END-OF-LIFE DECISION MAKING, THERAPEUTIC JURISPRUDENCE, AND PREVENTIVE LAW: HIERARCHICAL V. CONSENSUS-BASED DECISION-MAKING MODEL

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I. INTRODUCTION

Over the past three decades, courts addressing cases involving the forgoing of life-sustaining medical treatment ("LSMT")[1] have of necessity developed a new body of law to resolve what are frequently cases of first impression.[2] In addition to establishing the respective rights of the parties involved, courts have also had to address *how* end-of-life ("EOL") decisions should be made. Judges describe these cases as posing some of the most challenging, perplexing, and fiercely debated issues they have faced.[3] Nevertheless, courts have reached an almost uniform conclusion that decision-making authority should be given to a single individual drawn from the apex of a hierarchy of individuals with interests in

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1. Life-sustaining medical treatment has been defined as "any medical treatment that serves to prolong life without reversing the underlying medical condition." Council on Ethical and Judicial Affairs, Am. Med. Ass'n, *Decisions Near the End of Life*, 267 JAMA 2229, 2229 (1992).

2. *See* THOMAS L. HAFEMEISTER & PAULA L. HANNAFORD, RESOLVING DISPUTES OVER LIFE-SUSTAINING TREATMENT: A HEALTH CARE PROVIDER'S GUIDE 9 (1996).

3. *See infra* note 60 and accompanying text.

a given EOL decision—in other words, that a hierarchical decision-making model should be employed.

During this time span, however, two approaches for improving decision making on law-related issues have gained prominence, namely, Therapeutic Jurisprudence and Preventive Law. Although developed independently, they share many similar goals. One goal is adapting law-related decision making to take into account the short-term and long-term psychological well-being of individuals affected by these decisions. Another, related goal is avoiding the undue use of an adversarial approach as a means to routinely undertake this decision making.

This Article proposes that the integrated principles of Therapeutic Jurisprudence and Preventive Law can and should be applied to EOL decision making. Furthermore, this Article asserts that a consensus-based decision-making model, an approach harmonious with the integrated tenets of Therapeutic Jurisprudence and Preventive Law, is already being widely and appropriately employed in conjunction with these decisions. The use of this model has occurred, however, without explicit recognition of its linkage to Therapeutic Jurisprudence and Preventive Law and notwithstanding that court opinions in the United States, strictly construed, mandate the use of a hierarchical decision-making model.

By making this link to Therapeutic Jurisprudence and Preventive Law explicit, a stronger jurisprudential base can be established for the use of a consensus-based EOL decision-making model. Although such a model potentially conflicts with the hierarchical decision-making model generally endorsed by the courts, it can promote two objectives widely espoused by the courts and others concerned about these decisions—namely, respecting and promoting the interests of the various individuals directly affected by EOL decisions and minimizing the involvement of the courts in this decision-making process. Thus, courts should reappraise their endorsement of the hierarchical model and instead facilitate the use of a more consensus-based model for making EOL decisions in general. This argument is reinforced by a review of the literature generated by the medical community indicating that a consensus-based approach is already widely endorsed and employed by health care practitioners, and by data from an empirical study reported herein that indicates considerable support also exists among laypersons for the use of a consensus-based decision-making model in EOL decisions.

II. THERAPEUTIC JURISPRUDENCE

The underlying principle of Therapeutic Jurisprudence is that the law can have mental health and psychological consequences for the individuals it affects.[4] Proponents argue that the law can and should, when consistent with considerations

4. *See* Christopher Slobogin, *Therapeutic Jurisprudence: Five Dilemmas to Ponder*, 1 PSYCHOL. PUB. POL'Y & L. 193, 196–204 (1995); Dennis P. Stolle et al., *Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering*, 34 CAL. W. L. REV. 15, 17 (1997); David B. Wexler & Bruce J. Winick, *Introduction*, *in* LAW IN A THERAPEUTIC KEY: DEVELOPMENTS IN THERAPEUTIC JURISPRUDENCE xvii (David B. Wexler & Bruce J. Winick eds., 1996) [hereinafter LAW IN A THERAPEUTIC KEY].

of justice and other relevant normative values, function as a therapeutic agent.[5] However, the therapeutic or anti-therapeutic impact of the law is often overlooked.[6] Thus, judges, lawyers, and social scientists are urged to explore when this impact occurs and how to enhance the therapeutic and minimize the anti-therapeutic effects of the law.[7]

Therapeutic Jurisprudence initially targeted the potential therapeutic impact of mental health law.[8] However, Therapeutic Jurisprudence has since been applied to a broad range of substantive areas.[9] These include areas of specific relevance to EOL decision making, such as family law, health law, disability law, probate law, elder law, and personal injury and tort law.[10]

The goal of Therapeutic Jurisprudence is to make legal rules, legal procedures, and the actions of legal actors more therapeutic for individuals affected by the legal system.[11] The actions of legal actors are considered particularly relevant for shaping the law's effect.[12] Attending to how the law operates in practice facilitates reform by promoting changes in the application of existing law.[13] This, in turn, minimizes the necessity of changing the law on the books, which can be a slow and tenuous process.[14] At the same time, Therapeutic Jurisprudence emphasizes the need to recognize the broad reach of the law and thus does not limit its concern to parties associated with a formal legal proceeding.[15]

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5. *See* Stolle et al., *supra* note 4, at 17–18; Dennis P. Stolle & David B. Wexler, *Therapeutic Jurisprudence and Preventive Law: A Combined Concentration to Invigorate the Everyday Practice of Law*, 39 ARIZ. L. REV. 25, 25 (1997); Bruce J. Winick, *The Jurisprudence of Therapeutic Jurisprudence*, *in* LAW IN A THERAPEUTIC KEY, *supra* note 4, at 646.

6. *See* Stephen H. Behnke & Elyn R. Saks, *Therapeutic Jurisprudence: Informed Consent as a Clinical Indication for the Chronically Suicidal Patient with Borderline Personality Disorder*, 31 LOY. L.A. L. REV. 945, 978 (1998).

7. *See* Winick, *supra* note 5, at 646.

8. *See* David B. Wexler, *Reflections on the Scope of Therapeutic Jurisprudence*, 1 PSYCHOL. PUB. POL'Y & L. 220 (1995).

9. *See generally* David B. Wexler, *Applying the Law Therapeutically*, *in* LAW IN A THERAPEUTIC KEY, *supra* note 4, at 831; Winick, *supra* note 5, at 654.

10. *See, e.g.*, Behnke & Saks, *supra* note 6; Daniel W. Shuman, *The Standard of Care in Medical Malpractice Claims, Clinical Practice Guidelines, and Managed Care: Towards a Therapeutic Harmony?*, 34 CAL. W. L. REV. 99 (1997); Dennis P. Stolle, *Professional Responsibility in Elder Law: A Synthesis of Preventive Law and Therapeutic Jurisprudence*, 14 BEHAV. SCI. & L. 459 (1996); Bruce J. Winick, *Advance Directive Instruments for Those with Mental Illness*, 51 U. MIAMI L. REV. 57 (1996); Patricia Monroe Wisnom, Note, *Probate Law and Mediation: A Therapeutic Perspective*, 37 ARIZ. L. REV. 1345 (1995).

11. *See* Stolle et al., *supra* note 4, at 33; Wisnom, *supra* note 10, at 1352.

12. *See* Stolle et al., *supra* note 4, at 37 (discussing the impact of judges, lawyers, police officers, and state-employed clinicians).

13. *See* Stolle & Wexler, *supra* note 5, at 25.

14. *See* Wexler, *supra* note 9, at 840; David B. Wexler, *Reflections on the Scope of Therapeutic Jurisprudence*, *in* LAW IN A THERAPEUTIC KEY, *supra* note 4, at 827.

15. *See* Behnke & Saks, *supra* note 6, at 945; Wisnom, *supra* note 10, at 1354.

Therapeutic Jurisprudence principles have been widely recommended for matters that rely frequently on the judiciary for resolution.[16] For example, decision-making proceedings are considered more fair and satisfactory by individuals permitted to voice their own views and to share in the decision-making process.[17] Furthermore, obviating the need for judicial resolution can have considerable therapeutic benefit for individuals that otherwise will face each other as adversaries.[18] As will be discussed, such principles have strongly influenced proponents of both Preventive Law and a consensus-based decision-making model for EOL decisions.

III. PREVENTIVE LAW

Proponents of a Preventive Law approach assert that appropriate legal decision making can occur without recourse to the courts. As originally formulated, Preventive Law (also referred to as preventive lawyering) focused on the valuable contribution attorneys could make to the welfare of their clients by anticipating potential disputes and defusing them before dispute resolution became necessary.[19] However, the arguments and principles directed to lawyers have been generalized to address the value of avoiding litigation in general.[20] Indeed, Preventive Law may have more inherent appeal to and be more widely accepted by the general public

16. *See, e.g.*, David B. Wexler, *Therapeutic Jurisprudence and Changing Conceptions of Legal Scholarship*, *in* LAW IN A THERAPEUTIC KEY, *supra* note 4, at 605–08.

17. *See* E. Alan Lind et al., *Voice, Control, and Procedural Justice: Instrumental and Noninstrumental Concerns in Fairness Judgments*, 59 J. PERSONALITY & SOC. PSYCHOL. 952, 957–58 (1990); E. Alan Lind et al., *In the Eye of the Beholder: Tort Litigants' Evaluations of Their Experiences in the Civil Justice System*, 24 L. & SOC'Y REV. 953, 980–82 (1990); Tom R. Tyler, *Psychological Models of the Justice Motive: Antecedents of Distributive and Procedural Justice*, 67 J. PERSONALITY & SOC. PSYCHOL. 850, 854 (1994); Ellen A. Waldman, *The Evaluative-Facilitative Debate in Mediation: Applying the Lens of Therapeutic Jurisprudence*, 82 MARQ. L. REV. 155, 160 (1998).

18. *See* Edward D. Re, *The Lawyer as Counselor and the Prevention of Litigation*, 31 CATH. U. L. REV. 685, 690–91 (1982); Stolle et al., *supra* note 4, at 36; Waldman, *supra* note 17, at 160. Concern about the anti-therapeutic impact of adversarial judicial proceedings has been a primary impetus behind calls from therapeutic jurisprudence proponents for increased use of mediation and other forms of alternative dispute resolution in lieu of judicial proceedings. *See id.* at 160–63.

19. *See* LOUIS M. BROWN, LAWYERING THROUGH LIFE: THE ORIGIN OF PREVENTIVE LAW (1986); LOUIS M. BROWN, PREVENTIVE LAW (1950); Louis M. Brown, *Preventive Law and Public Relations: Improving the Legal Health of America*, 39 A.B.A. J. 556 (1953); Louis M. Brown, *The Practice of Preventive Law*, 35 J. AM. JUDICATURE SOC'Y 45 (1951).

20. *See, e.g.*, Kathryn E. Maxwell, *Preventive Lawyering Strategies to Mitigate the Detrimental Effects of Clients' Divorces on Their Children*, 67 REVISTA JURIDICA UNIVERSIDAD DE PUERTO RICO 137, 145 (1998) (discussing the the effects of an amorphous best interests of the child standard in custody litigation); Re, *supra* note 18, at 692; Stolle et al., *supra* note 4, at 16.

than attorneys.[21] Proponents argue that relying solely on legal solutions for resolving a dispute can be counter-productive.[22]

In recent years, legal clients have demanded a greater role in legal decision making and have placed greater emphasis on avoiding litigation.[23] One of the major recurring client complaints about litigation is the acrimony caused by the adversarial process.[24]

Preventive Law seeks to find ways to avoid the need for formal dispute resolution.[25] Litigation can disrupt relationships, diminish understanding and cooperation, impose an economic and emotional toll, and extend the time needed to resolve a matter.[26] Furthermore, playing a more direct role in the decision-making process has been found to foster satisfaction and higher compliance with the ultimate decision among the individuals involved.[27]

Like Therapeutic Jurisprudence, Preventive Law has expanded its scope in recent years and its principles are especially applicable in the context of EOL decision making.[28] Avoiding contentious litigation has been identified as particularly important when parties share an intimate past relationship, are likely to

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21. Attorneys may find a non-adversarial approach contrary to their education and training, their personality, their financial well-being, and, in some cases, the expectations of their clients. *See, e.g.*, John Scott Hoff, *Attorneys as Warriors*, 1998-DEC NEBRASKA LAWYER 16 (1998). Furthermore, confining preventive law to the practices of attorneys is likely to limit the ability of its proponents to accomplish its goals. For example, law reform to enhance the well-being of those affected by the law in general is beyond what can be achieved by most preventive lawyers practicing under most everyday circumstances. *See* Stolle et al., *supra* note 4, at 33. Regardless, individuals and entities are reported to increasingly self-represent or to avoid the legal system completely. *See* Forrest S. Mosten, *Unbundling of Legal Services and the Family Lawyer*, 28 FAM. L.Q. 421, 426 (1994) ("The profession is beginning to recognize its vulnerability in the marketplace as clients are increasingly self-representing, turning to nonlawyer providers, or just living with a recognized legal need.").

22. *See* Stolle et al., *supra* note 4, at 36.

23. *See* Susan Beck, *No More Mr. Tough Guy*, 17-AUG CAL. LAW. 43, 43 (1997); Mosten, *supra* note 21, at 421–22; Leonard L. Riskin, *Mediation and Lawyers*, 43 OHIO ST. L.J. 29, 30 (1982).

24. *See* Mosten, *supra* note 21, at 424–25; Waldman, *supra* note 17, at 160 (discussing the "psychological brutality of the adversary system").

25. *See, e.g.*, Maxwell, *supra* note 20, at 151–52 (discussing the American Association of Matrimonial Lawyers voluntary code); Mosten, *supra* note 21, at 440; David Plimpton, *Mediation of Disputes: The Role of the Lawyer and How Best to Serve the Client's Interest*, 8 ME. B.J. 38, 39 (1993).

26. *See* Re, *supra* note 18, at 695.

27. *See* Tom R. Tyler, *The Psychological Consequences of Judicial Procedures: Implications for Civil Commitment Hearings*, 46 SMU L. REV. 433 (1992).

28. *See* Stolle et al., *supra* note 4, at 36 n.75. Historically, preventive law focused on estate and business planning. *See id.* at 36. Among the areas it now addresses that are directly relevant to EOL decision making are elder law and family law. *See, e.g.*, Peggy Sheahan Knee, *Preventive Lawyering for Elder Law Attorneys: How to Please the Client Yet Stay on the Ethical High Road*, 164-OCT N.J. LAW. 11 (1994); Maxwell, *supra* note 20; Mosten, *supra* note 21.

continue to interact, and need to put aside animosity and work together after the dispute is resolved.[29] An analogy has been drawn between Preventive Law and preventive medicine as both seek to prevent problems from developing or exacerbating and both emphasize the value of shared decision making.[30]

A means of avoiding adversarial judicial proceedings that is increasingly endorsed by Preventive Law proponents is mediation.[31] Mediation applies a consensus-based decision-making model (similar to that discussed later in this Article as being widely used in conjunction with EOL decision making) where parties, assisted by a mediator who cannot impose a solution or result on the parties, work together to reconcile their differences.[32] This approach is favored over adversarial proceedings because it better enables parties to privately order their lives through direct negotiations; to reach resolutions that reflect their own goals, needs, and values; to preserve existing relationships; to save time and expense; to generate creative solutions; and to avoid the psychological trauma of a judicial confrontation.[33] A desire to avoid litigation in general, especially for very personal and private matters, has led to general support for mediation and the consensus-based model it employs.[34]

Mediation is likely to be successful when the parties have a complex, interdependent relationship that they wish to continue, are motivated to work out their own relationship with minimal reliance upon others, face complex problems, seek confidentiality or privacy, and want to avoid the possible animosity and aggravating effects of an adversarial proceeding.[35] In addition, participants are better able to experience the therapeutic benefits of venting their emotions, of feeling that they have been heard and understood after presenting their perspectives, and of playing an active role in the decision-making process.[36]

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29. *See* Maxwell, *supra* note 20, at 153 (discussing child custody issues).

30. *See* Stolle et al., *supra* note 4, at 16.

31. *See* Diane E. Hoffmann, *Mediating Life and Death Decisions*, 36 ARIZ. L. REV. 821, 850 (1994); Maxwell, *supra* note 20, at 149; Mosten, *supra* note 21, at 435; Plimpton, *supra* note 25, at 38; Re, *supra* note 18, at 694; Riskin, *supra* note 23, at 30, 52.

32. *See* Plimpton, *supra* note 25, at 38, 42; Riskin, *supra* note 23, at 29 ("The mediator lacks authority to impose a decision on the parties; he can only facilitate the process."). A major motivating force for accepting mediation is to avoid legal fees. *See* Mosten, *supra* note 21, at 435.

33. *See* Edward A. Dauer & Leonard J. Marcus, *Adapting Mediation to Link Resolution of Medical Malpractice Disputes with Health Care Quality Improvement*, 60 LAW & CONTEMP. PROBS. 185, 218 (1997); Hoffmann, *supra* note 31, at 850; Maxwell, *supra* note 20, at 149–50; Mosten, *supra* note 21, at 436; Plimpton, *supra* note 25, at 40; Riskin, *supra* note 23, at 29, 52, 57.

34. *See* Dauer & Marcus, *supra* note 33, at 199; Hoffmann, *supra* note 31, at 849–50; Mosten, *supra* note 21, at 438–39.

35. *See* Plimpton, *supra* note 25, at 42; Riskin, *supra* note 23, at 33.

36. *See* Hoffmann, *supra* note 31, at 849. Concern has been raised that the mediation process may be skewed if a power or knowledge imbalance exists between the parties involved. *See id.* at 859 (noting that an imbalance may exist between physicians and patients, patient surrogates, and/or family members in mediating end-of-life decisions); Maxwell, *supra* note 20, at 137–38; Mosten, *supra* note 21, at 436–37; Riskin, *supra* note

Mediation can be and has been successful in resolving disputes between physicians and patients over health care, and, in so doing, it has enhanced the general level of care provided.[37] Although concerns have been raised about using mediation in cases involving the forgoing of LSMT,[38] commentators raising these concerns have also noted the problems associated with using the two primary alternative dispute-resolution forums (i.e., the courts[39] and institutional ethics committees[40]) and the ability to adapt mediation to generally redress these concerns.[41] Furthermore, the medical literature and the results of the study subsequently reported in this Article indicate that a mediation-style consensus-based model is preferred by healthcare providers and laypersons for EOL decision making.[42]

IV. INTEGRATION OF THERAPEUTIC JURISPRUDENCE AND PREVENTIVE LAW

Therapeutic Jurisprudence and Preventive Law share common features and goals.[43] These commonalities include recognizing the broader ramifications of law-related decision making, taking these ramifications into account when crafting an approach to a given issue with legal implications, and promoting the psychological well-being of individuals involved or potentially involved in such

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23, at 35. For other criticisms of mediation, see Hoffmann, *supra* note 31, at 859; Mosten, *supra* note 21, at 435 n.68; and Plimpton, *supra* note 25, at 42–43. However, a range of modifications, including a number specifically designed for EOL decision making, has been proposed or implemented to redress the impact of such imbalances and other concerns. *See* Hoffmann, *supra* note 31, at 826; Mosten, *supra* note 21, at 437.

37. *See* Dauer & Marcus, *supra* note 33, at 206, 211, 217. *See also* Hoffmann, *supra* note 31, at 824 (citing bioethical disputes in health care facilities); Marshall B. Kapp, *Medical Decisionmaking for Older Adults in Institutional Settings: Is Beneficence Dead in an Age of Risk Management?*, 11 ISSUES L. & MED. 29, 31 (1995) (citing disagreements and problems arising in nursing facilities).

38. For a discussion of the limitations of mediation when applied to EOL decisions, see Hoffmann, *supra* note 31, at 861. *But see* Robert Gatter, Preserving Patient Trust by Mediating End-of-Life Treatment Disputes (Dec. 8, 1998) (unpublished manuscript, on file with author) (directly responding to Hoffman and arguing that limitations of mediation can be redressed and that mediation should be used to resolve EOL disputes).

39. *See* Thomas L. Hafemeister & Donna M. Robinson, *The Views of the Judiciary Regarding Life-Sustaining Medical Treatment Decisions*, 18 LAW & PSYCH. REV. 189 (1994) (stating that trial court judges report struggling with evaluating prior statements of the patient, evaluating the testimony of witnesses reporting prior statements of the patient, deciding what weight to give the opinions of family and friends of the patient, determining whether the patient's expressed choice had been altered by time or intervening events, and the medical issues involved in these cases); Hoffmann, *supra* note 31, at 825.

40. *See* Hoffmann, *supra* note 31, at 846–48; Kapp, *supra* note 37, at 44.

41. *See* Hoffmann, *supra* note 31, at 875–77. *But see* Gatter, *supra* note 38, at 8–46.

42. *See infra* Parts VII, VIII.

43. *See* Maxwell, *supra* note 20, at 154; Stolle, *supra* note 10, at 469; Stolle et al., *supra* note 4, at 33; Stolle & Wexler, *supra* note 5, at 29.

matters.[44] For example, a therapeutically-oriented preventive lawyer can relieve the stress of participants in legal decision making, diminish dysfunctional and enhance positive effects attributable to the law, and serve the well-being of clients by avoiding litigation when possible and employing alternative means for resolving disputes.[45]

An integrated Preventive Law and Therapeutic Jurisprudence approach has been considered particularly useful for working with populations such as the elderly or the disabled, populations for whom EOL decisions are especially likely to be relevant.[46] For instance, planning for possible future incapacity or disability is an important consideration for attorneys working with elderly clients,[47] particularly since resulting advance directives[48] can prevent subsequent family disputes or alienation, diminish future stress on family members, or provide psychological comfort and security for the clients.[49] Likewise, for individuals with a terminal illness, ordering their affairs in anticipation of death can have therapeutic value by relieving anxieties about these matters and by helping them to feel that they have been able to exert some control over their final days.[50] The therapeutic value of avoiding court proceedings can also accompany the use of advance directives in anticipation of a loss of decision-making capacity.[51] Finally, mediation can have direct therapeutic benefit by resolving health care disputes through a consensus-based approach in lieu of more traditional litigation.[52] As will be discussed further, the application of an integrated Therapeutic Jurisprudence/Preventive Law approach for these populations reflects many of the goals and gains associated with the use of a consensus-based decision-making model in EOL decisions.[53]

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44. *See* Stolle et al., *supra* note 4, at 24 ("[I]f more than one legal tool is available to achieve the [client's] intent, the role of the integrated framework is to choose the most therapeutic, or, at minimum, the least anti-therapeutic alternative.... Even where only one legal solution is available, that solution may, in some cases, be tailored to enhance its therapeutic effect."); Stolle & Wexler, *supra* note 5, at 27.

While there is considerable overlap between these two perspectives, they are not identical. Merely preventing future legal dilemmas may have little if any effect on the mental health or psychological functioning of those involved. *See* Stolle et al., *supra* note 4, at 37. Similarly, a legal action may have positive therapeutic consequences but be largely unrelated to avoiding future legal problems. *See id.* However, the goals of each can be enhanced in areas of confluence. *See id.* at 38.

45. *See* Stolle et al., *supra* note 4, at 33, 38.

46. *See id.* at 19.

47. *See id.* at 23.

48. An advance directive has been defined as "[w]ritten or verbal instructions about future medical treatment that an individual with decision-making capacity would like his or her health care providers to follow in the event that he or she loses decision-making capacity." HAFEMEISTER & HANNAFORD, *supra* note 2, at 119.

49. *See* Stolle et al., *supra* note 4, at 25.

50. *See* MARK S. SENAK, HIV, AIDS AND THE LAW: A GUIDE TO OUR RIGHTS AND CHALLENGES (1996); Stolle et al., *supra* note 4, at 28. For some individuals, it may provide an opportunity for reconciliation with alienated family members.

51. *See* Winick, *supra* note 10, at 84, 85.

52. *See* Dauer & Marcus, *supra* note 33, at 199.

53. *See infra* Part VII.

V. END-OF-LIFE DECISION MAKING: THE HIERARCHICAL MODEL

In 1990, the United States Supreme Court issued its first "right-to-die" opinion in *Cruzan v. Director, Missouri Department of Health*.[54] The Court ruled that competent individuals have a right to forego LSMT (i.e., that a person with decision-making capacity can refuse such treatment or have it halted).[55]

Although *Cruzan* was a landmark case, its holding was relatively narrow.[56] Because *Cruzan* did not for the most part preclude the use of state constitutional or common law to resolve questions associated with EOL decisions, state court opinions that both predate and postdate *Cruzan* generally continue to be good law.[57] In addition, the Supreme Court largely deferred to the states on the procedural rules to be used in deciding whether LSMT should be forgone in a given case, providing states with considerable latitude in selecting the decision-making model to be used for these decisions.[58]

The courts in many states have addressed EOL decisions.[59] They have frequently noted the difficulty they experienced in trying to resolve the issues associated with them.[60] Nevertheless, in the numerous opinions addressing EOL

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54. 497 U.S. 261 (1990). The Court has subsequently issued two opinions that address the question of physician-assisted suicide, but which leave the opinion in *Cruzan* basically undisturbed. *See* Washington v. Glucksberg, 521 U.S. 702 (1997); Vacco v. Quill, 521 U.S. 793 (1997).

55. *Cruzan*, 497 U.S. at 278. In its more recent decisions, the Court reiterated (and arguably solidified) its position in *Cruzan*. *See Glucksberg*, 521 U.S. at 724–25; *Vacco*, 521 U.S. at 807.

56. *Cruzan*, 497 U.S. at 280.

57. *See generally* ALAN MEISEL, THE RIGHT TO DIE (1997 & Supp. 1999).

58. *See* David Orentlicher, *The Supreme Court and Terminal Sedation: Rejecting Assisted Suicide, Embracing Euthanasia*, 24 HASTINGS CONST. L.Q. 947, 949 (1997) [hereinafter Orentlicher, *The Supreme Court*]; David Orentlicher, *The Right to Die After* Cruzan, 264 JAMA 2444, 2444 (1990) [hereinafter Orentlicher, *The Right to Die*] ("States may differ in terms of the procedural safeguards that they employ to ensure that withdrawal of treatment reflects the patient's wishes when the patient is unable to make treatment decisions.").

59. *See generally* MEISEL, *supra* note 57.

60. *See, e.g.*, Rasmussen v. Fleming, 741 P.2d 674, 678–79 (Ariz. 1987) ("[W]e approach this case...with extreme caution and humility, mindful of the profound and overwhelming sense of responsibility that accompanies the power to resolve what...are all too often life-and-death issues...."); Wendland v. Superior Court, 56 Cal. Rptr. 2d 595, 601 (Cal. Ct. App. 1996) (Raye, J., concurring) ("I write separately to emphasize the complexity of the life and death issues underlying this litigation."); DeGrella v. Elston, 858 S.W.2d 698, 712 (Ky. 1993) (Wintersheimer, J., dissenting) ("It is always a struggle for the judicial system to properly resolve such weighty questions."); *In re* Martin, 538 N.W.2d 399, 401 (Mich. 1995) ("We enter this arena humbly acknowledging that neither law, medicine nor philosophy can provide a wholly satisfactory answer to this question."); McKay v. Bergstedt, 801 P.2d 617, 637 (Nev. 1990) (Springer, J., dissenting) ("I have agonized over this case."); *In re* Conroy, 486 A.2d 1209, 1221 (N.J. 1985) ("No one person or profession has all the answers."); *In re* Guardianship of Grant, 747 P.2d 445, 463 (Wash. 1987) (Goodloe, J., dissenting) ("Few areas demand greater judicial wisdom...than the one before us."). *Cf. Cruzan*, 497 U.S. at 292 (Scalia, J., concurring) ("difficult, indeed agonizing,

decision making, there has been virtually unanimous agreement that a hierarchical decision-making model should be employed with the patient or the patient's decision-making surrogate placed at the apex of this model.[61]

Patients with decision-making capacity are uniformly viewed as having a paramount right to make EOL decisions.[62] In addition, courts have uniformly held that this right does not end if the patient loses decision-making capacity.[63]

Typically, courts have focused on the importance of protecting and preserving patient autonomy.[64] This right is generally balanced against the interests

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questions").

61. *See* Hoffmann, *supra* note 31, at 821 n.1.

62. *See, e.g.*, Washington v. Glucksberg, 521 U.S. 720, 722–23 (1997).

63. *See, e.g.*, *Cruzan*, 497 U.S. at 280; *Rasmussen*, 741 P.2d at 685–86 (Ariz. 1987); Conservatorship of Drabick, 245 Cal. Rptr. 840, 852 (Ct. App. 1988); *In re* Tavel, 661 A.2d 1061, 1068 (Del. 1995); *In re* Guardianship of Browning, 568 So. 2d 4, 12 (Fla. 1990); *DeGrella*, 858 S.W.2d at 709–10; Mack v. Mack, 618 A.2d 744, 756 (Md. 1992); Guardianship of Doe, 583 N.E.2d 1263, 1267 (Mass. 1992); *In re Martin*, 538 N.W.2d at 409; *In re* Jobes, 529 A.2d 434, 451 (N.J. 1987); *In re* Quinlan, 355 A.2d 647, 664 (N.J. 1976); *In re* Fiori, 673 A.2d 905, 910 (Pa. 1996); *In re Guardianship of Grant*, 747 P.2d at 449; *In re* Guardianship of L.W., 482 N.W.2d 60, 67 (Wis. 1992). *See also* Orentlicher, *The Supreme Court, supra* note 58, at 949 n.14 ("[S]tate courts before *Cruzan* had come to a consensus that competent adults enjoyed a right to refuse life-sustaining treatment and that the right survived when the patient lost decision-making capacity.").

64. Courts have typically based their rulings either on the patient's common law right to self-determination and the derivative right to accept or refuse medical treatment, widely referred to as the doctrine of informed consent, or various federal or state constitutional provisions. *See, e.g.*, *Cruzan*, 497 U.S. at 271 ("[M]ost courts have based a right to refuse treatment either solely on the common-law right to informed consent or on both the common-law right and a constitutional privacy right."); *id.* at 278 (liberty interest under the Due Process Clause); *Rasmussen*, 741 P.2d at 681–83 (Ariz. 1987) (federal constitution, state constitution, and common law); *Conservatorship of Drabick*, 245 Cal. Rptr. at 853 n.20 (constitutional right of privacy and common law); *In re Tavel*, 661 A.2d at 1068 (common law, Fifth Amendment, and state constitution); *In re* Dubreuil, 629 So. 2d 819, 822 (Fla. 1993) (state constitution); *In re* L.H.R., 321 S.E.2d 716, 718 (Ga. 1984) (federal right to privacy); *In re* Estate of Longeway, 549 N.E.2d 292, 297 (Ill. 1989) (common law); *DeGrella*, 858 S.W.2d at 703, 709 (common law); *Mack*, 618 A.2d at 755–56 (common law); *Guardianship of Doe*, 583 N.E.2d at 1267 (common law); *In re Martin*, 538 N.W.2d at 405 (common law); *Bergstedt*, 801 P.2d at 622 (federal and state constitutions and common law); *In re Quinlan*, 355 A.2d at 663 (right of privacy under federal and state constitutions); *In re* Westchester County Med. Ctr., 531 N.E.2d 607, 611–12 (N.Y. 1988) (common law); State v. Vogel, 537 N.W.2d 358, 360 (N.D. 1995) (federal constitution); Anderson v. St. Francis-St. George Hosp., Inc., 671 N.E.2d 225, 227 (Ohio 1996) (right recognized in *Cruzan*); *In re Fiori*, 673 A.2d at 909–10 (common law); *In re Guardianship of Grant*, 747 P.2d at 449 (right of privacy in federal constitution and state constitution and common law); *In re Guardianship of L.W.*, 482 N.W.2d at 65 (common law, Fourteenth Amendment, and state constitution).

It has been argued that the legal basis for the right to refuse medical treatment is not critical because the scope of the right has not varied as a function of the source of the right. 1 MEISEL, *supra* note 57, at 50. However, basing this right on a common law rather than a constitutional basis makes it easier for a legislative body to reverse or modify a

of the state.[65] The consideration of these state interests has been asserted as a rationale for expanding the decision-making model by involving the courts in EOL decision making.[66] However, the interests of the state have not been considered sufficient to outweigh the patient's right of self-determination in almost all judicial opinions involving an adult patient,[67] and courts have generally been reluctant to interject themselves into the EOL decision-making process.[68]

Furthermore, all states have enacted statutes that permit individuals, while they have decision-making capacity, to execute an advance directive regarding their treatment intent.[69] The use of written advance directives to guide EOL decisions after a patient loses decision-making capacity has been routinely upheld.[70] Although not discussed extensively, courts appear willing to also uphold reliance upon a patient's prior oral expression of an advance directive,[71] although such expressions are more subject to dispute.[72]

Advance directive statutes, however, generally do not resolve the frequent dilemma posed by patients without current decision-making capacity who have not expressed their intent or who have provided conflicting or ambiguous advance

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decision reached by the judiciary. This, in turn, suggests that a legislature has the discretion to mandate a consensus-based rather than a hierarchical decision-making model for EOL decisions, at least for patients without current decision-making capacity, particularly if they have not previously expressed their EOL intent or there is a question about their intent.

65. Four state interests have commonly been recognized—the state's interest in (1) the preservation of life; (2) the protection of third parties (such as children or other individuals dependent on the patient); (3) the prevention of suicide; and (4) the safeguarding of the ethical integrity of the medical profession. *See, e.g.*, *Rasmussen*, 741 P.2d at 683–85; *In re Dubreuil*, 629 So. 2d 819; *In re Guardianship of Browning*, 568 So. 2d at 14; *In re Estate of Longeway*, 549 N.E.2d at 299; *Mack*, 618 A.2d at 755 n.7; *Guardianship of Doe*, 583 N.E.2d at 1269–70; Brophy v. New England Sinai Hosp. 497 N.E.2d 626, 634–38 (Mass. 1986); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 425 (Mass. 1977); *In re Fiori*, 673 A.2d at 910; *In re Guardianship of Grant*, 747 P.2d at 451; *In re Guardianship of L.W.*, 482 N.W.2d at 74.

66. *See* Hoffmann, *supra* note 31, at 825.

67. *See, e.g.*, *Rasmussen*, 741 P.2d at 683–85; *In re Longeway*, 549 N.E.2d at 299; *Brophy*, 497 N.E.2d at 634–38; *Bergstedt*, 801 P.2d at 622–28; *In re Jobes*, 529 A.2d at 451; *In re* Guardianship of Crum, 580 N.E.2d 876, 880 (Ohio Prob. Ct. 1991); *In re Fiori*, 673 A.2d at 910; *In re Guardianship of Grant*, 747 P.2d at 451.

68. *See infra* notes 93–94 and accompanying text.

69. For a listing of the advance directive statutes of the various states, see *Vacco v. Quill*, 521 U.S. 793, 845 n.9 (1997).

70. *See generally* Orentlicher, *The Right to Die*, *supra* note 58, at 2445.

71. *See, e.g.*, *Rasmussen*, 741 P.2d at 688 n.21; *In re* Guardianship of Browning, 568 So. 2d 4, 15 (Fla. 1990); *In re* Swan, 569 A.2d 1202, 1205 (Me. 1990); Mack v. Mack, 618 A.2d 744, 758 (Md. 1992); *In re* Martin, 538 N.W.2d 399, 410 (Mich. 1995); *In re* Westchester County Med. Ctr., 531 N.E.2d 607, 614 (N.Y. 1988); Elbaum v. Grace Plaza of Great Neck, Inc., 544 N.Y.S.2d 840, 845–46 (N.Y. App. Div. 1989).

72. *See, e.g.*, DeGrella v. Elston, 858 S.W.2d 698, 708 (Ky. 1993) (holding that, while of significant value, previous oral statements cannot be considered conclusive); *In re Martin*, 538 N.W.2d at 410; *In re* Jobes, 529 A.2d 434, 443 (N.J. 1987); *In re Westchester County Med. Ctr.*, 531 N.E.2d at 614.

directives.[73] Although one court has ruled that for certain patients the absence of an advance directive precludes the foregoing of LSMT and thus brings to a halt further EOL decision making,[74] most courts have ruled that the absence of a determinative advance directive does not end the decision-making process.[75]

Under these circumstances, the approach widely adopted by the courts is to recognize a single surrogate decision maker.[76] Generally, the surrogate is directed to exercise "substituted judgment" on behalf of the patient.[77] A surrogate decision maker is expected to choose the course of treatment the patient would

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73. *See* Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring); *In re* Guardianship of L.W., 482 N.W.2d 60, 67–68 (Wis. 1992); Orentlicher, *The Right to Die*, *supra* note 58, at 2445. *See also infra* Part VI.B.

74. *See* Spahn v. Eisenberg (*In re* Guardianship and Protective Placement of Edna M.F.), 563 N.W.2d 485, 490 (Wis. 1997) (stating that if the patient is not in a persistent vegetative state, then the guardian cannot conclude that it would be in the patient's best interests to forego treatment "unless the ward has executed an advance directive or other statement clearly indicating his or her desires"). *See also DeGrella*, 858 S.W.2d at 706 ("In all but two states, Missouri and New York, even when the court has been unable to precisely determine the express wishes of the patient, it has allowed the patient's family, or the patient's guardian, to exercise substituted judgment as to what the patient would wish.").

75. *See, e.g.*, *Rasmussen*, 741 P.2d at 685–86 (finding, in accord with other states, that individual's right to refuse medical treatment not lost because individual has become incompetent and failed to previously articulate medical treatment desires); Conservatorship of Drabick, 245 Cal. Rptr. 840, 852, 859–60 (Ct. App. 1988); *In re* Tavel, 661 A.2d 1061, 1067–68 (Del. 1995); *DeGrella*, 858 S.W.2d at 706; *In re Fiori*, 673 A.2d at 911 n.7; *In re* Guardianship of Grant, 747 P.2d 445, 449 (Wash. 1987); *In re Guardianship of L.W.*, 482 N.W.2d at 68.

76. *See, e.g.*, *Cruzan*, 497 U.S. at 280; *In re Fiori*, 673 A.2d at 912; *In re Guardianship of L.W.*, 482 N.W.2d at 68–69.

The person filling the role of surrogate decision maker may be the product of statutory or common law guidelines or may have been designated by the patient under a previously executed advance directive. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 124. Massachusetts requires that a judge assume the EOL decision-making role for a never competent patient. *See* Guardianship of Doe, 583 N.E.2d 1263 (Mass. 1992). *See also In re* Estate of Longeway, 549 N.E.2d 292, 300–01 (Ill. 1989) (intervention of judge required to halt artificial sustenance for incompetent patient). Most states also involve at least one medical practitioner in this decision-making process, although this role is generally limited to ascertaining whether certain prerequisite medical conditions have been met. *See, e.g.*, *In re Guardianship of Browning*, 568 So. 2d at 16; *In re Estate of Longeway*, 549 N.E.2d at 297; McKay v. Bergstedt, 801 P.2d 617, 630 (Nev. 1990); *In re Jobes*, 529 A.2d at 448; *In re Fiori*, 673 A.2d at 912–13; *In re Guardianship of Grant*, 747 P.2d at 456; *In re Guardianship of L.W.*, 482 N.W.2d at 72.

77. *See, e.g.*, *Rasmussen*, 741 P.2d at 688; *In re Guardianship of Browning*, 568 So. 2d at 13; *DeGrella*, 858 S.W.2d at 705; Mack v. Mack, 618 A.2d 744, 757 (Md. 1992); *Guardianship of Doe*, 583 N.E.2d at 1267–68; *In re Martin*, 538 N.W.2d at 407–08; *In re Jobes*, 529 A.2d at 444; *In re Fiori*, 673 A.2d at 912 n.11; *In re Guardianship of Grant*, 747 P.2d at 456–57.

choose if the patient could currently express his or her choice, and then take the steps necessary to effectuate that choice.[78]

Courts have differed somewhat with regard to what factors should affect the surrogate's determination;[79] however, they have uniformly directed the surrogate to consider any prior statements or express indications provided by the patient.[80] Although the surrogate can consult other individuals for their recollections and impressions of what the patient previously indicated would be his or her choice under these circumstances,[81] such consultation and the consideration of this information is generally left to the discretion of the surrogate.[82]

In adopting the substituted judgment standard, courts have recognized that this approach involves a legal fiction that the surrogate is making the choice that the patient would make if the patient currently had decision-making authority.[83] Courts have also noted that this approach does not ensure that the surrogate's choice will be the same as the patient's choice would have been.[84] Nevertheless, the courts have widely endorsed having surrogates fill this role. At the same time, surrogates may not be required to consider factors beyond the intent of the patient, such as the impact this decision may have on the patient's family, and indeed may be precluded from considering such factors.[85]

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78. *See, e.g., In re Tavel*, 661 A.2d at 1068; *In re Guardianshp of Browning*, 568 So. 2d at 13; *In re Estate of Longeway*, 549 N.E.2d at 299; *In re* Torres, 357 N.W.2d 332 (Minn. 1984); *In re Jobes*, 529 A.2d at 444; *In re Guardianship of L.W.*, 482 N.W.2d at 69 n.11. *But see In re* Westchester County Med. Ctr., 531 N.E.2d 607 (N.Y. 1988) (surrogate decision maker limited to the clearly expressed wishes of the patient).

79. *Compare Guardianship of Doe*, 583 N.E.2d at 1267 ("Lack of a prior expressed intention regarding medical treatment does not bar use of the doctrine of substituted judgment."), *with In re Westchester County Med. Ctr.*, 531 N.E.2d at 613 ("[The] inquiry must always be narrowed to the patient's expressed intent.").

80. *See, e.g.*, Brophy v. New England Sinai Hosp., 497 N.E.2d 626, 634 (Mass. 1986); *In re* Jobes, 529 A.2d 434, 444 (N.J. 1987); *In re Guardianship of L.W.*, 482 N.W.2d at 69. Some states require a more objective approach for patients who have never had decision-making capacity, thus rendering questionable any previously expressed intent. *See In re Martin*, 538 N.W.2d at 408 n.15; *In re* Storar, 420 N.E.2d 64, 73 (N.Y. 1981); *In re* Matthews, 650 N.Y.S.2d 373, 376–77 (N.Y. App. Div. 1996). *But see In re Guardianship of L.W.*, 482 N.W.2d at 68 (same approach applied for individuals who never had decision-making capacity).

81. *See, e.g., In re Guardianship of L.W.*, 482 N.W.2d at 73–74 (finding that among the factors the guardian may consider are the opinion of a bioethics or institutional ethics committee from the health care facility where the patient resides and the opinion of a spouse, next of kin, close friend, or associate over a significant period of time).

82. *See, e.g., In re Guardianship of Grant*, 747 P.2d at 456 (finding that guardian not required to provide notice of decision to incompetent patient's immediate family, patient's physicians, or health care facility).

83. *See, e.g.*, Conservatorship of Drabick, 245 Cal. Rptr. 840, 854 (Ct. App. 1988); *Guardianship of Doe*, 583 N.E.2d at 1268; *In re Martin*, 538 N.W.2d at 407.

84. *See, e.g.*, Wendland v. Superior Court, 56 Cal. Rptr. 2d 595, 601 (Cal. Ct. App. 1996) (Raye, J., concurring); *Conservatorship of Drabick*, 245 Cal. Rptr. at 855; *In re Martin*, 538 N.W.2d at 407. *See also* Winick, *supra* note 10, at 75.

85. *See, e.g., In re* Westchester County Med. Ctr., 531 N.E.2d 607, 613 (N.Y.

When a patient's intent is not evident, a number of courts have ruled that although the surrogate may not be able to exercise substituted judgment, this does not necessarily end the surrogate's role. These courts direct the surrogate to apply a "best interests" analysis that bases the EOL decision on the best interests of the patient.[86] Under this approach, if prior indications of the patient's intent are available, the surrogate is generally expected to consider, but is not limited to, these prior indications.[87]

However, some courts adopting a best interests approach explicitly note that indications of the patient's intent should be one of the most important factors considered, and, under some circumstances, the only factor the surrogate may consider.[88] Furthermore, the broader best interests standard has been resisted by a number of courts.[89] Included in the rationale for rejecting this approach is that it permits too much information to be considered, loses sight of the patient's right of self-determination, and is subject to varying application by the surrogate.[90]

Regardless of the standard applied, a specific individual, typically a family member, assumes the role of surrogate.[91] Family members are favored for this role because they are believed to be particularly likely to know the patient's

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1988). *But see Guardianship of Doe*, 583 N.E.2d at 1268 (finding that among the five factors to be considered in substituting judgment for that of incompetent people is the impact on the patient's family).

86. *See, e.g.*, Rasmussen v. Fleming, 741 P.2d 674, 689 (Ariz. 1987); *Conservatorship of Drabick*, 245 Cal. Rptr. at 855; *Guardianship of Doe*, 583 N.E.2d at 1268; *In re Guardianship of Grant*, 747 P.2d at 456; *In re* Guardianship of L.W., 482 N.W.2d 60, 68 (Wis. 1992).

87. *See, e.g., In re Guardianship of Grant*, 747 P.2d at 457; *In re Guardianship of L.W.*, 482 N.W.2d at 72–73.

88. *See, e.g.*, Spahn v. Eisenberg (*In re* Guardianship and Protective Placement of Edna M.F.), 563 N.W.2d 485, 489 (Wis. 1997).

89. *See, e.g., In re* Estate of Longeway, 549 N.E.2d 292, 299 (Ill. 1989); DeGrella v. Elston, 858 S.W.2d 698, 705 (Ky. 1993); Mack v. Mack, 618 A.2d 744, 759 (Md. 1992); *In re* Martin, 538 N.W.2d 399, 407 (Mich. 1995); *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613.

90. *See, e.g., Mack*, 618 A.2d at 759; *In re Martin*, 538 N.W.2d at 408; *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613.

91. *See, e.g.*, Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 292 (1990) (O'Connor, J. concurring); *In re* Guardianship of Browning, 568 So. 2d 4, 13 (Fla. 1990); *In re* Jobes, 529 A.2d 434, 445 (N.J. 1987); *In re* Fiori, 673 A.2d 905, 912 (Pa. 1996); *In re Guardianship of Grant*, 747 P.2d at 456. *See also* Hoffmann, *supra* note 31, at 833; Kapp, *supra* note 37, at 38–39.

However, the U.S. Supreme Court has rejected the argument that there is a constitutional requirement that a family member or that family relationships be given primacy in conjunction with substituted judgment. *See Cruzan*, 497 U.S. at 286. In addition, there may be circumstances when a family member is not qualified or is unavailable to act as surrogate. *See id.* at 281 ("Not all incompetent patients will have loved ones available to serve as surrogate decisionmakers."); *In re Jobes*, 529 A.2d at 447 ("There will, of course, be some unfortunate situations in which family members will not act to protect a patient. We anticipate that such cases will be exceptions.... [In such cases] termination of life-sustaining treatment should not occur without the appointment of a guardian.").

preferences and values, and are likely to have special bonds with the patient and thus can be particularly trusted with decision making on behalf of the patient.[92]

In assigning this decision-making role, judges have generally sought to avoid, and, indeed, have discouraged routine involvement of the courts in making EOL decisions.[93] They emphasize that courts are ill-suited to resolve these types of issues; that an adversarial proceeding is not appropriate for these matters; that courts lack the necessary expertise and insights; that these are questions better left to family members, guardians, or surrogates, who are already adequately resolving them; and that judicial resolution is too slow, cumbersome, and expensive, and too intrusive into the personal and sensitive matters associated with these decisions.[94]

As a result of these judicial opinions, the applicable decision-making model is essentially hierarchical in nature. A single individual, the patient or the patient's decision-making surrogate, is placed at the apex of this model and is given decision-making authority. When the patient lacks current decision-making capacity, most courts essentially seek to place the surrogate in the shoes of the patient and charge the surrogate with making the decision that the patient would have made if the patient currently had decision-making capacity. As will be discussed, this model runs contrary to the consensus-based decision-making model favored by both health care providers and laypersons.[95]

VI. LIMITATIONS OF THE HIERARCHICAL END-OF-LIFE DECISION-MAKING MODEL

Even though courts have uniformly recognized a right to make EOL decisions, endorsed a relatively straightforward, hierarchical decision-making model, and widely noted the undesirability of involving courts in EOL decision

92. *See, e.g.*, Conservatorship of Drabick, 245 Cal. Rptr. 840, 861 n.38 (Ct. App. 1988); *In re Jobes*, 529 A.2d at 445; *In re* Fiori, 673 A.2d 905, 912 (Pa. 1996).

93. *See, e.g.*, Rasmussen v. Fleming, 741 P.2d 674, 692 (Ariz. 1987); *Conservatorship of Drabick*, 245 Cal. Rptr. at 846; *In re Guardianship of Browning*, 568 So. 2d at 15; *In re Estate of Longeway*, 549 N.E.2d at 295; *DeGrella*, 858 S.W.2d at 710; *In re Jobes*, 529 A.2d at 449, 451; *In re* Quinlan, 355 A.2d 647, 669 (N.J. 1976); *In re Fiori*, 673 A.2d at 913; *In re* Colyer, 660 P.2d 738, 746 (Wash. 1983); *In re* Guardianship of L.W., 482 N.W.2d 60, 72 n.16 (Wis. 1992). *See also* Hoffmann, *supra* note 31, at 822 ("In a number of these cases, the courts have almost begged for an alternative decision-making process."); COORDINATING COUNCIL ON LIFE-SUSTAINING MEDICAL TREATMENT DECISION MAKING BY THE COURTS, GUIDELINES FOR STATE COURT DECISION MAKING IN LIFE-SUSTAINING MEDICAL TREATMENT CASES 2 (2d ed. 1993); HAFEMEISTER & HANNAFORD, *supra* note 2, at 9.

94. *See, e.g.*, *Rasmussen*, 741 P.2d at 691–92; *Conservatorship of Drabick*, 245 Cal. Rptr. at 846; *In re Guardianship of Browning*, 568 So. 2d at 15; *In re Estate of Longeway*, 549 N.E.2d at 295; *DeGrella*, 858 S.W.2d at 710; McKay v. Bergstedt, 801 P.2d 617, 629 (Nev. 1990); *In re Jobes*, 529 A.2d at 449, 456; *In re Quinlan*, 355 A.2d at 669; *In re Fiori*, 673 A.2d at 913; *In re Guardianship of Grant*, 747 P.2d at 456; *In re Guardianship of L.W.*, 482 N.W.2d at 72 n.16.

95. *See infra* Parts VII, VIII.

making, uncertainty remains and judicial review is often sought.[96] Cases continue to emanate from disputes among patients or their surrogates, family members of patients, and health care providers.[97] Generally these disputes focus on who has decision-making authority and what information should form the basis for the exercise of that authority.[98]

Furthermore, judge-made American law on LSMT can be anti-therapeutic because the hierarchical decision-making model it requires typically assumes that these decisions are ordinarily and best made by a single individual solely focused on carrying out the intent of the patient.[99] While judicial efforts to establish "bright-line" rules that obviate the need for case-by-case analysis by endorsing a specific decision-making model are laudable,[100] this hierarchical model fails to appreciate the complex dynamics of the EOL decision-making process.

EOL decision making is frequently clouded by three factors. First, the patient may demonstrate fluctuating or diminished decision-making capacity that prevents the patient from currently expressing his or her intent. Second, the patient may not have previously expressed or clearly expressed his or her EOL treatment choices. Third, because family members are often involved in, deeply affected by, and concerned about these decisions,[101] they tend to have a significant influence on EOL decision making.[102] As will be discussed, these factors indicate the need for an alternative decision-making model.

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96. *See* Thomas L. Hafemeister et al., *The Judicial Role in Life-Sustaining Medical Treatment Decisions*, 7 ISSUES L. & MED. 53 (1991) (1989 survey of 905 state trial court judges produced a "conservative" estimate that 2357 state trial court judges had heard at least one LSMT case and that these judges had heard over 7000 such cases); Hoffmann, *supra* note 31, at 822.

Although a relatively large number of trial court judges have been asked to preside over cases involving EOL decisions, these cases appear relatively infrequently on a court's docket, providing judges with little opportunity to establish standard procedures or to develop expertise to address the complex issues before them. *See* Hafemeister & Robinson, *supra* note 39.

97. *See* Hoffmann, *supra* note 31, at 822.

98. *See* Hafemeister & Robinson, *supra* note 39, at 214–16, 239.

99. *See* Mack v. Mack, 618 A.2d 744, 746–49 (Md. 1993); Hoffmann, *supra* note 31, at 825.

100. *See* Hoffmann, *supra* note 31, at 825.

101. Although relatively infrequent, there are patients for whom family or friends are not available to assist with the decision-making process. Although one of the primary dilemmas posed by these patients is who should make EOL decisions on their behalf, this Article does not address these patients. For suggestions on how to proceed with EOL decisions for such patients, see HAFEMEISTER & HANNAFORD, *supra* note 2, at 57.

102. For purposes of this Article, "family" is defined relatively broadly to encompass all individuals who know the patient well and can address from personal experience the patient's intent or well-being. Frequently this will encompass individuals who are related to the patient. Sometimes, however, other individuals will be better sources of information regarding a patient, particularly when the patient is estranged from kin or has outlived them. *See id.* at 55. This definition excludes individuals who seek to assert their belief of the patient's intent or well-being based solely on a philosophical or political agenda.

A. Fluctuating or Diminished Decision-Making Capacity Levels

As noted, American courts have placed patients at the apex of the EOL decision-making model, requiring that EOL decisions emanate from the patient. However, it is relatively unlikely that the patient will have the current capacity to express his or her intent.

Perhaps as many as seventy percent of the deaths occurring in hospitals and long-term care facilities in the United States each year involve a decision to forego LSMT (nearly a million deaths per year).[103] However, many patients are unable to make these decisions contemporaneously.[104] A range of cognitive and emotional impairments, some temporary but many permanent, deprive patients of decision-making capacity.[105] Furthermore, the nature of the injury or disease that necessitates the consideration of LSMT frequently challenges their ability or willingness to make these decisions.[106] Indeed, most disputes over EOL decision making that result in judicial interjection involve patients who lack decision-making capacity.[107]

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103. *See* Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 302 (1990) (Brennan, J., dissenting); Brief Amicus Curiae for the American Hospital Association at 3, Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261 (1990) (No. 88-1503); Kathy Faber-Langendoen, *A Multi-institutional Study of Care Given to Patients Dying in Hospitals: Ethical and Practice Implications*, 156 ARCHIVES OF INTERNAL MED. 2130, 2132 (1996); John F. Fader II, *The Precarious Role of the Courts: Surrogate Health Care Decisionmaking*, 53 MD. L. REV. 1193, 1209 n.65 (1994); John M. Luce, *Making Decisions about the Forgoing of Life-Sustaining Therapy*, 156 AM. J. RESPIRATORY CRITICAL CARE MED. 1715, 1715–16 (1997); Orentlicher, *The Right to Die*, *supra* note 58, at 2444.

104. *See, e.g.*, Faber-Langendoen, *supra* note 103, at 2131–32 (finding 84% died after some intervention was forgone, but only 35% were able to participate in the decision making); Linda A. O'Brien et al., *Nursing Home Residents' Preferences for Life-Sustaining Treatments*, 274 JAMA 1775, 1777 (1995) (finding 38% of nursing home residents were able to evidence sufficient comprehension to meet standards for informed consent); Nicholas G. Smedira et al., *Withholding and Withdrawal of Life Support from the Critically Ill*, 322 NEW ENG. J. MED. 309, 311 (1990) (finding only 5 of 115 patients made the actual decision to limit care with the other patients incompetent at the time).

105. *See, e.g.*, JAMES M. HOEFLER, MANAGING DEATH 91 (1997) (stating that nearly two million patients in the United States are severely demented, with dementia progressing to the severe state in one of every seven Americans over age 65 and in one of every four Americans over age 85); Kapp, *supra* note 37, at 32 (stating that more than half of 1.6 million nursing facility residents suffer substantial degree of cognitive or emotional impairment making meaningful direction of LSMT difficult, if not impossible).

106. *See, e.g.*, Nelson Lund, *Two Precipices, One Chasm: The Economics of Physician-Assisted Suicide and Euthanasia*, 24 HASTINGS CONST. L.Q. 903, 915 (1997) (stating that for patients with serious or terminal illness, depression or diminished mental capacity frequently clouds judgment or weakens resolve); Joanne Lynn et al., *Perceptions by Family Members of the Dying Experience of Older and Seriously Ill Patients*, 126 ANNALS INTERNAL MED. 97, 101–02 (1997) (finding that in the last three days of life, 55% of patients were conscious, 40% had severe pain most of the time, 80% experienced severe fatigue, and 63% had difficulty tolerating physical or emotional problems).

107. *See* Hoffmann, *supra* note 31, at 827. Cases that involve patients with decision-making capacity typically involve patients whose decision to forego LSMT is

As a result, merely establishing that patients with decision-making capacity have a right to forego LSMT does little to resolve how EOL decisions should be made. The resolution to this dilemma posed by the hierarchical decision-making model, as noted above, is to permit the patient's previously expressed LSMT intent (i.e., intent expressed when the patient had decision-making capacity through an advance directive) to function as if it is the patient's currently expressed intent.[108] However, as will be discussed in the following section, the majority of patients have not previously expressed or clearly expressed their intent, and exclusive reliance on previously expressed LSMT intent may be an unreliable reflection of current intent.[109]

B. Unexpressed Treatment Choices

Widespread efforts have been made to encourage individuals to execute LSMT advance directives in anticipation of a time when they no longer have the capacity to express their intent.[110] Most individuals, however, fail to express in advance their treatment choices.[111] Perhaps because it is such a monumental decision, because many people procrastinate or are unwilling to address issues associated with their own mortality, or because they prefer to leave such decisions to family members,[112] the majority of Americans have not recorded their intent regarding LSMT,[113] despite nearly a decade's worth of concerted attention having

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perceived to be premature (e.g., a state may limit the forgoing of LSMT to terminally ill patients or patients in a persistent vegetative state) or patients seeking the active assistance of a physician. *See, e.g.*, Washington v. Glucksberg, 521 U.S. 702 (1997); Vacco v. Quill, 521 U.S. 793 (1997); Bartling v. Superior Court, 209 Cal. Rptr. 220 (Ct. App. 1984); Krischer v. McIver, 697 So. 2d 97 (Fla. 1997); McKay v. Bergstedt, 801 P.2d 617 (Nev. 1990).

108. *See, e.g.*, *In re* Martin, 538 N.W.2d 399, 401 (Mich. 1995); *In re* Guardianship of L.W., 482 N.W.2d 60, 69 (Wis. 1992).

109. *See infra* Part VI.B.

110. *See, e.g.*, Patient Self-Determination Act (Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388 (1990)).

111. *See* Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring); *In re* Martin, 538 N.W.2d 399, 416 n.23 (Mich. 1995); *In re Guardianship of L.W.*, 482 N.W.2d at 68 n.8. *See also* Laura C. Hanson et al., *Emergency Triage to Intensive Care: Can We Use Prognosis and Patient Preferences?*, 42 J. AM. GERIATRICS SOC'Y 1277, 1277 (1994); Smedira et al., *supra* note 104, at 312, 314.

112. *See In re Guardianship of L.W.*, 482 N.W.2d at 67–68; Jean L. Holley et al., *Factors Influencing Dialysis Patients' Completion of Advance Directives*, 30 AM. J. KIDNEY DISEASE 356, 359 (1997) (finding that the most commonly given reason for not completing advance directive was that the family knew their preferences); Shirley L. Patterson et al., *Durable Powers of Attorney: Issues of Gender and Health Care Decision-Making*, 21 J. GERONTOLOGICAL SOC. WORK 161, 173 (1993).

113. *See* Mortimer D. Gross, *What Do Patients Express as Their Preferences in Advance Directives?*, 158 ARCHIVES INTERNAL MED. 363, 364 (1998) (finding that 11% of inpatient admissions had executed an advance directive; 15% of outpatients); Jan C. Hofmann et al., *Patient Preferences for Communication with Physicians about End-of-Life Decisions*, 127 ANNALS INTERNAL MED. 1, 1 (1997) (finding that among seriously ill hospitalized adults, 23% had discussed preferences with physicians); Sarah Coate Johnston

been given to the value of doing so.[114] Individuals seem reluctant to do so even when infected with a disease known to be fatal and associated with a difficult dying process.[115]

Furthermore, it can be very difficult to fully envision and anticipate what treatment choices one is likely to make when actually faced with such a decision, particularly when, as they typically are, these choices are expressed some time before (often years in advance) and under very different circumstances.[116] The choices made by individuals may also vary with the nature and course of the disease or the injury and thus be hard to capture within a single generic and abstract document.[117] In addition, it can be very difficult to identify and describe the specific circumstances under which an individual wants LSMT to be withheld or withdrawn.[118] Typically dying today is a protracted process, with many steps along the way at which LSMT can be forgone and the decision may vary depending on what stage of the process is involved.[119]

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et al., *The Discussion About Advance Directives: Patient and Physician Opinions Regarding When and How It Should Be Conducted*, 155 ARCHIVES INTERNAL MED. 1025, 1025 (1995) (finding fewer than 10% of Americans have prepared advance directives); O'Brien et al., *supra* note 104, at 1778 (1995) (finding that among nursing home residents with sufficient comprehension to participate in study, 12% reported having previous discussions with health care provider; for residents able to name someone they would want to act as surrogate, 31% reported having spoken to that individual about treatment preferences).

114. *See* 42 U.S.C. § 1395cc(f) (1994) (requiring health care providers to give information and education about advance directives to their patients, staff, and the community); 42 U.S.C.A. § 1396a(w) (West Supp. 1998); Pub. L. No. 101-508, § 4751 (1990) (mandating a public education campaign regarding advance directives). Although it has been suggested that physicians should be more proactive in encouraging advance directives, studies indicate that physicians are reluctant or unsuccessful in assuming this role. *See* Susan Door Gould et al., *Discussions About Limiting Treatment in a Geriatric Clinic*, 41 J. AM. GERIATRICS SOC'Y 277, 277–80; Johnston et al., *supra* note 113, at 1029.

115. *See* Lauris C. Kaldjian et al., *End-of-Life Decisions in HIV-Positive Patients: The Role of Spiritual Beliefs*, 12 AIDS 103 (1998) (finding 17% of hospitalized HIV patients had a living will, 24% had discussed resuscitation status with physician).

116. *See* Ron L.P. Berghmans, *Ethical Hazards of the Substituted Judgement Test in Decision Making Concerning the End of Life of Dementia Patients*, 12 INT'L J. GERIATRIC PSYCHIATRY 283, 284–86 (1997); James Lindemann Nelson, *Dementia and Advance Decision Making: Who's Choosing for Whom?* 8 ALZHEIMER DISEASE & ASSOCIATED DISORDERS 3 (1994); Orentlicher, *The Right to Die*, *supra* note 58, at 2445. If considerable time has passed since the individual expressed his or her choice, a court may be reluctant to permit a surrogate to rely solely upon such evidence. *See, e.g.*, Spahn v. Eisenberg (*In re* Guardianship and Protective Placement of Edna M.F.), 563 N.W.2d 485, 492 (Wis. 1997).

117. *See* Scott R. Berry & Peter A. Singer, *The Cancer Specific Advance Directive*, 82 CANCER 1570, 1570, 1575 (1998); Orentlicher, *The Right to Die*, *supra* note 58, at 2445; Daniel P. Sulmasy et al., *The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses*, 128 ANNALS INTERNAL MED. 621, 626–27 (1998).

118. *See* Orentlicher, *The Right to Die*, *supra* note 58, at 2445.

119. *See* Faber-Langendoen, *supra* note 103; Kathy Faber-Langendoen & Dianne M. Bartels, *Process of Forgoing Life-Sustaining Treatment in a University Hospital: An*

As a result, when advance directives are provided, they tend to be phrased in very general terms and to describe very broadly and relatively ineffectively what should be done and when.[120] This requires surrogates and health care providers to frequently engage in a great deal of interpretation of the advance directives to determine when the individual wanted LSMT to be forgone.[121]

Furthermore, recent studies have indicated that advance directives, verbal or written, prior or contemporaneous, have little impact on the actual care provided.[122] A failure to accurately perceive or follow expressed patient EOL choices has been reported for physicians,[123] nurses,[124] patient surrogates,[125] and

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Empirical Study, 20 CRITICAL CARE MED. 570 (1992); Cheryl B. Mwaria, *The Concept of Self in the Context of Crisis: A Study of Families of the Severely Brain-Injured*, 30 SOC. SCI. & MED. 889 (1990).

120. *See* Berry & Singer, *supra* note 117, at 1570, 1575; Stephen C. Hines et al., *Communication and Problematic Integration in End-of-Life Decisions: Dialysis Decisions Among the Elderly*, 9 HEALTH COMM. 199, 212 (1997); Orentlicher, *The Right to Die*, *supra* note 58, at 2445; Sulmasy et al., *supra* note 117, at 628; Joan M. Teno et al., *Role of Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data*, 13 J. GEN. INTERNAL MED. 439, 441 (1998); Jaya Virmani et al., *Relationship of Advance Directives to Physician-Patient Communication*, 154 ARCHIVES INTERNAL MED. 909, 912–13 (1994).

121. *See* Berghmans, *supra* note 116, at 284; Joan M. Teno et al., *Do Advance Directives Provide Instructions that Direct Care?*, 45 J. AM. GERIATRICS SOC'Y 508, 508–09, 511 (1997); Virmani et al., *supra* note 120, at 912–13. Health care providers are also often somewhat reluctant to raise the need to execute an advance directive. Kay Weiler et al., *Iowa Nurses' Knowledge of Living Wills and Perceptions of Patient Autonomy*, 12 J. PROF. NURSING 245, 250 (1996). Patients have also been found to not understand the treatments they address in their advance directives. *See* Gary S. Fischer et al., *Patient Knowledge and Physician Predictions of Treatment Preferences After Discussion of Advance Directives*, 13 J. GEN. INTERNAL MED. 447, 452 (1998).

122. *See* Marion Danis et al., *A Prospective Study of the Impact of Patient Preferences on Life-sustaining Treatment and Hospital Cost*, 24 CRITICAL CARE MED. 1811, 1815 (1996); Laura C. Hanson et al., *Impact of Patient Incompetence on Decisions To Use or Withhold Life-Sustaining Treatment*, 97 AM. J. MED. 235, 239–40 (1994); Smedira et al., *supra* note 104, at 313; Teno et al., *supra* note 120, at 441; Joan Teno et al., *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. AM. GERIATRICS SOC'Y 500, 505–07 (1997). *But see* Bernard J. Hammes & Brenda L. Rooney, *Death and End-of-Life Planning in One Midwestern Community*, 158 ARCHIVES INTERNAL MED. 383, 388–91 (1998) (following an extensive two-year-long education program, written advance directives were more likely to be executed and followed).

123. *See* Danis et al., *supra* note 122, at 1815; Jennifer A. Druley et al., *Physicians' Predictions of Elderly Outpatients' Preferences for Life-Sustaining Treatment*, 37 J. FAM. PRAC. 469, 469–70, 472–74 (1993); John E. Heffner et al., *Attitudes Regarding Advance Directives Among Patients in Pulmonary Rehabilitation*, 154 AM. J. RESPIRATORY & CRITICAL CARE MED. 1735, 1737, 1739 (1996); Lund, *supra* note 106, at 915; S. Van McCrary et al., *Treatment Decisions for Terminally Ill Patients: Physician's Legal Defensiveness and Knowledge of Medical Law*, 20 LAW MED. & HEALTH CARE 364, 368 (1992); Lawrence J. Schneiderman et al., *Do Physicians' Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences? A Second Look*, 6 CAMBRIDGE Q. HEALTHCARE ETHICS 131, 131 (1997); Ira B. Wilson et al., *Is*

family members.[126] Among the reasons given for not following advanced directives are: perceptions of potential legal risk associated with foregoing treatment, family requests to disregard, a treating physician's refusal to follow them, deference given to recommendations by physicians, an assumption by health care providers that they know what patients want but in actuality inserting their own preferences, a lack of information that they existed or an inability to apply them to the current situation, and greater weight being given to other factors.[127] In addition, forcing patients to articulate their advance directives, particularly upon admission to a health care facility, may be resisted by or be difficult for the patient and have anti-therapeutic effects.[128]

Nevertheless, as discussed, the decision-making scenario that courts in the United States routinely endorse is one where either patients with current decision-making capacity contemporaneously express their intent or single individuals acting as surrogates are designated with authority to ascertain the intent of patients who currently lack decision-making capacity. In turn, treatment decisions are viewed as a relatively simple and straight-forward application of this intent. As will be discussed in the next section, this hierarchical decision-making model fails to take into account the roles typically played by a range of individuals in this decision-making process. Furthermore, it fails to recognize that such decisions are rarely the exercise of a single individual making such decisions in isolation or exclusive of the input and views of this range of concerned individuals, particularly the patient's family members and health care providers.[129]

C. Role of the Family and Interested Individuals Outside the Family

As discussed, when a patient lacks current decision-making capacity, most courts have endorsed a hierarchical decision-making model that essentially places a surrogate in the shoes of the patient and provides the surrogate with exclusive

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Experience a Good Teacher? How Interns and Attending Physicians Understand Patients' Choices for End-of-Life Care, 17 MED. DECISION MAKING 217, 217, 223–25 (1997).

124. *See* Mary J. Kennard et al., *Participation of Nurses in Decision Making for Seriously Ill Adults*, 5 CLINICAL NURSING RES. 199, 208–09, 213 (1996).

125. *See* Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 JAMA 2067, 2068–69 (1992); Jan Hare et al., *Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions*, 152 ARCHIVES INTERNAL MED. 1049, 1050–53 (1992); Sulmasy et al., *supra* note 117, at 623, 626. Furthermore, even when agreement was relatively low, surrogate conficence in the prediction was relatively high. *See* Hare, *supra*, at 1052–53.

126. *See* Michele J. Karel & Margaret Gatz, *Factors Influencing Life-Sustaining Treatment Decisions in a Community Sample of Families*, 11 PSYCHOL. & AGING 226, 231–33 (1996); Moshe Sonnenblick et al., *Dissociation Between the Wishes of Terminally Ill Parents and Decisions by Their Offspring*, 41 J. AM. GERIATRICS SOC'Y 599 (1993); Weiler et al., *supra* note 121, at 249.

127. *See* Berghmans, *supra* note 116, at 285–86; Danis et al., *supra* note 122, at 1815; McCrary et al., *supra* note 123, at 368, 371–72; Weiler et al., *supra* note 121, at 249.

128. *See* Kapp, *supra* note 37, at 37.

129. *See infra* Part VI.C.

decision-making authority.[130] Under this approach, the surrogate is generally charged with making the decision that the patient would have made if the patient currently had decision-making capacity.[131]

The surrogate decision-making role is typically assigned to a member of the patient's family.[132] Allowing a family member to serve as surrogate is widely supported because such authority is generally consistent with patient preferences. Family members are generally considered to have the greatest insight into the patient's intent, can normally be trusted to promote the patient's intent and well-being, and are usually the most affected by these decisions and thus highly motivated to address them conscientiously.[133] What the hierarchical model fails to appreciate, however, is that families often consist of a constellation of members and that this constellation frequently plays a significant role in EOL decision making as the various members are concerned about, contribute to, and, at times, disagree over EOL decisions.[134] In addition, individuals outside the family may similarly play a significant role in EOL decision making.[135]

A single, given family member may not always be in the best position or be the most appropriate person to make EOL decisions on behalf of a patient, notwithstanding this individual's apparent authority or demand that he or she be allowed to do so.[136] Surrogates, typically family members, have been shown to often make decisions that are poorly informed or that are inconsistent with the advance directives of the patient.[137] In addition, the events that necessitate a family member filling this role as surrogate may flood the individual with a range of emotions that hinder the individual's ability to exercise this authority[138] or the

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130. *See supra* Part V.

131. *See supra* Part V.

132. *See, e.g., In re* Jobes, 529 A.2d 434, 447, n.11 (N.J. 1987); *In re* Guardianship of Grant, 747 P.2d 445, 456 n.5 (Wash. 1987). *See also* Lynn et al., *supra* note 106, at 100; Orentlicher, *The Right to Die*, *supra* note 58, at 2444; Virginia P. Tilden et al., *Decisions about Life-Sustaining Treatment: Impact of Physicians' Behaviors on the Family*, 155 ARCHIVES INTERNAL MED. 633, 633 (1995); Winick, *supra* note 10, at 78.

133. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 17; Dan W. Brock, *What Is the Moral Authority of Family Members to Act as Surrogates for Incompetent Patients?*, 74 MILBANK Q. 599, 602–15 (1996); Dallas M. High & Howard B. Turner, *Surrogate Decision-Making: The Elderly's Familial Expectations*, 8 THEORETICAL MED. 303, 310, 315; Richard Sherlock & C. Mary Dingus, *Families and the Gravely Ill: Roles, Rules, and Rights*, 33 J. AM. GERIATRICS SOC'Y 121, 122 (1985).

134. *See* Carin E. Reust & Susan Mattingly, *Family Involvement in Medical Decision Making*, 28 FAM. MED. 39, 41–44 (1996).

135. *See infra* notes 164–71 and accompanying text.

136. *See* Howard Brody, *The Family and Terminal Care Decisions*, 20 J. FAM. PRAC. 343, 343 (1985); Hoffmann, *supra* note 31, at 836–37; Teno et al., *supra* note 120, at 441, 443–46.

137. *See* Hare et al., *supra* note 125, at 1050–53; Kapp, *supra* note 37, at 41–42; Sulmasy et al., *supra* note 117, at 623, 626; Weiler et al., *supra* note 121, at 249.

138. *See* Hoffmann, *supra* note 31, at 835–36; Teno et al., *supra* note 120, at 443–44.

individual may be overwhelmed by the difficulty of this decision and a lack of guidance for making it.[139]

Also, assigning exclusive decision-making responsibility to a single member of the patient's family may exacerbate rather than prevent or resolve disputes associated with EOL decision making, even when the surrogate is drawn from the patient's family.[140] Disagreements involving family members tend to be a primary source of cases necessitating judicial involvement.[141] Because of their emotional nature, these events may result in relatively volatile interactions among family members and may accentuate conflicting, deeply entrenched positions.[142] In some cases, these conflicts may reflect ongoing or long-standing tensions, rivalries, and the like among family members.[143]

Family members may disagree about what the patient would have wanted or what is best for the patient, or who should act as surrogate.[144] These disagreements may stem from family members having spoken to the patient at different times, having different interpretations of what the patient said or intended, or having different perceptions of what the patient's values or behavior indicated.[145] Alternatively, these disagreements may stem from differences in life experiences among family members and different views of medical treatment, the quality of life, and the medical profession.[146] On some occasions, specific family members may be driven by social or economic constraints,[147] or motivated by personal gain or self-interest.[148] However, disagreements are not inevitably based on antagonism and deep-seeded animosity, but instead may reflect strong, emotional bonds and diverging but sincerely felt desires to respect the intent and well-being of the patient.[149] Furthermore, additional family members are frequently

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139. *See* Mwaria, *supra* note 119, at 889–93.

140. *See* Tilden et al., *supra* note 132, at 635, 637 (family members identified practice of placing the full burden of decision making on one person to be unhelpful and to increase their burden).

141. *See* Hoffmann, *supra* note 31, at 829 ("Generally, when there are real disputes, they seem to fall into one of two categories: (1) disputes between an incapacitated patient's family members and the patient's treating physician or (2) disputes between family members of such patients.").

142. *See* Hoffmann, *supra* note 31, at.838.

143. *See, e.g.*, HAFEMEISTER & HANNAFORD, *supra* note 2, at 49; Susan S. Erstling, *The Shared Burden: When Physicians and Families Decide to Forego Life-Sustaining Treatment*, 20 J. FAM. PRAC. 393, 395 (1985); Hafemeister & Robinson, *supra* note 39, at 218–19; Hoffmann, *supra* note 31, at 836–37.

144. *See* Hoffmann, *supra* note 31, at 837; John C. Roberts et al., *Withdrawing Life Support: The Survivors*, 224 ACTA MEDICA SCANDANAVIA 141, 141, 144 (1988).

145. *See* Hoffmann, *supra* note 31, at 837.

146. *See id.*

147. *See* Lund, *supra* note 106, at 931; Mwaria, *supra* note 119, at 890–93.

148. *See, e.g.*, Mack v. Mack, 618 A.2d 744, 770–71 (Md. 1992) (Chasanow, J., concurring in part and dissenting in part). *See also* Lund, *supra* note 106, at 914.

149. *See, e.g.*, John E. Thomas & Elizabeth J. Latimer, *When Families Cannot "Let Go": Ethical Decision-Making at the Bedside*, 141 CANADIAN MED. ASS'N J. 389, 390 (1989).

present and are likely to participate or demand a role in this decision making regardless of whether they are designated as the patient's surrogate.[150]

Family members tend to be an important consideration in the formulation of the advance directives expressed by patients, with the well-being of the family sometimes being a specific consideration.[151] Even for those patients who retain decision-making capacity, the assumption that they will or even desire to exercise decision-making autonomy has been criticized for failing to recognize the dependence on family members and health care providers that often exists, particularly during times of serious or terminal illness or injury.[152] Such patients may defer decision making to those around them, frequently because of their emotional and physiological exhaustion at the time.[153] The illness or injury that necessitates these decisions may also cloud the patient's judgment or weaken the patient's resolve.[154]

Thus, even if the patient retains decision-making capacity or has executed an advance directive, family members frequently play an important role in the EOL decision-making process.[155] Indeed, family members may seek or need to play a role even when the patient has current decision-making capacity and no surrogate is needed.[156] As a result, although less frequent, disagreements may also exist between family members and the patient.[157]

A few courts have recognized the broader impact of these decisions on the family constellation and the importance of considering the interests and well-being of family members as well as the interests and well-being of the patient.[158] Some

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150. *See* Smedira et al., *supra* note 104, at 312.

151. *See* Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 311–12 (1990) (Brennan, J., dissenting); Hare et al., *supra* note 125, at 1051, 1053; High & Turner, *supra* note 133, at 307, 316.

152. *See* Deborah J. Bailly & Elizabeth DePoy, *Older People's Responses to Education About Advance Directives*, 20 HEALTH & SOC. WORK 223, 223–24 (1995); Sarah Coate Johnston & Mark P. Pfeifer, *Patient and Physician Roles in End-of-Life Decision Making*, 13 J. GEN. INTERNAL MED. 43, 44 (1998); Lund, *supra* note 106, at 914–15.

153. *See* Victor G. Cicirelli, *Views of Elderly People Concerning End-of-Life Decisions*, 17 J. APPLIED GERONTOLOGY 186, 196 (1998). In a survey of 447 individuals between the ages of 60 and 100, Cicirelli found that 36% expressed a preference for letting someone close to them make end-of-life decisions for them rather than making such decisions for themselves. *See also* Braulio Montalvo, *The Patient Chose to Die: Why?*, 31 GERONTOLOGIST 700, 701–02 (1991).

154. *See* Lund, *supra* note 106, at 915; Lynn et al., *supra* note 106, at 97. Lynn et al. found that in the last 3 days of life, 55% of patients were conscious, 40% had severe pain most of the time, 80% experienced severe fatigue, and 63% had difficulty tolerating physical or emotional problems.

155. *See* Reust & Mattingly, *supra* note 134, at 40–44; Teno et al., *supra* note 120.

156. *See* Steven R. Hahn, *The Doctor-Patient-Family Relationship: A Compensatory Alliance*, 109 ANNALS INTERNAL MED. 884 (1988).

157. *See, e.g.*, Thomas & Latimer, *supra* note 149, at 390–91.

158. *See, e.g.*, *In re* Guardianship of Grant, 747 P.2d 445, 455 (Wash. 1987) ("The prolongation of the existence of this vegetative state for possibly years to come...to

courts specifically allow the surrogate decision maker to consider the patient's likely attitude toward the impact of the treatment choice on family members.[159] However, court opinions that recognize a special role for the family in EOL decision making are typically phrased ambiguously with regard to whether a single member of the family should make this decision or whether the exercise of decision-making authority should represent a collective decision by family members.[160]

In general, except for those relatively few cases when a patient has no family or loved ones,[161] EOL decisions deeply affect many people beyond the patient, many of whom believe they have insights into the patient's intent and well-being and should be involved in these decisions.[162] The law often recognizes a pecking order among family members along the lines of next-of-kin in assigning decision-making authority.[163] However, there may be a much wider range of individuals with insights into the patient's intent, with concerns about the patient's well-being, and with interests and preferences of their own that are important and worthy of respect and recognition, including more distant relatives or individuals for whom a legally recognized relationship with the patient has ended (e.g., a former spouse) or was never established (e.g., a best friend, a gay lover).[164] The insights of these individuals may in some cases be more valuable than those provided by the patient's next-of-kin.[165]

In addition to these family members and other interested individuals with insights into the patient's intent and interests, the health care providers who are providing care and treatment to the patient may desire to be or believe that they should be involved in the patient's EOL decisions.[166] In addition to being

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the emotional and economic destruction of the survivors is a monstrous assault to the family concerned that we will not countenance.").

159. *See, e.g.*, *In re* Guardianship of Roe, 421 N.E.2d 40, 58 (Mass. 1981); *In re* Jobes, 529 A.2d 434, 444 n.10 (N.J. 1987). *But see* Mack v. Mack, 618 A.2d 744, 760 (Md. 1992).

160. *See, e.g.*, *In re Guardianship of Grant*, 747 P.2d at 456 n.5 ("Where no guardian has been appointed, the patient's immediate family shall make the decision on whether to withhold life sustaining treatment....").

161. *See* Smedira et al., *supra* note 104, at 311 (stating that family members could not be found for only 8 of 110 incompetent patients receiving intensive care for whom EOL treatment was forgone, with the decisions then made by attending physicians).

162. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 29; Sonnenblick et al., *supra* note 126, at 602–03.

163. *See, e.g.*, Conservatorship of Drabick, 245 Cal. Rptr. 840, 861 n.38 (Ct. App. 1988); Causey v. St. Francis Med. Ctr., 719 So. 2d 1072, 1074 (La. Ct. App. 1998); *Mack*, 618 A.2d at 752; *In re* Quinlan, 355 A.2d 647 (N.J. 1976).

164. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 17. Indeed, most bioethicists include close friends as part of the patient's "family." *Id.* at 17.

165. *See, e.g.*, *In re* Jobes, 529 A.2d 434, 447 (N.J. 1987) ("[If] another relative, e.g., a cousin, aunt, uncle, niece, or nephew, functions in the role of the patient's nuclear family, then that relative can and should be treated as a close and caring family member" for purposes of exercising substituted judgment.).

166. *See* Lawrence Markson et al., *The Doctor's Role in Discussing Advance Preferences for End-of-Life Care: Perceptions of Physicians Practicing in the VA*, 45 J.

personally involved and invested in the care being provided and its outcome, these individuals may come to know the patient quite well and to share communications and experiences that they believe provide them with relevant insights.[167] Health care providers, especially physicians, can be integrally involved in this decision-making process.[168] Patients may feel that physicians in particular should exercise considerable influence over these decisions.[169] Indeed, although not without controversy, many physicians believe that they should exercise ultimate control over these decisions.[170] In addition, administrative staff of the facility where treatment decisions are being made may have an interest in these decisions because of the ethical, legal, financial, and practical ramifications they may have for the facility.[171]

As a result, disagreements may also exist between the health care staff and the patient or family members.[172] In addition, disputes can also arise among the

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AM. GERIATRICS SOC'Y 399, 403, 405 (1997); Thomas J. Prendergast, *Resolving Conflicts Surrounding End-of-Life Care*, 5 NEW HORIZONS 62, 63–70 (1997).

167. *See* Hoffmann, *supra* note 31, at 833; Kapp, *supra* note 37, at 34.

168. *See* Johnston et al., *supra* note 113, at 1028–29; Schneiderman et al., *supra* note 123, at 136; Jacquelyn Slomka, *The Negotiation of Death: Clinical Decision Making at the End of Life*, 35 SOC. SCI. & MED. 251, 252–55 (1992).

However, physicians' and nurses' perceptions of their patients' EOL intent may be inaccurate. *See supra* notes 123–24 and accompanying text. Furthermore, physicians, perhaps inadvertently, sometimes substitute their own EOL preferences for those of their patients. *See, e.g.*, Schneiderman et al., *supra* note 123, at 131, 136. Because of this tendency and because of the great influence that physicians can exercise over these decisions, physicians have been exhorted to be cautious about interjecting their views into this decision-making process. *See, e.g.*, *id.* at 136.

169. *See* Heffner et al., *supra* note 123, at 1737; Sarah Coate Johnston, *Advance Directives: From the Perspective of the Patient and the Physician*, 89 J. ROYAL SOC'Y MED. 568, 569 (1996); Johnston et al., *supra* note 113, at 1026–29. *But see* High & Turner, *supra* note 133, at 308 (finding that elderly persons, particularly with surviving family members, unlikely to mention a doctor as a possible surrogate decision maker).

170. *See, e.g.*, Causey v. St. Francis Med. Ctr., 719 So. 2d 1072, 1075 (La. Ct. App. 1998) (finding an obligation to provide information about "all medically acceptable treatment options for patient or surrogate to consider...does not compel a physician to provide interventions that in his view would be harmful, without effect, or medically inappropriate"); Schneiderman et al., *supra* note 123, at 136 ("[P]hysicians are the ones who ultimately exercise control over these important decisions."). *But see* Richard Grant & Elizabeth K. Steel, *Decision-Making with Psychiatrically Impaired Patients: A Collaborative Endeavor*, 13 PSYCHIATRIC CLINICS N. AM. 149, 155 (1990) ("The role of physicians...is that of technical advisor and facilitator rather than actual decisionmaker.").

171. *See* Hoffmann, *supra* note 31, at 825. *But see In re* Storar, 420 N.E.2d 64, 69 n.3 (N.Y. 1981) (holding that medical facility generally has no responsibility or right to supervise or interfere with course of treatment recommended by patient's private physician; that the matter generally to be decided by private physician with patient's family; that the hospital ordinarily has no power to intervene or standing to sue).

172. *See, e.g.*, *Causey*, 719 So. 2d 1072; *In re* Matthews, 650 N.Y.S.2d 373, 376–77 (N.Y. App. Div. 1996); Elbaum v. Grace Plaza of Great Neck, Inc., 544 N.Y.S.2d 840, 842–45 (N.Y. App. Div. 1989). *See* Hoffmann, *supra* note 31, at 831–36; John M. Luce, *Withholding and Withdrawal of Life Support: Ethical, Legal, and Clinical Aspects*, 5 NEW

patient's various health care providers, which in turn may fuel disputes among family members.[173]

At the same time, disagreements in this context are not per se undesirable.[174] For example, they may facilitate the ability of the participants to address the issues they face by bringing disagreements into the open, they may relieve tensions, or they may prevent conflict from escalating unnecessarily.[175] Furthermore, rather than being actual disputes, they may instead reflect misunderstandings about the relevant facts or required actions that can be resolved by improved communication or by providing needed information.[176] They may also simply reflect a need to adjust to significant and in some cases sudden changes in the patient's condition.[177]

Nevertheless, such conflicts can be anti-therapeutic in that they can be very upsetting to the individuals involved and disruptive of patient care.[178] Excessive, uncontrolled, or unresolved conflict has the potential to create long-term rifts within family constellations, to confuse and prolong EOL decision making, and, when the patient has died, to unnecessarily extend the grieving process.[179] In extreme cases, this conflict can lead to outcomes that are contrary to the expressed intent or well-being of the patient or, when the patient's intent is unobtainable, the preferences and interests of virtually everyone associated with the patient.[180] Routine involvement of the courts in EOL decision making is widely criticized for promoting or exacerbating such conflict.[181]

These various individuals may reflect a diverse range of views of what constitutes a patient's intent and interests, and their own interests may be significantly effected by a given EOL decision. However, the hierarchical decision-making model tends to exclude these individuals and the information they can provide from the EOL decision-making process. This exclusion, as will be discussed in the following section, tends to have anti-therapeutic consequences for these individuals, to be deleterious to the decision-making process, and to enhance the likelihood of these matters being referred to the judiciary for resolution. Notwithstanding judicial efforts to establish a clearly defined decision-making

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HORIZONS 30, 36 (1997); Prendergast, *supra* note 166, at 62–69.

173. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 59; Judith Gedney Baggs, *Collaborative Interdisciplinary Bioethical Decision Making in Intensive Care Units*, 41 NURSING OUTLOOK 108, 109–11 (1993); Laura C. Hanson et al., *Who Decides? Physicians' Willingness to Use Life-Sustaining Treatment*, 156 ARCHIVES INTERNAL MED. 785 (1996); Hoffmann, *supra* note 31, at 833; Rurik Löfmark & Tore Nilstun, *Deciding Not to Resuscitate: Responsibilities of Physicians and Nurses—A Proposal*, 11 SCANDINAVIAN J. CARING SCI. 207, 209–11 (1997).

174. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 22.

175. *See id.* at 22.

176. *See id.* at 22, 26; Hoffmann, *supra* note 31, at 828.

177. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 21, 26.

178. *See* Prendergast, *supra* note 166, at 70.

179. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 27–29, 45.

180. *See id.*

181. *See supra* notes 93–94 and accompanying text.

hierarchy and their proclamations of the desirability of avoiding judicial intervention in resolving these matters,[182] disputes between various interested individuals, particularly among members of the patient's family, continue to be brought to the courts for resolution.[183]

VII. END-OF-LIFE DECISION MAKING: THE CONSENSUS-BASED MODEL

While courts in the United States have endorsed a "bright line" rule[184] that provides a single individual with EOL decision-making authority, many health care scholars and practitioners have promoted a consensus-based or shared decision-making model. More in accord with the goals of Therapeutic Jurisprudence/Preventive Law, this model seeks to minimize anti-therapeutic effects for those individuals who are directly affected by these decisions, while avoiding unnecessary judicial involvement.

Specifically, the consensus-based decision-making model explicitly seeks to broaden the circle of individuals who participate in this decision-making process, rather than narrowing the circle as tends to happen under the hierarchical decision-making model promoted by the legal system.[185] Although proponents of a consensus-based model may vary in terms of whom they would involve in the decision-making model, their common belief is that EOL decision making should be a shared responsibility.[186] Among the identified virtues of a consensus-based or

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182. *See supra* notes 93–94 and accompanying text.

183. *See, e.g.*, Wendland v. Superior Court, 56 Cal. Rptr. 2d 595 (Ct. App. 1996) (patient's wife opposed by patient's mother and sister); *In re* Dubreuil, 629 So. 2d 819 (Fla. 1993) (estranged husband and patient's two brothers aligned against patient and her mother); Mack v. Mack, 618 A.2d 744 (Md. 1992) (patient's wife challenged by patient's father and sister); *In re* Martin, 538 N.W.2d 399 (Mich. 1995) (patient's wife opposed by patient's mother and sister); Spahn v. Eisenberg (*In re* Guardianship and Protective Placement of Edna M.F.), 563 N.W.2d 485 (Wis. 1997) (patient's sister opposed by patient's niece).

184. *See* Conservatorship of Drabick, 245 Cal. Rptr. 840, 847 n.10 (Cal. Ct. App. 1988); *Spahn*, 563 N.W.2d at 490.

185. Although this discussion focuses on EOL decisions involving adult patients, a consensus-based approach is particularly appropriate when child patients are involved. Many of the tenets of this approach were first postulated by health care providers caring for child patients. *See, e.g.*, Pamela S. Hinds et al., *Decision Making by Parents and Healthcare Professionals when Considering Continued Care for Pediatric Patients with Cancer*, 24 ONCOLOGY NURSING F. 1523 (1997); Ruprecht Nitschke et al., *The Final-Stage Conference: The Patient's Decision on Research Drugs in Pediatric Oncology*, 2 J. PEDIATRIC PSYCHOL. 58, 61, 63 (1977).

186. *See, e.g.*, Baggs, *supra* note 173, at 110–11 (nurses, physicians, patients, and family); Caryn Christensen & James R. Larson, *Collaborative Medical Decision Making*, 13 MED. DECISION MAKING 339, 339 (1993) ("all involved"); Raymond S. Duff, *Patients, Families, and Health Professionals: Deciding the Use of Heroic Life-Sustaining Measures*, 75 J. MED. SOC'Y N.J. 43, 43 (1978) (patients, families, consequences for society, and future generations); Fader, *supra* note 103, at 1193 (patient, loved ones, family, physicians, and clergy); John Hardwig, *What About the Family?*, 20 HASTINGS CENTER REP., Mar./Apr.

shared decision-making model are that it will facilitate communication,[187] including enhancing the likelihood of material information being brought to bear,[188] promoting a better discussion of relevant intent, interests, and desires,[189] and enlarging family contributions;[190] share or relieve the burden of decision making;[191] better accommodate the grieving process;[192] address what may be unexpressed feelings, provide emotional support, and reduce feelings of tension and guilt;[193] promote better decision making[194] and improve collaborative problem solving;[195] empower, provide support to, and increase respect for the individuals

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1990, at 5 (patients and family); Denise A. Jacob, *Family Members' Experiences with Decision Making for Incompetent Patients in the ICU: A Qualitative Study*, 7 AM. J. CRITICAL CARE 30, 34 (1998) (clinicians and family members); Nancy S. Jecker, *The Role of Intimate Others in Medical Decision Making*, 30 GERONTOLOGIST 65, 66–69 (1990) (patient's intimate relations); Marshall B. Kapp, *Health Care Decision Making by the Elderly: I Get By with a Little Help from My Family*, 31 GERONTOLOGIST 619 (1991) [hereinafter Kapp, *Health Care Decision Making*] (staff, elderly patients, and family members); Marshall B. Kapp, *Treating Medical Charts Near the End of Life: How Legal Anxieties Inhibit Good Patient Deaths*, 28 U. TOL. L. REV. 521, 521 (1997) [hereinafter Kapp, *Treating Medical Charts*] (patient, family members and significant friends, physician, and other members of health care team); Douglas K. Miller et al., *Achieving Consensus on Withdrawing or Withholding Care for Critically Ill Patients*, 7 J. GEN. INTERNAL MED. 475, 475, 479 (1992) (physicians, family members, and patients when able); Richard Swartz & Erica Perry, *Advance Directives in End-Stage Renal Disease Inherently Involve Family and Staff*, 5 ADVANCED RENAL REPLACEMENT THERAPY 109 (1998) (families and staff); Thomas & Latimer, *supra* note 149, at 389 (enhanced consideration of family needs); Tilden et al., *supra* note 132, at 635 (physicians and family members to facilitate family consensus); Nelda Wray et al., *Withholding Medical Treatment from the Severely Demented Patient: Decisional Processes and Cost Implications*, 148 ARCHIVES INTERNAL MED. 1980, 1983–84 (1988) (providers and families, and increased family contribution).

187. *See* Melvin D. Dowdy et al., *A Study of Proactive Ethics Consultation for Critically and Terminally Ill Patients with Extended Lengths of Stay*, 26 CRITICAL CARE MED. 252, 255–58 (1998); Kapp, *Treating Medical Charts*, *supra* note 186, at 521; Swartz & Perry, *supra* note 186, at 114; Wray et al., *supra* note 186, at 1984.

188. *See* Baggs, *supra* note 173, at 109–10; Christensen & Larson, *supra* note 186, at 339.

189. *See* Hardwig, *supra* note 186, 5–6.

190. *See* Wray et al., *supra* note 186, at 1984.

191. *See* Christensen & Larson, *supra* note 186, at 339; Kapp, *Health Care Decision Making*, *supra* note 186, at 620; Ralph Porzio, *For Whom the Bell Tolls: The Emerging Decision-Makers for Life-Support Systems in Choices of Who Shall Live and Who Shall Die*, 38 ANGIOLOGY 889, 894 (1987); Tilden et al., *supra* note 132, at 635.

192. *See* Tilden et al., *supra* note 132, at 637.

193. *See* Erstling, *supra* note 143, at 394–97.

194. *See* Christensen & Larson, *supra* note 186, at 339; Dowdy et al., *supra* note 187, at 255–58; Kapp, *Health Care Decision Making*, *supra* note 186, at 620–21; Mileva Saulo et al., *Mediation: A Response to Aid-in-Dying and the Supreme Court Decision*, 28 J. NURSING ADMIN., Jan. 1998, at 54, 54.

195. *See* Kapp, *Treating Medical Charts*, *supra* note 186, at 521; Saulo et al., *supra* note 194, at 56, 60.

involved;[196] and better respond to the personalities and viewpoints of the individuals involved.[197] Furthermore, this approach has been described as preferred by patients and family members,[198] or as standard practice,[199] and one that rarely results in conflict.[200]

An exclusive focus on patient autonomy can be insensitive to the harm it causes the family, overlook relevant family dynamics and the needs of the family and the patient, undercut the principles of beneficence and justice, and be unachievable for patients who lack decision-making capacity.[201] The presence of an advance directive is not necessary to apply this approach,[202] and it has been recommended that this shared decision-making approach should be the focus of EOL decisions rather than the use of an advance directive.[203]

Studies have found that patients, particularly older patients, are more interested in being kept informed about the decision-making process or in having individuals they trust involved in the decision than in exercising decision-making authority.[204] Furthermore, as discussed, any single individual can be an imperfect reporter or predictor of the patient's intent and well-being.[205] At the same time, health care providers are becoming increasingly aware of the value of promoting dialogue and discussion among the various individuals with an emotional stake in

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196. *See* Baggs, *supra* note 173, at 109; Jacob, *supra* note 186, at 34; Kapp, *Health Care Decision Making*, *supra* note 186, at 620.

197. *See* Christensen & Larson, *supra* note 186, at 339.

198. *See* Lesley F. Degner & Jeffrey A. Sloan, *Decision Making During Serious Illness: What Role Do Patients Really Want to Play?*, 45 J. CLINICAL EPIDEMIOLOGY 941, 947 (1992); High & Turner, *supra* note 133, at 310; Johnston & Pfeifer, *supra* note 152, at 44; Tilden et al., *supra* note 132, at 635.

199. *See* Christensen & Larson, *supra* note 186, at 339; Claudia J. Coulton, *Research in Patient and Family Decision Making Regarding Life Sustaining and Long Term Care*, 15 SOC. WORK HEALTH CARE, No. 1, 1990, at 63, 69; Charles E. Denk et al., *How Do Americans Want to Die? A Factorial Vignette Survey of Public Attitudes About End-of-Life Medical Decision-Making*, 26 SOC. SCI. RES. 95, 114 (1997); Fader, *supra* note 103, at 1193; Hanson et al., *supra* note 122, at 238–39; Kapp, *Treating Medical Charts*, *supra* note 186, at 521; Thomas & Latimer, *supra* note 149, at 389.

200. *See* Hanson et al., *supra* note 122, at 239.

201. *See* Hardwig, *supra* note 186, at 5; Jecker, *supra* note 186; Kapp, *Treating Medical Charts*, *supra* note 186, at 542; Thomas & Latimer, *supra* note 149, at 389.

202. *See* Fader, *supra* note 103, at 1193.

203. *See* Hillel R. Alpert & Linda Emanuel, *Comparing Utilization of Life-Sustaining Treatments with Patient and Public Preferences*, 13 J. GEN. INTERNAL MED. 175, 179–80.

204. *See, e.g.*, Degner & Sloan, *supra* note 198, at 945–47, 945 tbl. 3; Jack Ende et al., *Measuring Patients' Desire for Autonomy: Decision Making and Information-Seeking Preferences Among Medical Patients*, 4 J. GEN. INTERNAL MED. 23, 25–28 (1989); Johnston & Pfeifer, *supra* note 152, at 44. *But see* Bonny Barry & Amanda Henderson, *Nature of Decision Making in the Terminally Ill Patient*, 19 CANCER NURSING 384, 388–90 (1996) (terminally ill patients initially stated they did not want much input into the decision-making process; however, as they learned more about their conditions, they desired greater input).

205. *See supra* notes 123–26, 137, 152 and accompanying text.

these decisions and in the virtue of adopting a participatory decision-making style.[206] A mediation model has been particularly recommended for this approach.[207]

In practice, when the consensus-based model is employed, the decision-making process is expanded to include the various individuals with some personal tie to the patient.[208] They are encouraged to voice and air their opinions and engage in what may be a lengthy give-and-take that attempts to reach agreement on what the patient would have wanted done if the patient could speak for him or herself at this time.[209] Discussion is continued until consensus is reached among these participants on the appropriate treatment choice.[210] Consensus does not require that a unanimous or majority position be reached. Indeed, a vote among these participants is neither required nor encouraged. Rather, discussions continue until, in essence, a position is reached to which no one strongly objects and which the group generally supports.[211]

Typically, a health care provider initiates the discussions associated with this decision-making model.[212] The health care facility may offer its resources to

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206. *See, e.g.*, Christensen & Larson, *supra* note 186, at 339; Duff, *supra* note 186, at 43; Erstling, *supra* note 143, at 396–98; Porzio, *supra* note 191, at 894; Roberts et al., *supra* note 144, at 141.

It should be recognized that for some health care providers, the endorsement of a consensus-based model is driven more by pragmatic than philosophical concerns. They may find waiting for a consensus to develop to be a "safer" decision in that they believe that as a result they do not have to fear a subsequent lawsuit by someone who disagreed with the decision ultimately reached. *See* Hoffmann, *supra* note 31, at 837 n.65; Kapp, *supra* note 37, at 29.

207. *See* NANCY NEVELOFF DUBLER & LEONARD J. MARCUS, MEDIATING BIOETHICAL DISPUTES ix (1994); Saulo et al., *supra* note 194.

208. *See* Erstling, *supra* note 143, at 393; Erich H. Loewy, *Decisions to Leave Home: What Will the Neighbors Say?*, 36 J. AM. GERIATRIC SOC'Y 1143, 1145–46 (1988); Robert M. Nelson, *Ethics in the Intensive Care Unit: Creating an Ethical Environment*, 13 CRITICAL CARE CLINICS 691, 694 (1997). Such an approach has been advised even when the patient retains decision-making capacity. *See* Hahn, *supra* note 156, at 884; Thomas & Latimer, *supra* note 149, at 389. Individuals who seek to influence the decision solely because of a political/social agenda are excluded, but health care providers, consultants, and administrators associated with the health care facility may be included.

209. *See* Erstling, *supra* note 143, at 396–98 (providing a description of specific techniques to use); Orentlicher, *The Right to Die*, *supra* note 58, at 2446; Valerie Swigart et al., *Letting Go: Family Willingness to Forgo Life Support*, 25 HEART & LUNG 483, 486–89 (1996).

210. *See, e.g.*, Thomas & Latimer, *supra* note 149, at 390–91. Although this emphasis on consensus primarily focuses on reaching agreement with respect to the patient's treatment intent or well-being, increasing attention is also being given to the importance of reaching consensus on the patient's medical state. *See, e.g.*, Spahn v. Eisenberg (*In re* Guardianship and Protective Placement of Edna M.F.), 563 N.W.2d 485, 500 (Wis. 1997) (Bablitch, J., concurring).

211. *See, e.g.*, Slomka, *supra* note 168, at 253, 256–57; Swigart et al., *supra* note 209 at 490–91, 493; Thomas & Latimer, *supra* note 149, at 390.

212. *See, e.g.*, Nitschke et al., *supra* note 185, at 59; Slomka, *supra* note 168, at 256–57. A health care provider often assumes this role because he or she is most familiar

facilitate the process, for example, by providing a consult by the facility's ethics committee, a group that generally has a multidisciplinary composition and represents a range of views on EOL decision making.[213] Such consults are often found helpful in forging a consensus.[214] In addition, input and participation is often solicited from the various members of the patient's treatment team and is not limited to the input of the physician, thereby enhancing the range of information obtained.[215] Other members of the treatment team may interact with patients or family members in different contexts, thereby providing additional information and insights.[216]

In general, the consensus-based decision-making model emphasizes the importance of health care providers promoting the sharing of information and responsibility, enhancing communication, and providing support and counseling for those individuals involved in the decision-making process.[217] A danger associated with both the hierarchical and the consensus-based decision-making models is that the health care providers, particularly physicians, may intentionally or unintentionally exert disproportionate influence over the decision making.[218] The health care provider should simply offer to facilitate the decision-making process and resist interjecting his or her own interests or personal views about EOL decisions in general into these discussions.[219] In addition, the wider range of

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with this process and is well suited to recognize the need to initiate discussions pertaining to EOL decisions. A physician is widely perceived as the appropriate person to initiate discussions; however, a physician may be unavailable for or fail to initiate such discussions. *See* Heffner et al., *supra* note 123, at 1737, 1739; Johnston, *supra* note 169, at 569; Johnston et al., *supra* note 113, at 1028–29. As a result, the process may be initiated by other health care providers, particularly when the patient appears to be experiencing considerable discomfort. *See* Kennard et al., *supra* note 124, at 201.

213. *See* Dowdy et al., *supra* note 187; John A. McClung et al., *Evaluation of a Medical Ethics Consultation Service: Opinions of Patients and Health Care Providers*, 100 AM. J. MED. 456 (1996); Robert D. Orr et al., *Evaluation of an Ethics Consultation Service: Patient and Family Perspective*, 101 AM. J. MED. 135 (1996).

214. *See* Orr et al., *supra* note 213, at 135.

215. *See* Christensen & Larson, *supra* note 186, at 340; Nitschke et al., *supra* note 185, at 62.

216. *See id.*

217. *See* Christensen & Larson, *supra* note 186, at 340; Marsha Lewis et al., *Decision Making by Elderly Patients with Cancer and Their Caregivers*, 20 CANCER NURSING 389, 396 (1997); Miller et al., *supra* note 186, at 475; Nitschke et al., *supra* note 185, at 59; Swigart et al., *supra* note 209; Thomas & Latimer, *supra* note 149, at 390.

218. *See* Markson et al., *supra* note 166, at 403, 405; P. Daniel McNeely et al., *Deciding About Mechanical Ventilation in End-Stage Chronic Obstructive Pulmonary Disease: How Respirologists Perceive Their Role*, 156 CMAJ 177, 180–81 (1997); Miller et al., *supra* note 186, at 477, 479; Karen E. Sullivan et al., *What Do Physicians Tell Patients with End-Stage COPD About Intubation and Mechanical Ventilation?*, 109 CHEST 258, 261–64 (1996). Indeed, some physicians assert that physicians should assert this influence. *See* Porzio, *supra* note 191, at 894.

219. *See* Nitschke et al., *supra* note 185, at 62.

individuals involved in this decision-making process can serve as a check on inappropriate interjections.[220]

The body of individuals involved in an EOL decision is generally allowed to adopt and develop its own means for resolving the matter, including adopting the decision-making style with which it is most comfortable.[221] Even though this may entail a relatively lengthy, uneven, and sometimes frustrating course, this process is necessary to ensure that the participants reach a decision that everyone who is directly affected by the decision can accept, both in the short-term and the long-term.[222] This, in turn, enhances the likelihood of an equitable and appropriate outcome and maximizes satisfaction levels among group members with the ultimate resolution.[223] Furthermore, such a consensus is generally consistent with the preferences of the patient.[224]

Often these discussions are facilitated by identifying a common goal among the participants, such as reaching a resolution that reflects and respects the patient's intent and well-being.[225] Avoiding recourse to the courts may also be espoused as a common and facilitating goal.[226] A secondary benefit of reaching consensus is that health care providers may not feel compelled to practice "defensive medicine," which tends to bypass the interests of patients and family members in order to reduce the possibility of liability exposure for health care providers.[227]

This consensus-based model is at odds with the hierarchical model employed by the majority of American courts for patients who lack decision-making capacity in at least two ways. First, a single individual is not accorded ultimate decision-making authority (whether it be the patient's next-of-kin or guardian), but rather all who know the patient well are involved in reaching a decision. Second, the legal fiction that this represents the actual decision of the patient is downplayed if not disregarded, although the paramount goal remains acting in accord with the patient's intent or wellbeing.

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220. *See generally* HAFEMEISTER & HANNAFORD, *supra* note 2, at 58–59.

221. *See* Nitschke et al., *supra* note 185, at 62. One course frequently used is to implement EOL decisions in a sequential manner over a period of time, beginning with less critical treatment modalities, allowing participants to progressively gauge the appropriateness of the chosen course of treatment. *See, e.g.*, Faber-Langendoen, *supra* note 103, at 2130.

222. *See, e.g.*, Jacob, *supra* note 186, at 36; Prendergast, *supra* note 166, at 67–71.

223. *See* Hanson et al., *supra* note 122, at 240. Unilaterally imposing a decision-making process may diminish the likelihood of reaching a result that is generally acceptable to the group.

224. *See, e.g.*, Duff, *supra* note 186, at 44.

225. *See* Erstling, *supra* note 143, at 397; Jacob, *supra* note 186, at 35; Miller et al., *supra* note 186, at 478–79.

226. *See* Fader, *supra* note 103, at 1219; Kapp, *Treating Medical Charts*, *supra* note 186, at 521–22.

227. *See, e.g.*, Kapp, *Treating Medical Charts*, *supra* note 186, at 523–24, 537; McCrary et al., *supra* note 123, at 368–72.

This approach is, however, relatively harmonious with the tenets of Therapeutic Jurisprudence, which seeks to minimize the negative effects on participants from law-related decision making,[228] and the goals of Preventive Law, which seeks to minimize unnecessary and unfruitful recourse to the legal system in general and the courts in particular.[229] By promoting and encouraging wider involvement of these various interested individuals, their needs and interests can be considered, lingering animosity and deep-seated disputes can be defused, and the need for recourse to the courts diminished.

In addition, by widening rather than narrowing the circle of decision makers, concerns expressed about the potential for improper motives driving the decisions of surrogates can be alleviated without interjecting the judicial system in this delicate and private decision-making process. For example, a family member whose decision making may be driven by inappropriate personal interests may be countered by other family members or involved health care providers acting pursuant to their codes of ethics.[230]

A consensus-based decision-making model may be perceived to have a lesser role to play when the patient is capable of expressing his or her own treatment intent. However, by widening the circle of individuals who are addressing the patient's intent, this model may provide useful safeguards to ensure that the patient retains independent decision-making authority and is not unduly exposed to coercive pressures. In addition, this model can help resolve issues that arise when a patient is unwilling to exercise decision-making authority on his or her own behalf. Furthermore, particularly with elderly or very ill patients, there is a tendency to "talk around" the patient, a tendency that can be reduced if there are a number of individuals concerned about the patient's intent or well-being.[231]

The consensus-based decision-making model has been found to result in very few major conflicts over decisions to withhold LSMT for patients without decision-making capacity.[232] Indeed, a few courts, albeit typically in relatively cursory or limited fashion, have indicated support for a model of decision making that involves multiple individuals.[233] Similarly, some legislation has embraced this

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228. *See supra* Part II.

229. *See supra* Part III. *See also* Fader, *supra* note 103, at 1219 ("[K]eep life and death medical decisions out of the courtrooms and...allow more of these decisions to remain with the individual patient and his family and friends, where they belong."); Kapp, *Treating Medical Charts*, *supra* note 186, at 521–22 ("Judges are asked to decide this question, not because they have any special expertise, but because only they can provide the physicians with civil and criminal immunity for their actions. In seeking this immunity, legal considerations quickly transcend ethical and medical judgments.").

230. *See* Mack v. Mack, 618 A.2d 744, 770–71 (Md. 1992) (Chasanow, J., concurring and dissenting); *id.* at 762 (McAuliffe, J., dissenting).

231. *See* Knee, *supra* note 28, at 13.

232. *See, e.g.*, Conservatorship of Drabick, 245 Cal. Rptr. 840, 847 (Ct. App. 1988). *See* Hanson et al., *supra* note 122, at 239–40.

233. *See, e.g.*, *In re* Longeway, 549 N.E.2d 292, 295 (Ill. 1989) ("There is reliable information that for many years, members of a patient's family, together with doctors and clergy, have made decisions to withdraw life-sustaining equipment from incompetent,

approach.[234] On those limited occasions when the consensus-based model is unable to foster agreement and an intractable or extreme dispute has arisen, particularly among family members, recourse to the courts can then play a therapeutic role by providing a forum to air disagreements, by promoting closure, or by serving as the ultimate decision maker to bring an end to the disagreement.[235]

VIII. LAY PREFERENCES FOR END-OF-LIFE DECISION-MAKING MODELS

While the courts have generally endorsed a hierarchical decision-making model for EOL decisions, the consensus-based model has been widely endorsed within the medical community.[236] However, little, if any, attention has been given to which of these decision-making models is preferred by laypersons.[237] The

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hopelessly ill patients without seeking judicial approval."); *Mack*, 618 A.2d at 762 (McAuliffe, J., dissenting) ("Decisions of this kind are often made by the immediate members of the patient's family, in conference with attending physicians...."); *id.* at 769–70 (Chasanow, J., concurring in part and dissenting in part) ("[T]hose closest to the patient, if unanimous, should be able to make the decision to terminate life support without judicial intervention. The courts are less suited than the patient's loved ones, acting with concurrence of the patient's physicians, to make these decisions."); *In re* Quinlan, 355 A.2d 647, 669 (N.J. 1976) ("Decision-making...should be controlled primarily within the patient-doctor-family relationship...."); *id.* at 671–72 (asserting that there must be concurrence of the patient's guardian, family, attending physicians, and hospital Ethics Committee); *In re* Storar, 420 N.E.2d 64, 75–76 (N.Y. 1981) (Jones, J., dissenting) ("There is reliable information that for many years physicians and members of patients' families, often in consultation with religious counselors, have in actuality been making decisions.... [N]o empirical evidence exists that either society or its individual members have suffered significantly in consequence of the absence of active judicial oversight."); *In re* Guardianship of Grant, 747 P.2d 445, 454 (Wash. 1987) ("[T]he burdens and benefits...must be evaluated by the guardian, the immediate family and the physicians...."); *id.* at 456 n.4 (finding that guardian need not be appointed if incompetent patient's immediate family members all agree); Spahn v. Eisenberg (*In re* Guardianship and Protective Placement of Edna M.F.), 563 N.W.2d 485, 494 (Wis. 1997) (Abrahamson, C.J., concurring) ("[O]rdinarily decisions...are to be made by a guardian in conjunction with doctors and the family, not by the courts.").

Courts do seem relatively comfortable with recommending the interjection into this process of the health care facility's ethics committee, typically, an inter-disciplinary group representing a range of views on EOL decisions. *See, e.g.*, *In re Quinlan*, 355 A.2d at 671; *Spahn*, 563 N.W.2d at 495 (Abrahamson, C.J., concurring).

234. *See, e.g.*, COLO. REV. STAT. ANN. § 15-18.5-103(4) (West 1997) ("It shall be the responsibility of the interested persons specified in subsection (3) of this section to make reasonable efforts to reach a consensus as to whom among them shall make medical treatment decisions on behalf of the patient."); N.M. STAT. ANN.§ 24-7A-5(E) (Michie 1997) ("If more than one member of a class assumes authority to act as surrogate and they do not agree on a health-care decision...the supervising health-care provider shall comply with the decision of a majority of the members of that class who have communicated their views to the provider."). *See also* Hoffmann, *supra* note 31, at 837 n.65.

235. *See* HAFEMEISTER & HANNAFORD, *supra* note 2, at 26, 101.

236. *See supra* Part VII.

237. To the best of the author's knowledge, a hypothetical scenario along the lines

following study explores whether lay persons are more likely to endorse a hierarchical or consensus-based EOL decision-making model.[238]

To examine this question, a hypothetical EOL scenario was constructed and administered to 160 undergraduate students at a large Midwestern university who volunteered for this study as partial credit towards completing an introductory psychology course.[239] Participants were provided a written vignette describing events leading up to the initiation of EOL discussions. The vignette reflected a relatively typical case where the patient's physician has concluded that the patient is not likely to live more than a few weeks at best, is uncertain about the patient's EOL intent, and seeks guidance on how to proceed.[240]

The patient had not executed a written advance directive but previously expressed verbally conflicting LSMT intent to the patient's best friend, to the patient's brother, and to the patient's home health care nurse.[241] A number of other family members were also described, but they had not discussed with the patient the patient's LSMT intent. Following the vignette was a series of written questions designed to explore who participants in the study believed should be involved in the EOL decision-making process.

An initial concern was that conducting this study with a group of undergraduate students might result in a sample that was relatively uninformed or naïve about EOL decisions. Although relatively young ($\underline{M}$ = 19.5 years), participants were likely to have experience with EOL decisions. Over half (56.6%)

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reported here has not been previously prepared and administered to various individuals, particularly lay individuals, to determine whether they would employ a hierarchical or consensus-based decision-making model in making EOL decisions. Social science research does support the use of a group decision-making model for complex decision making in general. *See* Mark J. Clayton, *Delphi: A Technique to Harness Expert Opinion for Critical Decision-Making Tasks in Education*, 17 EDUC. PSYCH. 373 (1997); Robert C. Erffmeyer & Irving M. Lane, *Quality and Acceptance of an Evaluative Task: The Effects of Four Group Decision-Making Formats*, 9 GROUP & ORG. STUD. 509 (1984).

238. The perceptions of lay persons regarding these contrasting decision-making models are important because lay persons, as opposed to judges, attorneys, and health care providers, are the most likely to be directly affected by these decisions and least likely to be able to shape these events when they are involved in them.

239. Hypothetical scenarios have similarly been given to undergraduate students to assess various other perceptions about EOL decisions. *See* Steven E. O'Neal & Lillian M. Range, *College Students' Hypothetical Responses to Suicidal Individuals Who Are HIV Positive, Substance Abusing, Depressed, or Anxious*, 17 DEATH STUD. 143 (1993) (using hypothetical to determine whether extenuating circumstances make a difference in how people respond to a suicidal individual); Lillian M. Range & Jerry R. Alliston, *Reacting to AIDS-Related Suicide: Does Time Since Diagnosis Matter?*, 19 DEATH STUD. 277 (1995) (using hypothetical to determine whether medical extenuating circumstances affect reactions to suicide).

240. The vignette is available upon request from the author.

241. For half of the participants, the patient was male, while for the other half the patient was female. The impact of the patient's gender on the data reported here was examined and generally found to not significantly change the results reported. Therefore, the gender of the patient is not further addressed here.

of them reported a close friend or family member with a serious, potentially life-threatening illness (cancer was the most prevalent, listed by 71.1%), 85.6% of them had experienced the death of a close friend or family member, and 23.8% had worked in a health care setting. The other demographic characteristics of this sample are believed reflective of undergraduate students at this university in general.[242]

The questionnaire was constructed so that it contained two parallel sets of questions completed by all participants: for some of the questions, participants were told to assume the patient had decision-making capacity, while for others, the patient was assumed to lack this capacity. Distinct differences were found depending on whether the patient was characterized as having or lacking decision-making capacity. As will be discussed, participants were more likely to favor a hierarchical decision-making model when the patient had decision-making capacity, and a consensus-based model when the patient lacked this capacity.

As shown in Table 1, for a patient with decision-making capacity, a majority (55%) of the participants were unwilling to let the patient's physician independently proceed with a meeting to discuss whether LSMT for the patient should be halted. Furthermore, virtually all participants felt that before the physician could proceed with this meeting, the physician should first have to contact the patient (95%) and obtain the agreement of the patient (91%), far outstripping anyone else's role in these initial matters. Thus, participants were unwilling to undercut the patient's decision-making authority even to the extent of allowing the patient's own physician, arguably a person with significant expertise and relevant experience with regard to whether EOL discussions are in order, take the relatively limited step of calling a meeting to discuss these issues. This suggests a strong belief in the appropriateness of a hierarchical decision-making model in this context with exclusive control of these decisions placed in the hands of the patient.

In contrast, as shown in Table 2, when the patient was characterized as lacking decision-making capacity, virtually all participants were willing to let the patient's physician independently proceed with this meeting (93%)[243] and few felt that the patient should initially be contacted (35%)[244] or agree to this meeting (15%).[245] Thus, a strictly hierarchical approach was much less likely to be considered appropriate (the hypothetical did not specify who, if anyone, should act

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242. The sample consisted of 41.3% males and 58.7% females. The religious affiliation of the participants was: Protestant = 42.9%; Catholic = 37.2%; Jewish = 1.3%; Other = 8.3%; and None = 10.3%.

243. Comparing the responses to this question for a patient assumed to have decision-making capacity with the responses for a patient assumed to lack this capacity, a statistically significant difference was found ($t(158) = 10.54$, $p < .001$).

244. Comparing the responses to this question for a patient assumed to have decision-making capacity with the responses for a patient assumed to lack this capacity, a statistically significant difference was found ($t(159) = 14.70$, $p < .001$).

245. Comparing the responses to this question for a patient assumed to have decision-making capacity with the responses for a patient assumed to lack this capacity, a statistically significant difference was found ($t(156) = 23.10$, $p < .001$).

at the patient's surrogate). Furthermore, various concerned individuals were more likely to be accorded a role before this meeting could be held. For example, when the patient lacked decision-making capacity, 78% of the participants believed that the patient's closest family member should have to be contacted prior to this meeting (versus 55% when the patient was assumed to have decision-making capacity),[246] and 61% felt that the patient's closest family member should first have to agree to this meeting before it could be held (versus 25% when the patient had decision-making capacity).[247] Although enhanced roles were also recommended for the patient's next-of-kin when the patient lacked decision-making capacity, for both patient categories the role of the patient's next-of-kin was less than that afforded to the patient's closest family member, suggesting that participants gave considerable weight to the emotional relationship with the patient rather than simply focusing on the individual's legal relationship with the patient.[248]

Interestingly, when it came to who should attend this meeting, as shown in Table 3, with one exception, there was little difference in the involvement of the various potentially relevant parties depending on whether the patient had or lacked decision-making capacity. In both conditions, roughly half of the participants felt that the patient's brother, sister, son, mother, best friend, home health care nurse, and a hospital ethics consultant should be present at this meeting, notwithstanding that they were likely to have different amounts or types of information to supply to this meeting regarding the patient's intent.[249] By being equally likely to include these individuals in this meeting, the participants were apparently less concerned with applying a hierarchical model that would focus on identifying the patient's expressed intent. They seemed more interested in involving a relatively wide circle of individuals in this decision making and not excluding individuals who were likely to be emotionally invested in this decision-making process, a position consonant with proponents of a consensus-based or shared decision-making model.

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246. Comparing the responses to this question, a statistically significant difference was found ($t(159) = 5.41$, $p < .001$).

247. Comparing the responses to this question, a statistically significant difference was found ($t(156) = 7.89$, $p < .001$).

248. As shown in Tables 1 and 2, when the patient lacked decision-making capacity, 66% of the participants believed that the patient's next-of-kin should have to be contacted prior to this meeting (vs. 49% when the patient had decision-making capacity ($t(159) = 4.58$, $p < .001$)), and 55% felt that the patient's next-of-kin should first have to agree to this meeting before it could be held (vs. 21% when the patient had decision-making capacity ($t(156) = 8.67$, $p < .001$)).

Other categories of relationships for whom there were substantial differences included: the patient's best friend (37% vs. 32%, respectively, with regard to requiring an initial contact ($t(159) = 1.47$, $p = .145$), and 18% vs. 6%, respectively, with regard to obtaining their prior agreement to the meeting ($t(156) = 4.02$, $p < .001$)); and a hospital ethics committee (23% vs. 13%, respectively, with regard to requiring an initial contact ($t(159) = 3.08$, $p = .002$), and 17% vs. 8%, respectively, with regard to obtaining their prior agreement to the meeting ($t(156) = 3.22$, $p = .002$)).

249. The patient's sister, son, and mother had not been described as having had any EOL conversations with the patient, while the patient's brother, best friend, and home health care nurse were described as having had such conversations.

Arguably, an exception to this inclination is shown by a greater preference for the attendance of a legal guardian at the meeting involving a patient lacking decision-making capacity, with 46% favoring this involvement, and only 36% favoring this involvement when the patient had decision-making capacity.[250] This guardian could have been viewed by participants as having EOL decision-making authority and thus reflective of a hierarchical approach. But considering the range of individuals (including the patient's home health care nurse) for whom involvement was more likely to be favored when the patient lacked decision-making capacity, this result suggests only that the participants were further widening the circle of individuals involved, with the guardian perhaps seen as ensuring that the decision-making process was fair and just.

A preference for such protections is further shown in Tables 4 and 5. Participants were virtually unanimous in asserting that a professional should evaluate both the patient's mental health status to ascertain the patient's decision-making capacity, and the patient's health status to determine whether the patient is terminally ill. Participants also were virtually unanimous in asserting that a second opinion be obtained for both judgments.

Finally, Table 6 indicates who the participants believed should be involved in deciding what the patient's treatment intent was if the patient currently lacked decision-making capacity and was terminally ill. Clearly, the preference was for the consensus-based decision-making model. Of the three most preferred decision-makers, only one of them, the patient's brother, would likely be recognized under the court-endorsed hierarchical model as the appropriate decision maker, and arguably he is recognized here because of all the family members, he was portrayed as being most familiar with the patient's wishes.[251] The patient's best friend, in contrast, who under the hierarchical model recognized by most courts would not have decision-making authority, was almost as likely to be accorded this authority by the participants in this study. In addition, two explicitly consensus-based decision-making approaches were almost as likely to be identified as the appropriate source of authority.[252] It is also worth noting that a legal guardian, an individual legally appointed to make these decisions for the patient, is less likely to be given decision-making authority than the people who are likely to know the patient best.[253] Furthermore, virtually none of the participants wanted a judge making this decision.[254]

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250. Comparing the responses to this question, a statistically significant difference was found ($t(158) = 2.29$, $p = .023$).

251. As shown in Table 6, 37% of the respondents believed that the patient's physician should be allowed to decide what the patient's EOL treatment intent was, 28% believed that the patient's brother should decide, and 23% believed that the patient's best friend should decide.

252. As shown in Table 6, 21% of the respondents believed that the family members should be allowed to decide among themselves what the patient's EOL treatment intent was, and 18% believed that the family members present who knew the patient well should be allowed to decide among themselves.

253. As shown in Table 6, 18% of the respondents believed that an individual legally appointed to make decisions for the patient (e.g., a legal guardian) should decide

To sum up briefly what this study shows: a sample of lay persons, many of whom have had some experience with the EOL decision-making process, was likely to distinguish between patients with decision-making capacity and those who lacked such capacity. For the former, considerable support was shown for a hierarchical decision-making model and its focus on patient autonomy. For the latter, however, participants in this study were more likely to favor a consensus-based decision-making model permitting participation by a wide range of individuals who are likely to have known the patient well, regardless of their formal legal status vis-à-vis the patient.

IX. CONCLUSIONS

For EOL decisions in general, courts have endorsed the use of a hierarchical decision-making model in which one person is provided sole decision-making authority. However, this exclusionary approach fails to consider the needs and well-being of the various individuals deeply affected by these decisions.

Notwithstanding these judicial rulings, a consensus-based decision-making model has evolved that respects the needs of all individuals effected by these decisions, while still promoting the intent and well-being of the patient. This approach is in accord with the integrated principles of Therapeutic Jurisprudence and Preventive Law in that it enhances the therapeutic and diminishes the anti-therapeutic aspects of these decisions while decreasing and perhaps avoiding the need for intrusive judicial involvement.

As discussed, there are a number of reasons why a consensus-based model may be preferable. Such an approach can improve the decision-making process, reduce acrimony, and preserve existing relationships among family members and other individuals interested in the well-being of the patient, enhance satisfaction levels of individuals involved in the decision-making process, promote acceptance of decision outcomes, and decrease the need for and likelihood of litigation, all while respecting the intent and well-being of the patient.

For these reasons, the courts instead should endorse the use of a consensus-based decision-making model for EOL decisions. Although the courts may still be required to resolve controversies associated with EOL decisions in a very limited number of instances, the use of the consensus-based decision-making model will better promote the interests of all individuals associated with these decisions.

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what the patient's EOL treatment intent was. The patient's home health care nurse was almost as likely to be accorded this status, with 15% of the participants stating that the home health care nurse should decide.

254. As shown in Table 6, 3% of the respondents believed that a judge should decide what the patient's EOL treatment intent was.

Table 1

Assume that B is competent (i.e., is capable of making his/her own end-of-life decisions). Should B's physician be able to call for this meeting?

45% Yes
55% No

Assume that B's physician is going to call for this meeting (where B is competent), should this physician first have to contact any of the following?

95% B (the patient)
55% B's closest family member
49% B's next-of-kin
49% Another physician who has not been treating B
47% A hospital expert who specializes in these decisions (e.g., an ethics consultant)
32% B's best friend
23% An expert from outside the hospital who specializes in these decisions (e.g., an outside ethics consultant)
18% Another physician who has not been involved in treating B
16% B's ex-husband/wife
13% A committee of individuals from the hospital not involved in the care & treatment of B (e.g., an Ethics Committee)
11% Everyone who is concerned about B
8% Most of those people who are concerned about B
4% Other
1% B's physician should be able to call for such a meeting at any time without contacting anyone first

Assume that B's physician is going to call for this meeting (where B is competent), should this physician first have to obtain the agreement of any of the following before holding the meeting?

91% B (the patient)
25% B's closest family member
22% Another physician who has not been treating B
21% B's next-of-kin
13% A hospital expert who specializes in these decisions (e.g. ethics consultant
8% A committee of individuals from the hospital not involved in the care and treatment of B (e.g., an Ethics Committee)
6% B's best friend
6% An expert from outside the hospital who specializes in these decisions (e.g., an outside ethics consultant)
4% B's ex-husband/wife
3% Another physician who has not been involved in treating B
3% Everyone who is concerned about B
3% B's physician should be able to call for such a meeting at any time without contacting anyone first
1% Most of those people who are concerned about B
1% Other

Table 2

Assume that B is incompetent (i.e., is incapable of making his/her own end-of-life decisions). Should B's physician be able to call for this meeting?

93% Yes
8% No

Assume that B's physician is going to call for this meeting (where B is incompetent), should this physician first have to contact any of the following before holding this meeting?

78% B's closest family member.
66% B's next-of-kin
55% Another physician who has not been treating B
51% A hospital expert who specializes in these decisions (e.g. ethics consultant)
37% B's best friend
35% B (the patient)
23% A committee from the hospital composed of individuals who are not involved in the care and treatment of B (e.g., an Ethics Committee)
23% An expert from outside the hospital who specializes in these types of decisions (e.g., an outside ethics consultant)
19% B's ex-husband/wife
18% Another physician who has not been involved in treating B
14% Everyone who is concerned about B
11% Most of those people who are concerned about B
5% Other
1% B's physician should be able to call for such a meeting at any time without contacting anyone first

Assume that B's physician is going to call for this meeting (where B is incompetent), should this physician first have to obtain the agreement of any of the following before holding the meeting?

61% B's closest family member
55% B's next-of-kin
30% Another physician who has not been treating B
24% A hospital expert who specializes in these decisions (e.g. ethics consultant)
18% B's best friend
17% A committee from the hospital composed of individuals who are not involved in the care and treatment of B (e.g., an Ethics Committee)
15% B (the patient)
12% An expert from outside the hospital who specializes in these types of decisions (e.g., an outside ethics consultant)
9% B's ex-husband/wife
6% B's physician should be able to call for such a meeting at any time without contacting anyone first
5% Another physician who has not been involved in treating B
5% Everyone who is concerned about B
5% Most of those people who are concerned about B
3% Other

Table 3

Assume that B is competent. Who should attend this meeting to decide whether life-sustaining medical treatment for B should be halted?

87% B (the patient)
54% B's brother
50% B's best friend
49% B's son
48% A hospital expert specializing in these decisions (e.g., an ethics consultant)
48% B's sister
46% B's home health care nurse
44% B's mother
36% An individual who has been legally appointed to make decisions on behalf of B (e.g., a legal guardian)
29% Any interested family member
26% A physician other than B's physician (i.e., a neutral physician)
21% An expert from outside the hospital who specializes in these decisions (e.g., an outside ethics consultant)
21% A mental health professional who has examined B
15% B's ex-husband/wife
14% A committee from the hospital composed of individuals who are not involved in the care and treatment of B (e.g., an Ethics Committee)
13% B's niece and nephew
8% Anyone who claims to have a right to present at this discussion
7% A judge
4% Anyone who claims to have an interest in this discussion

Assume that B is incompetent. Who should attend this meeting to decide whether life-sustaining medical treatment for B should be halted?

56% B's brother
52% B's son
50% B's mother
49% B's sister
48% A hospital expert who specializes in these decisions (e.g., an ethics consultant)
47% B's best friend
47% B's home health care nurse
46% An individual who has been legally appointed to make decisions on behalf of B (e.g., a legal guardian)
31% B (the patient)
25% A mental health professional who has examined B
23% Any interested family member
22% A physician other than B's physician (i.e., a neutral physician)
20% An expert from outside the hospital who specializes in these decisions (e.g., an outside ethics consultant)
17% A committee from the hospital composed of individuals who are not involved in the care and treatment of B (e.g., an Ethics Committee)
16% B's ex-husband/wife
13% B's niece and nephew
12% Anyone who claims to have an interest in this discussion
9% A judge
3% Anyone who claims to have a right to present at this discussion

Table 4

Before any decision is made about holding a meeting to decide the course of B's care, should a professional evaluate B's mental health status to determine if B knows and understands what is going on?

96% Yes
4% No

Should a second opinion be obtained?

93% Yes
7% No

Table 5

Before any decision is made about holding a meeting to decide the course of B's care, should a professional evaluate B's health status to determine if B is terminally ill?

95% Yes
5% No

Should a second opinion be obtained?

94% Yes
6% No

Table 6

Assume the meeting called for by B's physician is held and B is currently incompetent and terminally ill. Who, if anyone, should be allowed to decide what B's treatment wishes were?

37%	B's physician
28%	B's brother
23%	B's best friend
21%	The family members present should be allowed to decide among themselves
18%	The family members present who know B well should be allowed to decide among themselves
18%	An individual legally appointed to make decisions for B (e.g., a legal guardian)
15%	B's home health care nurse
11%	A consensus of those individuals present at the meeting (i.e., if everyone agrees, they can speak for B)
8%	A hospital expert who specializes in these decisions (e.g., an ethics consultant)
6%	A majority of those individuals present at the meeting
5%	B's ex-husband/wife
3%	A physician other than B's personal physician (i.e., a neutral physician)
3%	A judge
3%	B's treatment team at the hospital
3%	No one should be able to speak for B (the patient)
2%	An expert from outside the hospital who specializes in these decisions (e.g., an outside ethics consultant)
2%	A committee from the hospital composed of individuals who are not involved in the care and treatment of B (e.g., an Ethics Committee)
1%	A mental health professional