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ELDERS AND END-OF-LIFE MEDICAL DECISIONS: LEGAL CONTEXT, PSYCHOLOGICAL ISSUES, AND RECOMMENDATIONS TO ATTORNEYS SERVING SENIORS

Ed de St. Aubin,* Sheila Baer,** and Joan Ravanelli Miller***

'[A] good death'... is one that occurs after a person has put his or her affairs in order, reached some spiritual understanding of life and an acceptance of death, and said goodbye to loved ones. Once that is complete, a good death involves a swift and peaceful end.1

INTRODUCTION

Estate planning and elder law attorneys are faced with the challenge of counseling their clients in areas that deal with
transitions from life to illness to death. The legal actions surrounding these transitions typically occur during one or both of two time periods. The first time period is at the planning stage, when an individual is healthy, competent, and makes personal wishes known. At this time, the attorney can preserve the person's wishes in a form recognized by family members and medical care providers and in a form that is enforceable in that particular jurisdiction. The second time period is when the person is in a compromised state, in that he cannot make his wishes known but medical treatment decisions have to be made. The law is concerned, in both situations, with maintaining the dignity of the individual. Legal principles underpinning the first planning stage, the more ideal of the two and the focus of this paper, center on the individual's right to self-govern.

Psychological principles are also implicated in end-of-life medical decisions. Indeed, research highlights the importance of this area of psychology is paramount to the client's emotional well-being. This area of science has revealed the benefits of facilitating autonomy and legacy building for elder development. Attorneys who are mindful of these psychological dynamics will better serve their senior clients.

Elder attorneys are uniquely positioned to sustain or improve the psychological health of their clients because the end-of-life medical decisions they navigate are a foundation to the client's emotional well-being. Today, when medical advances allow for sustaining life at various levels of functioning and quality, it is imperative that legal professionals

advise clients to plan ahead. The attorney can educate the client about available alternatives to control this very personal aspect of medical decision making. Elder attorneys should enter these discussions equipped with some understanding of the psychology of elders, particularly the need for autonomy and the desire for legacy building. Such knowledge will greatly benefit clients who may themselves not articulate the psychological underpinnings inherent in medical decision planning. This article is not suggesting that attorneys act as psychologists; clear professional boundaries must be maintained. Yet it does contend that the psychologically mindful attorney is more effective in providing legal counsel.

This article explores the psychological dynamics related to end-of-life medical decision-making and how psychology and law can shape interactions between attorney and client regarding death, dying and medical care decisions. It begins with a brief historical review of case law and legislative pronouncements relevant to self-government and medical decisions. It then describes how autonomy and legacy building relates to the psychological well-being of the elderly and the perceived quality of their lives. This section introduces the concept of generativity, well known to those who study adult and elder development but little discussed within the legal community. Generativity is a developmental term that refers to the phase in the life course wherein one desires to create a legacy of self that will benefit younger and future generations. The final section of the article provides some recommendations for facilitating autonomy and legacy building to attorneys who draft advanced planning directives for their clients.

Having set forth the topic of the article, it is equally important to specify what the article is not about. The article does not address the issue of the terminally ill patient hastening death by undertaking affirmative acts. Nor is this article about whether others, be they family members, individuals in the

medical community, or surrogate decision makers, may withdraw life-support measures or medical treatment where an advanced directive recognized by the state is not in place.

**LEGAL CONTEXT: CASE LAW AND LEGISLATION**

**RELEVANT TO SELF-GOVERNMENT IN MEDICAL DECISION-MAKING**

Our society upholds the fundamental right of individual autonomy. Autonomy is defined in Black's Law Dictionary as the right of self-government.4 This right includes freedom from nonconsensual interference with the person, and also a moral principle that forcing people to act against their will is wrong.5 This principle is seen through the concept of informed consent, and it is deeply engrained in American tort law.6 Justice Benjamin Cardozo applied the concept of informed consent to the medical arena in *Schloendorff v. Society of New York Hospital*.7 "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."8 This sentiment was the foundation for the modern concept of informed consent, which was subsequently defined in *Salgo v. Leland Standford, Jr. University Board of Trustees*,9 and *Canterbury v. Spence*.10 In general, informed consent provides that, in order for a patient to consent to treatment, the person must knowingly, with a complete understanding of the benefits and risks, given the relevant facts and circumstances of their situation and the available alternatives, provide their voluntary

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7. 105 N.W. 92 (N.Y. 1914).
8. Id. at 93.
assent.11 Without a valid consent, administration of medical treatment may constitute a battery.12

Implicit in the doctrine of informed consent is the inherent right of the patient to not consent and, thereby, to refuse treatment even under circumstances where doing so means certain, eventual, death.13 In addition, courts have further come to acknowledge the right of the patient to refuse treatment in circumstances where the patient is unconscious, incompetent or is otherwise unable to participate in medical decision-making.14 The United States Supreme Court, in Cruzan v. Director, Missouri Department of Health, articulated the basic principles concerning refusal of medical treatment. Specifically, the majority decision written by Chief Justice William Rehnquist confirmed the common-law principle of patient self-determination, the common-law right to refuse treatment implicit in the doctrine of informed consent, and the constitutional right under the 14th amendment to be free from unwanted medical treatment.15 The majority opinion emphasized the need for advance directives. Also, in 1990, the American Medical Association formally took the position that a physician, with informed consent of the patient, can withhold or withdraw treatment from a patient who is close to death and may discontinue life support from someone in a permanent coma.16

Individuals exercise basic rights of self-determination and informed consent when medical care is sought, which include making end-of-life decisions. These rights remain valid and

11. PROSSER & KEETON, supra note 6, at 190.
12. Id. Note, however, that while it is still technically possible to bring a cause of action for battery in this context, it is now generally recognized that such a cause of action lies against the physician on a negligence claim of action, seen as a breach of professional conduct more than as battery. Indeed, Canterbury v. Spence, was brought as a negligence claim. However, the possibility of battery as a cause of action shows how serious we hold the personal right of voluntary consent.
15. Cruzan, 497 U.S. at 278.
present when individuals become physically or mentally unable to participate in medical decision-making as recognized by the highest court in the United States. End-of-life medical decision-making has also become more protected and accessible in recent years due to federal legislation, uniform acts, and state legislation.\(^{17}\)

The Patient Self-Determination Act of 1990 (PSDA)\(^ {18}\) and Uniform Health-Care Decisions Act of 1993\(^ {19}\) reflect current standards on a patients' right to manage his own treatment. A patient must be informed of her right to receive or refuse treatment when she receives services from a hospital that receives federal funds under the Patient Self-Determination Act.\(^ {20}\) Under this act, skilled nursing facilities, home health care agencies and hospice programs must provide written notification to patients of their rights under the respective state law.\(^ {21}\) In addition, these facilities must disclose their plan to comply with the patient's desires.\(^ {22}\) A review of the legislative history of the PSDA reveals its initial purpose was to empower people to control their lives and encourage additional use of advance directives.\(^ {23}\) Similar to the PSDA, the Uniform Health-Care Decisions Act codified self-determination in health-care decisions.\(^ {24}\) This act articulated the patient's right to decide all portions of his care including the right to refuse medical

\(^{17}\) The focus of this article is not to address all of the numerous ways that end-of-life medical decision-making has become more protected and accessible, but for a good contemporary discussion on protection of advanced directives in end-of-life medical decision-making, see generally Carol J. Wessels, Treated with Respect: Enforcing Patient Autonomy by Defending Advance Directives, 6 ELDER'S ADVISOR 217 (2005).


\(^{20}\) 42 U.S.C.A. §1396a(a)(57).


treatment even if death is the result. The PSDA and the Uniform Health-Care Decisions Act appear to have been an impetus for states to develop legislation and articulate procedures that permit people to exercise self-determination. Every state now recognizes some type of advance directive.

State law occupies a critical position in a person's legal rights regarding advance directives. State law is particularly important not only because the PSDA references state law directives, but also because of the recent attention state law directives have received in Gonzalez v. Oregon. In that case, the United States Supreme Court upheld Oregon's Death with Dignity Act against challenges under federal controlled substance laws. As is typical with federal statutes and uniform laws, state laws provide provisions for advance directives of some type, with limitations that vary from jurisdiction to jurisdiction. In general, however, state statutes uphold the individual's self-determination interests.

In summary, federal legislation, state legislation and case law have paved the way for a patient to exert self-determination through direction of her own end-of-life health care decisions. Although the legislation encourages patients to exercise this right and provides the mechanisms by which this right may be implemented and upheld, it is still incumbent upon the patient, with the advice of his attorney, to memorialize his end-of-life decisions for health care. Legal emphasis on self-determination is congruent with the psychological need for autonomy.

25. Id.
29. The limitations can be through the variation of the type of document that must be created, or the possibility of overriding the patient's wishes in certain states such as that provided in Wisconsin. For further treatment on limitations, see generally Wessels, supra note 18, at 225.
30. See, e.g., ORE. REV. STAT. ANN. § 127.805 (West 2003); WIS. STAT. ANN. § 154.03 (West 2003).
experienced by elders. The autonomy of the individual is both a legal principle and a psychological foundation.

**Psychological Issues: The Importance of Autonomy and Generativity in Medical Decision-Making**

A host of psychological topics are implicated in end-of-life medical decision making. Psychological science and practice are rife with insights pertinent to these dynamics. For example, clinical psychologists are trained to ascertain the cognitive competence of individuals making such serious decisions. Further, the burgeoning field of psychothanatology, the study of the psychology of death, has produced numerous studies relevant to end-of-life decision making. Also relevant are those psychologists who examine how phenomena such as spirituality, physical condition, and family dynamics are manifested in one's ultimate decisions about the transition from life to death.

There are two fundamental psychological issues relevant to attorneys who advise elder clients in end-of-life medical matters: (1) autonomy, and (2) generativity. Psychological science reveals the benefits that elder clients receive when they are afforded autonomy and facilitated in attempts to bestow a legacy of self to future generations. Each of these psychological concepts is discussed here.

**Autonomy**

Human functioning thrives under conditions that allow for self-determination. This correlation is true at all points in life; but it may be especially relevant in the lives of older adults, given the general age-related declines in physical, cognitive, and social functioning. There are two primary models of psychological self-determination that present autonomy as core to self-determination and have generated much research. One

model was developed by Ed Deci and Richard Ryan, and the other model was developed by Michael Wehmeyer. Both models have been implemented by many practitioners and have deepened the understanding of this basic human need. The most widely cited research in this area is lead by the collaborative efforts of Deci and Ryan.\textsuperscript{32} Through extensive research investigating their self-determination theory of human motivation, three basic psychological needs essential for well-being have been identified: (1) competence, (2) relatedness, and (3) autonomy.\textsuperscript{33} "Autonomy refers to the experience of volition, ownership, and initiative in one's own behavior, and it is facilitated when people are not coercively or seductively controlled and when choices are afforded when possible."\textsuperscript{34} This ability to exercise personal control over one's destiny is considered ideal across the lifespan and across cultures.\textsuperscript{35}

Michael Wehmeyer's psychological model defines self-determination as "acting as the primary causal agent on one's life and making choices and decisions regarding one's quality of life free from external influence or interference."\textsuperscript{36} As mentioned previously, psychology and the law both highlight the importance of self-determination. Further, psychology and the law purport a similar definition of the concept of self-determination.\textsuperscript{37} In Wehmeyer's framework:

[a]n act or event is self-determined if the individual's actions(s) reflect four essential characteristics: (1) the individual acts autonomously; (2) the behaviors are

\textsuperscript{33} Id. at 154-169.
\textsuperscript{35} Id. at 73.
\textsuperscript{37} A particularly salient example is articulated through the West Virginia's recognition of this right in W. VA. Code Ann. § 16-30-2 (LexisNexis 2001); see also Note, Last Resorts and Fundamental Rights: The Substantive Due Process Implications of Prohibition on Medical Marijuana, 118 Harvard L. Rev. 1985, 1989 (2005).
self-regulated; (3) the person initiates and responds to event(s) in a psychologically empowered manner; and (4) the person acts in [a] self-realizing manner. Behavior is autonomous if the person acts (a) according to his or her own preferences, interests and/or abilities, and (b) independently, free from undue external influence or interference. Behavior is self-regulated when individuals make decisions about what skills to use in a situation, examine the task at hand and their available repertoire, and formulate, enact and evaluate a plan of action, with revisions when necessary.

Individuals act in a Psychologically empowered manner when they do so based on the beliefs that (a) they have the capacity to perform behaviors needed to influence outcomes in their environment and (b) if they perform such behaviors, anticipated outcomes will result. Finally, self-realized people use a comprehensive, and reasonably accurate, knowledge of themselves and their strengths and limitations to act in such a manner as to capitalize on this knowledge in a beneficial way.38

Autonomy is presented as a basic psychological need essential to well-being.39 The link between autonomy and psychological well-being has been recognized by the research of Carol Ryff and her colleagues.40 Ryff's research indicates that a highly autonomous individual is self-determining and independent.41 Such an individual is able to resist social pressures to think and act in certain ways and is able to regulate

38. Wehmeyer, supra note 36, at 282 (citations omitted).
40. See generally Carol D. Ryff, Happiness is Everything, or is It? Explorations on the Meaning of Psychological Well-Being, 57 J. OF PERSONALITY AND SOCIAL PSYCHOLOGY 1069 (1989) [hereinafter Happiness is Everything]; Carol D. Ryff, Possible Selves in Adulthood and Old Age: A Tale of Shifting Horizons, 6 PSYCHOLOGY AND AGING 286 (1991); Ryff & Keyes, supra note 39; Pamela S. Schmutte & Carol D. Ryff, Personality and Well-Being Methods and Meanings, 73 J. OF PERSONALITY AND SOCIAL PSYCHOLOGY 549 (1997).
41. Ryff & Keyes, supra note 39.
behavior from within, evaluating the self by personal standards.\textsuperscript{42} Conversely, an individual low in autonomy is one who is concerned with the expectations and evaluations of others, relies on judgments of others to make important decisions, and conforms to social pressures to think and act in certain ways.\textsuperscript{43} Ryff's research demonstrates that the perception of personal autonomy is an essential psychological need associated with well-being and physical and psychological health.\textsuperscript{44} A lack of autonomy often results in increased depression and anxiety, poor health, and increased mortality.\textsuperscript{45} Clinical research has consistently demonstrated that a perceived lack of control over important events, and the resultant feelings of helplessness, is a potent stressor resulting in reduced motivation and emotional distress such as anxiety and depression. This stress can have negative effects on health, self-esteem, and life satisfaction.\textsuperscript{46}

When examined developmentally, researchers found that a perception of autonomy tends to increase with age across adulthood, with some realistic decline in old age; however, the importance of autonomy for well-being does not decrease with age.\textsuperscript{47} The inevitable decline in functional status in old age often results in a reduced quality of life; thus, the exercise of personal control or autonomy with respect to one's medical treatment becomes increasingly important.\textsuperscript{48} This is especially true given the increasing ability to prolong life after its natural conclusion. Additionally, lower self-determination is a risk factor for

\begin{itemize}
\item \textsuperscript{42} Ryff, \textit{Happiness is Everything}, \emph{supra} note 40, at 1072.
\item \textsuperscript{43} \emph{Id.}
\item \textsuperscript{44} \emph{Id.} at 1078.
\item \textsuperscript{45} Schmutte & Ryff, \emph{supra} note 40, at 557.
\item \textsuperscript{46} Robert J. Gatchel & Mark S. Oordt, \textit{CLINICAL HEALTH PSYCHOLOGY AND PRIMARY CARE: PRACTICAL ADVICE AND CLINICAL GUIDANCE FOR SUCCESSFUL COLLABORATION} (2003); William Rakowski & Cynthia D. Cryan, \textit{Associations Among Health Perceptions and Health Status Within Three Age Groups}, 2 J. OF AGING AND HEALTH 58 (1990).
\item \textsuperscript{47} Ryff & Keyes, \emph{supra} note 39, at 720.
\item \textsuperscript{48} Micheline Dubé et al., \textit{Relation Entre L'autonomie et Certain Facteurs Psychologiques} (actualization de soi, support social, resignation acquise, niveau d'espoir) \textit{Chez les Âges et lesTrès Âgés}. Research Report Presented at the C.Q.R.S., Trois-Rivieres: Universite du Quebec, Laboratoire de Geontoloogie 7, 8 (1992).
\end{itemize}
suicidal ideation. Some researchers suggest that suicide may provide a sense of control in cases of severe illness and unbearable pain; suicide then becomes the last form of personal control over one’s life. In fact, terminally ill patients often report feeling less distressed merely by knowing they have the option of refusing treatment in order to end their lives when they feel the time has come.

Autonomy has been found to be significantly lower among institutionalized elderly, resulting in helplessness, hopelessness, and a lack of self-esteem. Several studies have also found significant positive relationships among autonomy, physical health, and well-being in nursing home populations. A classic study by Langer and Rodin compared nursing home residents in two groups: those encouraged to make choices about their daily activities, and those allowed no choices. The study found that individuals in the group provided with opportunities for choice were happier, their general health was better, and they had half the mortality rate (fifteen percent mortality) of the group given no choices (thirty percent mortality) in an eighteen-month follow-up study.

The behavior of the nursing home staff towards each group of residents was significant to the outcome of the study. Those interacting with the “autonomy” group encouraged self-

49. Id. at 9; Andrée Fortin et al., Suicidal Ideation and Self-Determination in Institutionalized Elderly, 22 CRISIS: THE J. OF CRISIS INTERVENTION AND SUICIDE PREVENTION 15 (2001).


52. Dubé et al., supra note 48, at 9-10.


54. Id. at 193; Judith Rodin & Ellen J. Langer, Long-Term Effects of a Control- Relevant Intervention with the Institutionalized Aged, 35 J. OF PERSONALITY AND SOCIAL PSYCHOLOGY 897-898 (1977) [hereinafter Long-Term Effects].

55. Rodin & Langer, Long-Term Effects, supra note 54, at 899-901.
determination in their clients. This autonomy support is a key concept in Deci and Ryan's self-determination theory. Autonomy-supportive behavior involves fully considering the individual's "perspective, affording choice, offering information, encouraging self-initiation, providing a rationale for recommended actions, and accepting" the individual's decisions.

Research based on Deci and Ryan's self-determination theory of motivation has found a consistent association between perceived autonomy/autonomy support and physical health. These associations have been made with efforts to improve medication adherence in chronic illness, weight loss maintenance, glucose control in diabetics, smoking cessation and maintenance, and attendance and involvement in addiction treatment programs. Further, in commenting on this group of studies, Williams and his colleagues suggest that when patients perceive autonomy-supportive behavior by others, their behavior is more autonomously motivated leading to improved health outcomes.

A study by Kasser and Ryan examined the relationships

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56. Langer & Rodin, supra note 53, at 197.
64. Williams, Autonomous Regulation, supra note 59, at 274.
among personal autonomy, autonomy support from others, and a variety of health outcomes among fifty nursing home residents. The study found that autonomous self-regulation was positively associated with vitality and negatively associated with mortality at a thirteen month follow-up. The conclusion was made after controlling for perceived health and length of stay in the nursing home. The study also found that the perception of autonomy support from others was associated with lower depression, and increased well-being, vitality, and life satisfaction. Similarly, Williams and his colleagues found that nursing home residents treated by relationship-centered, autonomy-supporting physicians showed higher satisfaction, better adherence to medication, better maintained behavior change, better physical and psychological health, and were less likely to initiate malpractice litigation. Similarly, bio-ethicists who write in this area contend that autonomy is the key ethical component in quality long term care. This concept of autonomy includes the right of competent residents to refuse treatment and to participate in their own care planning.

Autonomy support research has been presented primarily in education, parenting, and medical literature. Research on autonomy support in educational settings indicates that students treated in autonomy-supportive ways by their teachers become significantly more autonomous in their pursuit of knowledge, show greater conceptual understanding, and are generally better adjusted. Conversely, students with more controlling teachers

66. Id. at 944-947.
67. Id. at 948.
68. Williams, Relationship-Centered, supra note 58, at 84.
70. Id.; Dierdre Hyland, An Exploration of the Relationship Between Patient Autonomy and Patient Advocacy: Implications for Nursing Practice, 9 NURSING ETHICS 472, 476 (2002); H. Wayne Nelson et al., Rights-Based Advocacy in Long-Term Care: Geriatric Nursing and Long Term-Care Ombudsmen, 28 CLINICAL GERONTOLOGIST 1, 4-5 (2005).
71. See, e.g., Williams, Relationship-Centered, supra note 58.
72. Id. at 83.
tend to exhibit declining motivation and initiative, eventually losing interest in their coursework.\textsuperscript{73} Research on autonomy support in medical settings indicates similar results.\textsuperscript{74} Patients treated in an autonomy-supportive manner by their healthcare providers become more autonomously motivated to engage in healthy behaviors and to participate fully in suggested medical treatments and procedures. In contrast, those treated in more controlling ways often resist complying with medical directives.\textsuperscript{75}

The Health-Care Climate Questionnaire, available on the Self Determination Theory website, is a fifteen item measure of perceived autonomy support that has been used in numerous research studies.\textsuperscript{76} Items include the following: I feel that my physician has provided me choices and options, and my physician tries to understand how I see things before suggesting a new way to do things.\textsuperscript{77} These and other items demonstrate that autonomy-supportive behavior emphasizes the partnership aspects of professional interactions, incorporating a focus on understanding, responsiveness, and a willingness to share power. The items in this scale are easily generalized to a wide variety of professionals and authority figures, including attorneys.

In addition to the above, attorneys who wish to exhibit autonomy-supportive behaviors should be careful not to make assumptions concerning a client's beliefs. This care can be accomplished through an awareness of personal biases, and careful, respectful listening. Awareness of one's personal beliefs and biases is essential in preventing projection of those beliefs onto clients and perhaps being perceived as coercive. For example, an autonomy-supportive physician, in helping a patient decide whether or not to quit smoking, would elicit the

\textsuperscript{73} Id.  
\textsuperscript{74} Id. at 81.  
\textsuperscript{75} Id. at 84.  
\textsuperscript{76} Geoffrey C. Williams, et al., Health-Care, Self Determination Theory Packet, http://www.psych.rochester.edu/SDT/measures/health_scl.html.  
\textsuperscript{77} Id.
patient's opinions and feelings about smoking and quitting smoking, encourage the patient to decide whether or not to smoke, share his or her expertise and information in a way that may help in the patient's decision-making, and respect the patient's right to choose to continue to smoke. While the physician has a deep and abiding belief that smoking should be avoided at all costs, there is respect for the patient's right to make that choice. The primary concern is ensuring that the patient has all the information required in order to make an informed and freely chosen decision.

The importance of careful and respectful listening is highlighted in the research of Beckman and Frankel. Their study revealed that over three-quarters of the physicians in the study interrupted patients' opening statements about their reasons for the visit; the average time until interruption was only eighteen seconds. The study suggests that physicians are concerned with patients withholding information, and this concern may be associated with controlling or non-autonomy-supporting behaviors exhibited by the physicians. Beckman and Frankel conducted a follow-up study, and they found a direct association between physician interruptions early in the interview and patients withholding important information. Interestingly, Frankel, with colleagues in later studies, also found that physician-patient interviews were more efficient at yielding useful information when physicians were more autonomy-supportive.

Autonomy support may also be an important factor in ensuring client satisfaction with services. Healthcare surveys linked patient satisfaction with perceived willingness of the physician to listen to concerns and engage in open discussion about choices. Research also indicates that doctors who are

79. Id. at 694-695.
less autonomy-supportive with their patients are sued for malpractice more often than autonomy-supportive physicians.82

Ultimately, the distinction between autonomy and dependence-independence must be kept in mind. In supporting autonomy, one is neither fostering independence nor discouraging dependence. The primary deterrent to autonomy is coercion, not dependence. Clients come to lawyers for their expert guidance. Accepting that, while remaining mindful of the need for authentic and autonomous decisions, will enable attorneys to more adequately fulfill the client’s needs for counsel in establishing end-of-life care plans.

A primary issue underlying the increased interest in autonomy in medical treatment decision-making is the effect of medical treatment on quality of life. Many medical professionals now acknowledge that their goal of extending life cannot be pursued ethically without also considering the effects of that treatment on the quality of life before death.83 After all, the issue of autonomy in medical decision-making is often driven by fears of a poor quality of life.84 While many think of this issue as focused generally on pain relief or palliative care, multiple psychological and physical aspects of functioning contribute to determining whether one has a good or poor quality of life. These physical and psychological aspects include physical symptoms and pain, functional status, role activities such as the ability to work or study, social functioning, emotional status, cognitive and intellectual functioning, vitality, and satisfaction with life.

Few studies examine the general preferences of older adults regarding what constitutes quality end-of-life care. Concerns about control, quality of life, loss of independence, and

84. E.g., Mark D. Sullivan, The Desire for Death Arises From an Intolerable Future Rather than an Intolerable Present, 27 GENERAL HOSPITAL PSYCHIATRY 256 (2005) [hereinafter Desire for Death].
individual autonomy, rather than adequate pain control or family or financial burden, appear to be primary motivators for patients requesting physician-assisted death. These studies rely on physician and family perceptions of patients' reasons for requesting physician-assisted death, rather than surveying patients directly. In a study to examine patients' self-reported views of what constitutes quality end-of-life care, Singer and his colleagues found that patients identified five domains of quality end-of-life care: "receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden; and strengthening relationships with loved ones." In common to all of these studies is the issue of autonomy; it appears that end-of-life treatment decisions themselves are partially motivated by the degree of personal autonomy and control one perceives one's self to have.

Results of several studies have indicated numerous benefits associated with the facilitation of autonomy and autonomy-supportive relationships, including psychological well-being, satisfaction with life, overall quality of life, authentic emotional communication, quality of personal relationships, reduced depression and anxiety, sense of personal vitality, improved health outcomes, and reduced mortality. While these results are supportive of the overall positive effects of autonomy on health and well-being, further research is necessary to examine the interaction between individual characteristics such as the need for autonomy and effects of autonomy and autonomy support. O'Connor and Vallerand's study found a relationship between self-determination and psychological health only for those


86. Peter A. Singer et al., Quality End-Of-Life Care: Patients' Perspective, 281 JAMA 163, 166-167 (1999).
nursing home residents with high levels of need for autonomy.\textsuperscript{87} This study suggests that person-environment fit is an important consideration in understanding the importance and effects of autonomy-facilitating applications.

Critics often claim that autonomy is a western ideal akin to individualism and independence that has little applicability in collectivist cultures. However, Deci and Ryan, as well as Chirkov and his colleagues, distinguish autonomy from the concepts of dependence/independence, and individualism/collectivism.\textsuperscript{88} Dependence is defined as reliance on others for guidance, support, or needed supplies. Conversely, independence is defined as the circumstance of not relying on others for guidance, support, or needed supplies.\textsuperscript{89} An individual may be autonomous-dependent or autonomous-independent. Autonomous-dependent individuals accept and even welcome expert advice or guidance, while autonomous-independent individuals tend to resist any and all external influence. Similarly, autonomous individualists place a higher priority on individual goals, while autonomous collectivists value group goals more highly.\textsuperscript{90} Koestner and his colleagues have made a similar distinction between reactive and reflective autonomy, with reactive autonomy being the tendency to resist all external influence, and reflective autonomy being the willingness to seek and follow expert advice.\textsuperscript{91}

\textsuperscript{87} Brian P. O'Conner & Robert J. Vallerand, \textit{Motivation, Self-Determination, and Person-Environment Fit as Predictors of Psychological Adjustment Among Nursing Home Residents}, 9 PSYCHOLOGY AND AGING 189, 193 (1994).


\textsuperscript{90} \textit{Id.}

Chirkov and his colleagues examined the distinction of autonomy from dependence/independence and individualism/collectivism among Turkish, Russian, American, and Korean populations. The study found that autonomy was distinct from dependence/independence and individualism/collectivism in all four populations. The study also found a significant relationship between well-being and autonomy in both individualist and collectivist cultures.\textsuperscript{92}

In summary, autonomy is considered a core human need for individuals at all points in the life course and from all cultures. Within the elder population, contact with autonomy-supportive contexts and professionals has been determined to lead directly to physical and psychological well-being. Research on autonomy support suggests that when attorneys are perceived as autonomy-supportive in the context of elders' medical treatment decision-making, elders will be more autonomously motivated, and they will experience increased well-being and reduced depression or anxiety when dealing with these difficult areas. Adopting an autonomy-supportive demeanor, including listening to clients' viewpoints, fully answering their questions, providing them with choices, encouraging discussion of options, and supporting their participation in decision-making, may go a long way toward ensuring that they feel respected and understood. However, when interactions are perceived as controlling or intrusive, rather than autonomy-supportive, they may have negative rather than positive effects on clients' perceived autonomy. Careful observation of the client's wishes and ultimate respect for their need for autonomy are essential aspects of assisting elderly clients in formulating their end-of-life care documents.

\textbf{GENERATIVITY}

Generativity is a psycho-developmental concept first defined by Erik Erikson in 1950 as a desire to contribute to the

\textsuperscript{92} Chirkov, supra note 88, at 105-108.
well-being of younger and future generations.\textsuperscript{93} Erikson's life cycle theory suggests that adolescents grapple with issues of identity; young adults strive to find intimacy; mid-life adults invest in generativity; and then elders seek ego-integrity, which is one's acceptance of the life lived coupled with a readiness for one's inevitable death.\textsuperscript{94} Although current scholars tend not to see the life course as proceeding along such discrete and sequential stages, there is empirical evidence and a general agreement that Erikson accurately captured the major psychosocial issues characterizing healthy human development.\textsuperscript{95}

One's desire for generativity shapes one's end-of-life medical decision-making, and estate planning is one example of how generativity is played out through legal activities. By delineating precisely who will receive one's particular assets upon death, a client is able to specify the material legacy left behind. But, the relation between generativity and end-of-life decisions is often more subtle and complex than that. For instance, the generativity motives shaping legal actions may not be fully articulated by the client since much of this resides outside of the client's awareness in the subconscious. After a brief review of the most relevant research addressing generativity, the research will be linked to the psychology of an elder facing end-of-life medical decisions.

Erikson presented generativity as the psychosocial challenge of adulthood, the lengthiest of his eight life stages.\textsuperscript{96} The generative adult is one who promotes the well-being of younger and future generations.\textsuperscript{97} Although parenting is certainly one possible and typical path, generativity may be manifested in numerous behaviors, including mentoring, artistic endeavors, environmental efforts, political activism, and

\textsuperscript{93} ERIK H. ERIKSON, CHILDHOOD AND SOCIETY (35th anniversary ed. 1985).
\textsuperscript{94} Id. at 269.
\textsuperscript{96} Erikson, supra note 93, at 266.
\textsuperscript{97} Id. at 267.
community involvement. The artist who isolates herself from others yet creates objects of beauty that will later be enjoyed by future generations is behaving generatively. In fact, Erikson writes of creativity as nearly synonymous with generativity. Healthy adults create, maintain, and pass along projects such as children, books, traditions, and charitable fund-raising drives. The adult unable to achieve generativity is considered stagnant, which Erikson attributed primarily to a narcissistic self-love that precludes one from working to benefit others.

John Kotre wrote the first book-length treatise dedicated entirely to the concept of generativity. A major theme of his book is that generativity affords adults the opportunity for symbolic immortality; it is a way to outlive the self. Unlike other species, humans are painfully aware that death is inevitable. Indeed, existentialists present this idea as the central paradox of human living: having the intelligence to master much of nature yet being hopelessly vulnerable to and aware of the ultimate natural occurrence of death. Through generativity, one does not die. One's physical existence ceases, but left behind are products created and the results of efforts to positively influence the future.

Kotre also articulates how agentic and communal proclivities intermingle in the generative enterprise. Agency is the personality attribute describing a tendency for self promotion and self expression. Agentic individuals seek to

98. Id.
99. Id.; see also, Dan P. McAdams et al., Generativity Among Young, Midlife, and Older Adults, 8 PSYCHOLOGY AND AGING 222 (1993).
100. Erikson, supra note 93, at 267.
101. Id. at 267-268.
103. Id. at 10. See also GENERATIVITY AND ADULT DEVELOPMENT: HOW AND WHY WE CARE OF THE NEXT GENERATION xix (Dan P. McAdams & Ed de St. Aubin eds., 1998).
105. Id. at 69.
106. KOTRE, supra note 102, at 1 & 18.
107. Id. at 16-18.
108. Id. at 16.
master, dominate, and control the self, others, and the environment.\textsuperscript{109} Communion is the tendency to merge or unite with others in order to benefit others by surrendering the self to a larger whole.\textsuperscript{110} The first step in generativity, which is likened to creating a gift, is highly agentic in that the individual infuses self into the process.\textsuperscript{111} Human beings attempt to instill their values into their children; to create a company according to their vision; or to influence the political process according to their ideas about the good society.\textsuperscript{112} Subsequently, this created gift must be given in the communal act that will benefit others. In this second step, elders must let go and allow generative products some independence as they merge with the wider society.\textsuperscript{113} The young adult child takes those instilled values and moves independently through the world.\textsuperscript{114} The generative product will be interpreted by others in ways the creator cannot control; its impact may be one that was not intended. In this way the generative adult, Kotre and others tell us, is both selfish and selfless.\textsuperscript{115}

This integration of agency and communion is also found in the model of generativity first presented by McAdams and de St. Aubin in 1992 that has helped to stimulate so much empirical investigation of the vicissitudes and meaning of generativity.\textsuperscript{116} Much of this recent scholarship has been collected together in two edited volumes, the first addresses the generative adult,\textsuperscript{117}

\begin{enumerate}
\item \textsuperscript{109} \textit{Id.} at 17.
\item \textsuperscript{110} \textit{Id.} at 16.
\item \textsuperscript{111} Dan P. McAdams et al., \textit{The Anatomy of Generativity, in GENERATIVITY AND ADULT DEVELOPMENT: HOW AND WHY WE CARE FOR THE NEXT GENERATION} 8-14 (Dan P. McAdams & Ed de St. Aubin eds., 1998).
\item \textsuperscript{112} KOTRE, \textit{supra} note 102, at 16-17.
\item \textsuperscript{113} \textit{Id.}
\item \textsuperscript{114} Mark Snyder & E. Gil Clary, \textit{Volunteerism and the Generative Society, in THE GENERATIVE SOCIETY: CARING FOR FUTURE GENERATIONS} 230-231 (Ed de St. Aubin et al. eds., 2003).
\item \textsuperscript{115} KOTRE, \textit{supra} note 102, at 257.
\item \textsuperscript{117} See generally \textit{GENERATIVITY AND ADULT DEVELOPMENT: HOW AND WHY WE CARE FOR THE NEXT GENERATION} (Dan P. McAdams & Ed de St. Aubin eds. 1998).
\end{enumerate}
and the second examines generativity at the societal level. A key to this increase in scientific examination regarding generativity was the development of methods to measure individual differences in several aspects of generativity. While there are currently several measures of generativity that demonstrate sound psychometric properties, the Loyola Generativity Scale (LGS) and the Generative Behaviors Checklist (GBC) have received the most attention. The LGS quantifies the extent to which an adult has generative concern, a general preoccupation with the wellness of younger generations. The GBC assesses the amount of actual behaviors one exhibits towards generative outcomes.

Research employing these and other measures has yielded a bounty of information regarding generativity. Indeed, empirical evidence shows that the most generative adults score high on agentic-communal integration, relative to less generative adults. Also, there is now some support for Erikson's theoretical contention that generative activity is greater in mid-life than it is during young adulthood or old age, though some studies have found no relation to age.

Sufficient research now exists to construct a prototypical

120. Id.
121. Id. at 1006 & 1112.
profile of the highly generative adult. Relative to those scoring lower on indices of generativity, the generative man or woman has more extensive social networks,125 is more politically active,126 maintains a higher quality of parenting,127 and is committed to and involved with community volunteerism.128 Finally, it appears that Erikson was right to present generativity as the mark of a healthy adult. Several studies have positively linked levels of generativity to dimensions of psychological and physical health.129

As one moves into old age and beyond the generative phase, the developmental challenge becomes ego-integrity.130 The psychosocial virtue inherent to this life phase is wisdom, which is defined as an approval of the life one lived and an acceptance of the death that is to soon come.131 These last two life stages are yoked together in that one's generative efforts during mid-life pave the way for the acceptance of life and death.132 Elders engage in a specific form of life review133 or reminiscence,134 which involves an accounting of the life lived

126. Bill E. Peterson et al., Generativity and Authoritarianism: Implications for Personality, Political Involvement, and Parenting, 72 J. OF PERSONALITY AND SOCIAL PSYCHOLOGY 1202, 1208 (1997).
127. Id. at 1209; Michael W. Pratt et al., Adult Generativity and the Socialization of Adolescents: Relations to Mothers and Fathers' Parenting Beliefs, Styles, and Practices, 69 J. OF PERSONALITY 89, 99 (2001).
128. ROSSI, supra note 123, at 299.
130. Erikson, supra note 93, at 268-269.
131. Id. at 274.
132. Id. at 271.
including its shape, its movement, and ultimately, its worth.\textsuperscript{135} There is a self judgmental nature to this process as the elder asks difficult autobiographical questions regarding the honesty and fidelity of one’s relationships and commitments. Not that any recalled moral infraction invalidates one’s life, but the elder is searching for the sentiment of integrity, the feeling and belief that, on balance, he has lived a good life made meaningful contributions to the human enterprise. This sense of ego-integrity, and the wisdom that accompanies it, may exist unconsciously such that the individual is unable to articulate it.

Erikson says that there are feelings of despair for those whose life review results in a negative evaluation.\textsuperscript{136} One does not have the time or energy to go back and right wrongs. Although a man who perceives himself to have been a poor father may try to counter this poor image through an inheritance, he is unable to re-write history by returning to an earlier time and attend those jazz recitals of his child or to respond more lovingly in a recalled family situation.\textsuperscript{137}

This desire to bequeath material assets to loved ones, which is a generative inclination, is implicated in end-of-life medical decision-making. For example, one may craft medical directives based on the understanding that prolonging one’s own life artificially through medical techniques may drain resources to the point that this generative wish can not be feasibly carried out. But generativity influences these matters more subtly as well. For many, one component of the legacy of self that is to remain after biological existence is the memory others have of us. Some may make medical decisions based on the need to control and protect this image.

Elders are not centrally focused on behaving generatively. This focus occurred earlier in life. But elders are attempting to achieve ego-integrity, and the sense that their life has been meaningful is founded, in part, on one’s belief that their

\textsuperscript{135} Id. at 56.
\textsuperscript{136} Erikson, supra note 93, at 268-269.
\textsuperscript{137} Id. at 269.
generative legacy will positively impact younger and future generations. Healthy elders believe that they have fully participated in the cycles of life. The particular legacy one hopes to leave behind is unique to each individual. Each adult varies with regard to the content and target of their generativity. End-of-life medical decisions are partly based on the adult's need for this symbolic immortality. Attorneys should be aware of the power of generativity and the need elders have to find meaning in the transition from life to death.

RECOMMENDATIONS TO ELDER LAW ATTORNEYS WHO ADVISE CLIENTS IN END-OF-LIFE MEDICAL DECISION MAKING

Elder law attorneys meet with individuals about planning for the end of their lives. A great deal of time is spent guiding clients through the legal process in a way that maximizes the client's best interests. This counsel involves the delicate issue of disposition of property among their loved ones, which is an explicit act of generativity tacitly invoked in medical end-of-life decisions. Another difficult and equally delicate issue to discuss with clients is their actual end-of-life medical decisions. The time of the decision to invoke or withdraw life sustaining or prolonging treatment is necessarily fraught with pain and anxiety for those who love the patient. The patient can exert her autonomy and maintain some control over her legacy of self, while relieving loved ones of some pain and anxiety, by making her wishes to invoke or withdraw life sustaining treatment known. Elder law attorneys should be mindful of how relevant the psychological issues of autonomy and generativity are at these times.

This article does not suggest that lawyers engage in the practice of psychology. Rather it encourages lawyers to be cognizant of the psychological implications that come into play when a client is counseled about end-of-life decisions. Lawyers are encouraged to develop a heightened sensitivity to the psychological dimensions in the attorney-client relationship to better counsel the client's end of life decision making.
The elder law lawyer who broaches the subject of end-of-life decisions may be met with resistance and dismissed by the client who is not willing, ready, or able to deal with this matter. The lawyer may observe the client becoming anxious, withdrawn, angry, hostile, or sad by even the mention of the subject. The client may say or think, "It can't happen to me; I'm too healthy." Or, the client may say, "I can't think about this right now and not for many years to come." Lawyers must acknowledge and respect that some clients are not ready to face this issue. Some clients may need time to consider the issue perhaps in the privacy of their home, at a time they select, in a frame of mind that permits a more receptive acceptance of the end of their life on earth. The attorney may need to ask the client whether he needs time to think about what medical decisions he would like at the end of his life. The client may need to be invited back at a later date to discuss the issue further.

What cannot be stated with sufficient emphasis is that, as with other areas, the lawyer can counsel their client, but the lawyer should accept the client's decision for what it is: a decision made by a competent individual even though that decision may be at odds with what the lawyer believes is in the client's best interest. If the client indicates no intention to execute advanced directives, the lawyer must respect that decision. Further, if the lawyer observes that the client is in psychological distress or is experiencing profound death anxiety, a referral to a mental health professional should be offered. The American Psychological Association, state psychological associations, and local mental health associations are some sources the lawyer may want to consult for a list of mental health providers in their community. Lawyers should do what they do best, which is represent the interests of their client to the best of their ability. Lawyers are not therapists, but they are encouraged to be psychologically minded in their relationship with their client, especially at this delicate time period.
So how should the elder law attorney proceed in these conversations?

Remember law school and recall one of the basic lessons: assume nothing. First, answer the question of who is the client. Is this a case of individual representation, joint representation or intermediary representation, to list just a few of the many options that exist? Just as it is not possible to enumerate the various forms of clients that may present in an office, so too it is beyond the scope of this article to identify the virtually infinite ethical considerations, obligations, or decisions that may arise and have to be addressed for adequate representation. Regardless of who is defined as the client, be mindful of the loyalty owed to that client. Also, be mindful of the attorney-client privilege when drafting the various types of advance directives and dealing with non-clients.

Second, educate the client about the advanced care directives and instruments available in which the client can articulate her preferences concerning medical-end-of-life-decisions. Depending upon the state of residence, the client can put in place advance medical directives, living wills, durable power of attorneys for health care, health care proxies, or surrogates for medical decision making. Let the client know that, as a competent individual, he can preemptively dictate his wishes concerning medical treatment should he become incompetent by taking certain actions and drafting specific documents while competent. As a lawyer would in advising clients in other legal areas, provide the client with the various available alternatives, discussing in detail the positives and negatives of each and which particular legal steps may best suit his needs. Discuss the value of documenting how the client would like to be dealt with at times of vulnerability and distress.

138. See Elisabeth Belmont et al., supra note 2, for a good general treatment and checklist for issues to discuss with your elderly clients. Additionally, see Sy Moskowitz, Still Part of the Clan: Representing Elders in the Family Law Practice, 38 FAM. L. Q. 213 (2004), for a good recent source on handling multiparty representations within a family and the numerous concerns raised therein.
For example, make the client aware that there may be a considerable cost savings, both emotional and financial, to her and her loved ones if litigation can be avoided and the need for guardianship proceedings curtailed. The client’s attention may be directed to emotional savings to family members and financial preservation if undesired medical treatment, as articulated in an advanced directive, is not undertaken. So too, make the client aware of the potential negative consequences of not documenting his end-of-life medical desires such as undergoing treatment or being sustained on artificial life support systems against his wishes.

Third, start a conversation with the client about his goals and interests in end-of-life medical treatment. Keep in mind the need for autonomy and the desire to achieve ego-integrity through generativity.

**Ask the Client About His Life**

Let the client speak about his life, current, past, and future. Encourage the client to talk about accomplishments, which, at some level, facilitates the client’s own meaning-making, affording her the opportunity to accept both life and death. Listen to what the clients say. Ask follow up questions: What was it about that event or situation that was important to you? How do you want to be remembered? What do you most value about your life? To help the client speak in concrete terms, ask him to explore what their life would look like if he knew he had several weeks or a month to live. What would she do? Who would he be with? What would she say? Also, listen as much for what is not said as for what is said. Be sensitive, non-judgmental, empathic and creative in discussing the client’s perception of these issues.

**Ask Fundamental Threshold Questions**

For example, what are the client’s views about self-determination in health care decision-making? Is the question
that they cannot make the decision or that they chose not to at this time? What role does the client’s spirituality or religion play in her views? Let the client know that you understand that these are difficult topics for him. An attorney may offer to schedule another time to meet after the client has had an opportunity to give it some thought. Be willing to terminate the discussion and schedule another appointment.

**ASK THE HARD QUESTIONS**

An attorney should facilitate a discussion that allows the client to maintain autonomy as she makes end-of-life decisions for medical care. The client should be asked to imagine situations that may seem unimaginable, and given this imagined situation, what she would want to be done in terms of medical treatment. An attorney could present the following scenarios to determine if the client would desire medical treatment, and if so, what kind: (1) what if the client were in pain most of the time and that pain could not be adequately relieved; (2) what if the client could no longer care for their daily needs suffering from hardships such as incontinence and loss of bowel control; (3) what if the client could not recognize her loved ones; (4) what if the client was confined to a wheelchair or confined in his home; (5) what if the client could not think or was dependent on a machine to live, such as a feeding tube, dialysis machine or breathing machine? An attorney should introduce scenarios that prompt the client to consider specific directives.

When an attorney speaks with a client about selecting a healthcare proxy or agent, the attorney should begin the discussion by asking who should know the client’s views or who must know the client’s views. The attorney should advise the client that the proxy or agent should be someone who would be willing to speak and act on her behalf and on her wishes. A good suggestion to the client is to elect someone she trusts who lives near by, is likely to be available into the future, and can be a strong advocate should family or medical provider conflict arise. The attorney should also take care that the client’s proxy
or agent can sit down with the client and the attorney to go over the advance care directive to ensure that his will be implemented. Moreover, the client should be made aware that in order for the proxy or agent to know how to act in the future with as much specificity as the client would want, the client needs to have a candid conversation with the named proxy or agent.

Finally, the attorney should draft the appropriate advance care directive and carefully review it with the client to ensure that the directive documents actually express what the client intended. If the client has designated a proxy or agent, the client should be advised to review the document with that proxy or agent to reiterate and clarify the understanding of her end-of-life medical treatment desires. Engaging in this discussion enables the client to exercise control over their future medical decisions.

CONCLUSION

End-of-life decision making has captured public interest given recent advances in medical treatments and prominent coverage of social and political issues related to death and dying. The elder law attorney is in a unique position to assist the older adult who desires to ensure that his wishes concerning end-of-life care are observed. In order to provide quality legal services to the aging population, it is essential that attorneys have an awareness and basic understanding of psychological issues relevant to the older adult making end-of-life plans. Although numerous issues that could have been included here, this article focused on two of the most important and basic psychological needs of older adults: (1) autonomy and (2) generativity. Incorporating these issues into elder law practice will certainly yield benefits. When done correctly, this type of planning process enables clients to exercise control over their future financial and medical decisions. Explicitly, this type of planning promotes and supports autonomy and allows for generativity. Implicitly, it promotes psychological well-being and meaning in life.

Attorneys are positioned to assure their client obtains peace
of mind knowing that his wishes will most likely be honored and enforced as he intended. Elder law attorneys have the unique opportunity to act as a counselor when the client is already contemplating their will, making plans for their future and their legacy, as well as maintaining control over their assets. The attorney can and should respectfully educate the client about the alternatives available to control a very personal asset, their medical decision-making.