they adapt, create new systems and processes to manage their end-of-life-journey.

CONCLUSION

This Article explored novel ways in which the field of conflict engagement could contribute to closing the gap in ACP disparities by partnering with disadvantaged communities. The implementation of a comprehensive DSD that effectively incorporates ACP in a community may seem impractical to many. In fact, the mere process of thinking about it can be daunting. However, there have been communities that have been able to improve end-of-life care and increase the use of ACP by taking incremental steps in adopting a "whole community" or "compassionate cities" approach to end-of-life care.[150] This Article has shared some processes used in the conflict field that could enhance ACP and allow community members to have a forum and acquire the necessary skills to prevent and/or deal with end-of-life conflicts.

The dying process could be a positive experience for many people, but when the process of dying is protracted and one has not discussed goals of care, it can be agonizing for all involved. Taking a culturally sensitive DSD approach to ACP would allow community members to see dying as part of their community system, which could prevent conflict when possible or at least engage with it in a constructive manner. Conflict interveners and community members could partner in developing a DSD that improves end-of-life care in marginalized communities and closes the gap in ACP. The reality of dying as a social process has implications for the role of the community, conflict practitioners, and attorneys in ACP. Conflict practitioners may facilitate through a culturally sensitive DSD approach the manner in which death transforms the relationship with the living and the community.

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150. *See generally* Byock et al., *supra* note 37; KELLEHEAR, *supra* note 39; Hammes & Rooney, *supra* note 126.