

# UC Irvine

## UC Irvine Previously Published Works

### Title

Deciding with Others: Interdependent Decision-Making

### Permalink

<https://escholarship.org/uc/item/3ph3n6s4>

### Journal

The Hastings Center Report, 52(6)

### ISSN

0093-0334

### Authors

Largent, Emily A

Clapp, Justin

Blumenthal-Barby, Jennifer S

et al.

### Publication Date

2022-11-01

### DOI

10.1002/hast.1444

Peer reviewed



# HHS Public Access

Author manuscript

*Hastings Cent Rep.* Author manuscript; available in PMC 2023 November 01.

Published in final edited form as:

*Hastings Cent Rep.* 2022 November ; 52(6): 23–32. doi:10.1002/hast.1444.

## Deciding with Others: Interdependent Decision Making

**Emily A. Largent, JD, PhD, RN,**

Department of Medical Ethics and Health Policy, University of Pennsylvania Perelman School of Medicine

**Justin Clapp, PhD, MPH,**

Department of Anesthesiology and Critical Care, University of Pennsylvania Perelman School of Medicine

**Jennifer S. Blumenthal-Barby, PhD, MA,**

Center for Medical Ethics and Health Policy, Baylor College of Medicine

**Christine Grady, RN, PhD,**

Department of Bioethics, National Institutes of Health Clinical Center

**Amy L. McGuire, JD, PhD,**

Center for Medical Ethics and Health Policy, Baylor College of Medicine

**Jason Karlawish, MD,**

Department of Medicine, Department of Medical Ethics and Health Policy, Department of Neurology, University of Pennsylvania Perelman School of Medicine

**Joshua D. Grill, PhD,**

Department of Psychiatry and Human Behavior, Department of Neurobiology and Behavior, University of California, Irvine

Institute for Memory Impairments and Neurological Disorders, Institute for Clinical and Translational Science

**Shana D. Stites, PsyD, MS, MA,**

Department of Psychiatry, University of Pennsylvania Perelman School of Medicine

**Andrew Peterson, PhD**

Department of Philosophy, Institute for Philosophy and Public Policy, George Mason University

### Abstract

This article argues for greater recognition that, over the course of the human lifespan, health care decision making is interdependent. Interdependence refers to the engagement of non-clinicians—for example, family members or trusted friends—with patients to reach health care decisions. Interdependence, we suggest, is common for patients in all stages of life, from early childhood to late adulthood. This view contrasts with the common bioethical assumption that medical decisions are either wholly independent or dependent, and that independence or dependence tracks a person's decision-making capacity. By arranging standard approaches to decision making

---

**Corresponding Author:** Emily A. Largent, JD, PhD, RN, Blockley Hall, Room 1403, 423 Guardian Drive, Philadelphia, PA 19104, 215.573.8106, elargent@penncmedicine.upenn.edu.

along a continuum of interdependence we demonstrate independence and dependence are not siloed from one another. Instead, they are situated along a continuum. An appreciation of this continuum should empower patients and elucidate ethical challenges that arise when people transition between different kinds of interdependence across the lifespan.

---

## Introduction

For most individuals, childhood is marked by the progressive development of decisional abilities and a growing realization of independence.<sup>1</sup> Decisions—and, here, our focus is decisions about health and health care—are generally made by a parent or guardian who, ideally, prepares the growing child to assume an ever-greater role directing their own health care. This may be accomplished by means such as ensuring that the child is present for discussions with clinicians, increasing awareness of their health, calibrating expectations about prognosis and possibility, and creating opportunities for the child to provide input, when such input is appropriate.<sup>2</sup> Knowing that individuals will face many health-related decisions over the lifespan, the parent or guardian fosters the child's emerging ability to self-determine.

Decisional abilities are legally recognized as sufficient when individuals reach the age of majority, though they generally have not yet reached developmental maturity at this point.<sup>3</sup> For most, the apotheosis of our decision-making abilities comes somewhat later in adulthood, when we enjoy the benefits of accumulated life experience but still rest unaffected by age-related cognitive changes.<sup>4</sup> Although we can make decisions on our own in this period, many of us turn to trusted others—often, but not exclusively, family or friends—when weighing options and making choices. In adulthood, some of us may experience injuries or illnesses that hamper our decisional abilities beyond what is characteristic of aging.<sup>5</sup> Others have disabilities that affect decision making. Of necessity, we may come again to rely on or continue to rely on others to assist us, or even to make decisions on our behalf, in adulthood as in childhood.

Here, we present a framework that reflects this trajectory. *Decision-making capacity*—the ability to make a particular decision at a particular time by receiving, processing, and retaining information; rationally deliberating among available options; and expressing a decision<sup>6</sup>—varies over the life course, not just with age but also with circumstance. It is typically assumed in bioethics that individuals move between *independence*—deciding alone—and *dependence*—having a surrogate decide on their behalf—as capacity emerges developmentally or as it wanes with illness or disability. Yet these binaries and the tight couplings of capacity and independence, and of incapacity and dependence, are inconsistent with how many medical decisions are made in practice. People commonly engage others in decision-making processes, whether they have or lack decision-making capacity, though the nature and intensity of the others' engagement varies. Between total independence and total dependence lies a range of ways people decide with others, and these ways are not necessarily determined by a patient's decision-making capacity.

*Interdependent decision making* is an umbrella term we use to encompass the diverse ways in which individuals other than the patient and clinician might be included in health

care decision making. We understand interdependent to mean that two or more people—in this case, the patient and trusted others—rely on or are accountable to each other. This interdependence may be the result of: the reliance of the patient on the other party to accomplish the process of decision making; the interest of both parties in the content or outcome of decision making; or both. Notably, we are not contemplating *shared decision making* between a patient and clinician; we regard that as distinct and address it below.

People with different degrees of decision-making capacity are engaged, were engaged, or will again engage in interdependent decision making. In acknowledging the expansive role of interpersonal relationships in medical decision making, we are advocating for the construction of more inclusive approaches to health care decisions. Our embrace of relationality is not a rejection of individuality. Rather, recognizing that interdependence is a ubiquitous feature of the human condition, regardless of decision-making capacity, can allow clinicians, families, and bioethicists to empower patients who might otherwise be marginalized in medical decision making and better address patients' needs across the life course<sup>7</sup>

In what follows, we discuss two salient axes of decision making: (1) the patient's decision-making capacity and (2) the parties to decision making. Rather than reducing axes these to binaries—capacity or incapacity, patient or surrogate—we dilate them. These axes allow us to plot a decision-making function or continuum. The continuum, we argue, illuminates interrelationships between historically siloed decision-making processes and also reveals ways in which clinicians and bioethicists might better serve patients. Further, it exposes ethical tensions that arise as individuals traverse the continuum. This raises unresolved questions for bioethics; in the final section, we examine four of these questions to spark future scholarship on medical decision making.

## Two Axes of Decision Making

We distinguish two axes of decision-making. These two axes represent graded properties.

The first axis is a person's decision-making capacity. Decision-making capacity is dimensional, and individuals can possess its constitutive abilities—understanding, appreciation, reasoning, and communication—to a greater or lesser extent. When they possess all the necessary abilities at adequate levels, they are said to have capacity. When they lack all the necessary abilities, they are said to lack capacity. But some individuals fall in between: while not entirely lacking the necessary abilities, they have notable deficits in one or more. They have marginal capacity, and so it is unclear where they fit if we simply dichotomize capacity. Do they retain decision-making capacity or lack it? The answer is often uncertain. What is often certain is that even as capacity dissolves, some constitutive abilities are present to a degree that the person ought to have input in medical decisions.

The second axis is involvement of others in the decision-making process, irrespective of considerations of the patient's decision-making capacity. All people who make decisions are embedded in interpersonal relationships, and those relationships can bear on the decision-making process. Many patients have relationships with family members, friends,

or others who are differentially involved in their medical decisions.<sup>8</sup> They may be involved to different degrees, in different roles, or in different decisions—some but not others. Nonetheless, all such individuals can play an important role in the process and outcome of a patient’s decisions.

A patient can have more or less decision-making capacity, just as others can be involved in a patient’s decisions to a greater or lesser extent. Assuming there is a bright line between incapacity and capacity may lead us to wrongly deny decision-making authority to some individuals who should rightly have it, or to under protect the vulnerable. Similarly, suggesting that a patient makes decisions completely independently, or is wholly dependent on others to make decisions for them, might overshadow the normative importance of trust and collaboration in decision-making processes.

Uncoupling these two axes, and illuminating the gray areas between capacity and incapacity and independence and dependence, permits us to better describe the range of processes by which medical decision-making occurs and provides an enriched ethics of how we decide *with* others.

## A Continuum of Medical Decision Making

The two axes described in the prior section allows us to plot a continuum of medical decision making, as depicted in Figure 1. While the extremes of the continuum reflect total independence and total dependence, respectively, the broad middle reflects interdependence. In this section, we array recognized decision-making processes along this continuum; these processes are neither novel nor exhaustive—though some processes may be more or less familiar. We, however, believe that situating these processes in relation to one another can offer important insights into how people navigate medical decision making over the course of life. In the next section, we look at how others’ interests influence the content or outcome of decision making.

### Self-Directed Decision Making

*Self-directed decision making* occurs when individuals make decisions about their own medical care. Notably, we argue that self-directed decision making has various sub-types. It may be truly *independent decision making*—wherein a decision is made solely by the individual patient—or it may be *collaborative decision making*—a type of interdependent decision making wherein a decision-maker engages with others in the decision-making process.

Adults with capacity are, legally and ethically, recognized as autonomous decision makers empowered to make decisions free from the involvement or interference of others.<sup>9</sup> This conception of autonomy—of the idealized independent decision maker—emerges from a long history in social and political theory on the relation between individual liberty and the authority of the state.<sup>10</sup> The Kantian notion of a “rational agent,” a person who is free to set their own life goals and plans, heavily influenced this view. Subsequent philosophical interpretations of autonomy have since articulated independent decision makers as having a set of rational capacities, such as:

[b]eing able to value, being able to reason, being able to resist impulses, being able to imagine an ordered life, being able to order one's life, being able to put one's plans into practice, being able to participate in moral deliberation of an idealized kind, and being politically free.<sup>11</sup>

Among different interpretations of autonomy in contemporary bioethics are the evidentiary view and the responsibility view.<sup>12</sup> The *evidentiary view* of autonomy asserts that decision makers should be free to make decisions for themselves because they are in the best position to know which decisions will advance their own goals and values.<sup>13</sup> The *responsibility view*, by contrast, asserts that autonomy imposes responsibility on decision makers to shape their own life with a distinctive character and integrity. Though by different means, these two views of autonomy lead to the common notion of independence. Whether by special epistemic access to knowledge of what's best, or through a sense of responsibility, the autonomous person is empowered to make decisions independently; failure to respect these decisions is regarded as a moral wrong.

However, independent decision making—and particularly the notions of autonomy underlying it—has been subject to philosophical critique.<sup>14</sup> While the idealized independent decision maker has proven influential in shaping political, legal, and bioethical theory, it might not reflect how many—if not most—decisions are made over the course of the human lifespan. Adults who have full decision-making capacity often engage in collaborative decision making about their health and health care. Though decision-making authority legally and ethically rests with the individual patient and is still meaningfully self-directed, others are implicitly or even explicitly involved in decision-making processes. For example, couples often arrive at critical decisions regarding one partner's medical care as a dyad.<sup>15</sup> Family members' or friends' involvement in the decision-making process can range from more passive to more active (i.e., lesser to greater reliance by the patient), and the contours of their involvement may be informed by the stage of clinical care, demographics, or cultural norms.<sup>16</sup> Evidence suggests that others can serve in various roles, such as gathering or reviewing information, being active listeners, persuading, or even directing decision making.<sup>17</sup> Within collaborative decision making, there are doubtlessly further subdivisions characterized by different kinds and degrees of others' involvement.

Standard conceptions of autonomy assert that a person is free when she acts according to principles chosen independently.<sup>18</sup> Deciding with others—interdependent decision making—could therefore be understood to undermine a person's decision-making authority. But like decision-making capacity, decision-making independence also comes in degrees, and the grant of some authority to trusted others does not imply a loss of independence.<sup>19</sup> When a pregnant person seeks a sister's advice while developing a birth plan because the sister has previously given birth, that person is carefully evaluating and reflecting on treatment options, not relinquishing autonomy to others.<sup>20</sup> These decision-making relationships are described as a kind of “shared” or “wide” agency, according to which agency, intention, and planning can be distributed across more than one person.<sup>21</sup> Wide agency contrasts with the narrow agency idealized in independent decision making, where individuals make decisions for and by themselves.

## Supported Decision Making

In *supported decision making*, an individual with marginal capacity enters freely into an agreement with one or more persons who assist the individual in reaching decisions.<sup>22</sup> This other person is called a *supporter*, while the individual with marginal capacity is the *beneficiary* of support. Proponents of supported decision making note that beneficiary-supporter relationships often arise out of informal, trust-based connections between people. These connections are the kind of relationships central to the collaborative decision making just described. Yet, there is a difference between collaborative decision making, on the one hand, and supported decision making, on the other. Collaborative decision making involves two or more people, including a decision-maker with unimpaired decision-making capacity. In contrast, supported decision making is described by an agreement—formal or informal—between a beneficiary with diminished capacity and a supporter.

The type and degree of support depends on the beneficiary's needs and desires. A supporter for a person with mild cognitive impairment—an acquired cognitive impairment that causes inefficiencies in the performance of instrumental daily activities such as managing finances or medications—might accompany the beneficiary to medical appointments to take notes, while a supporter for a person with intellectual or developmental disabilities might collaborate with the beneficiary in tallying pros and cons of different treatment options. Though receiving assistance, beneficiaries retain the authority to make their own decisions and to have them recognized by third-parties.

Presently, nearly half of U.S. states recognize or are contemplating supported decision-making agreements for adults.<sup>23</sup> Supported decision making has to date primarily been used by transition-aged adults with intellectual and developmental disabilities; these individuals are aging out of their parents' care but continue to need decision-making assistance and wish to avoid the considerable challenges associated with guardianship, which reflects binary assumptions of capacity/incapacity and independence/dependence and strips individuals of the ability to make decisions about their own life.<sup>24</sup> Supported decision making is a less restrictive alternative to guardianship.<sup>25</sup> More recently, lawyers and ethicists have advocated for the use of supported decision making with cognitively impaired older adults—for example, those with neurodegenerative diseases.<sup>26</sup> Supported decision making may be helpful for other patient populations as well, such as those recovering from traumatic brain injury.<sup>27</sup>

The principle of respect for persons requires that we treat people with capacity as empowered decision makers; but it also requires that we protect vulnerable individuals with impaired decision-making capacity. Individuals with emerging, marginal, fluctuating, or recovering capacity present a particular challenge for realizing the principle of respect for persons. An appropriate balance must continuously be achieved between a beneficiary's liberty and welfare interests. Recently, theorists have framed supported decision making in the language of “non-domination.”<sup>28</sup> This framing draws attention to the power dynamics implicit to decision making, and how interdependence should be understood as a collaborative process, not as paternalism or as supporters “filling in the gaps” of cognitive impairment. Significantly, supported decision making emphasizes what people



with marginally impaired capacity can do with the provision of support, rather than focusing on what they cannot do.

### Permission + Partial Involvement in Decision Making

*Partial involvement* is appropriate when an individual lacks decision-making capacity but nevertheless has enough decisional abilities that participation in decisions is possible—for example, by expressing relevant preferences or values. Partial involvement strategies typically require a surrogate decision maker—for instance, a parent or guardian—who gives permission for medical care. For that reason, permission + partial involvement could be subsumed under surrogate decision making, which we turn to next. However, because not all surrogate decision making will or can permit partial involvement, we have chosen to distinguish the two approaches to further highlight the variety of interdependent decision-making processes.

Assent and dissent are two well-known partial involvement strategies. Opportunities for *assent*—an expression of approval—demonstrate respect by engaging an individual in an interactive decision-making process and allowing them to express treatment preferences when it is reasonable to do so.<sup>29</sup> In limited instances, it may be proper to proceed only if there is a lack of *dissent*. Notably, dissent does not require a reason or justification, and the patient generally does not have to demonstrate any understanding for dissent to be respected. Although partial involvement strategies do not meet the criteria for informed consent, they nevertheless realize some of its key functions, such as providing transparency and allowing control.<sup>30</sup>

### Surrogate Decision Making

When individuals lack capacity to make their own medical decisions, the need arises for a surrogate or proxy to decide on their behalf. *Surrogate decision making*—the legally recognized practice of allowing clinicians to consult a designated individual or individuals who can provide informed consent for health care interventions—may be justified, depending on the decision-making standard, by considerations of autonomy (i.e., substituted judgment) or beneficence (i.e., best interests).

We would argue that surrogate decision making—particularly when the patient was formerly competent—should be understood as an instance of temporally diffuse interdependent decision making. The surrogate makes decisions, but the voice of the patient is still heard in these decisions. This is because the *substituted judgment standard* directs the surrogate to approximate the decisions the patient would have made, if the patient was able to decide. Ideally the surrogate does this by using information about the patient’s values, preferences, and interests, expressed before the impairment of capacity—typically in an advance directive—or as evidenced in analogous circumstances.

Among patients who have written an advance directive, some want them strictly followed, while others wish to grant surrogates leeway.<sup>31</sup> The latter has parallels to the concept of “wide” or “shared” agency, described above. Granting a surrogate leeway should not be regarded as an abrogation of decision-making authority. Rather, patients may make a well-reasoned decision to do this, recognizing that their surrogates are well acquainted with their



intentions and values. Moreover, patients may recognize that it is impossible to prospectively account for every medical decision during their period of incapacitation. Understanding a patient's general compass bearing through intentions and values, while leaving flexibility to work out a precise route allows surrogates to adapt decisions in the face of unforeseen circumstances.

Some individuals have not yet developed, or will never develop, decision-making capacity. Even here, surrogates might still have insights into a person's values and preferences that should guide decisions. Parents deciding for an adult child with intellectual and developmental disabilities might be guided by their past experiences within the health care system and what those have revealed about their child's interests and inclinations. If, however, the surrogate is unable to approximate the patient's choice, a surrogate will make decisions to promote the patient's *best interests*—that is, what would be objectively good for the patient. Consider, for example, parents working together to make decisions about the care of a sick newborn. The child is, here, wholly dependent upon the parents to make decisions.

As an aside, surrogates themselves may find collaborative decision making useful—even unavoidable—in the face of uncertainty. In making consequential decisions, such as whether to withdraw life-sustaining treatment, a surrogate is likely to engage with additional family members or trusted others. In some cases, state laws governing medical decision making for incapacitated adults who have not previously named a proxy require that the patient's health care representatives, identified by law, reach consensus on a decision. Collaboration might inform the decision but also provides emotional support for the surrogate.

## Opportunities and Challenges Regarding Interdependent Decision Making

Exploration of the decision-making continuum illustrates that interdependence is not an incidental feature of the human experience; it is central to it. Individuals progressively negotiate and renegotiate their roles with trusted others throughout life. A parent decides for their child, but then fosters the child's burgeoning capacity—first through seeking assent then by supporting decision-making. An adult makes self-directed decisions, collaborating with others, though an acute illness may necessitate surrogate decision-making. Interdependence characterizes how we make medical decisions throughout our lives, and people can transition between the decision-making processes arrayed along the continuum—moving forward and backward, perhaps many times—over the life course.

Attending to the conceptual relationships amongst decision-making approaches also highlights ethical tensions: between autonomy and welfare, domination and collaboration, and self-determination and paternalism. We turn now to describing four challenges and opportunities for future ethical analysis.

### Is shared decision making a kind of interdependent decision making?

As a hallmark of patient-centered care, shared decision making emphasizes the active participation of the patient and *also* the clinician in the decision-making process.<sup>32</sup> Together, clinicians and patients evaluate the intervention, consider the patient's values, preferences,

and interests, and reach a joint decision.<sup>33</sup> Shared decision making has gained traction in the ethics literature as an alternative to other patient-physician decision-making models. These alternatives include *paternalistic decision making*—in which the clinician encourages the patient to accept or even imposes a decision the clinician thinks is best—as well as *consumerist decision making*—in which the clinician conveys technical expertise while the patient selects from a menu of options.<sup>34</sup> In paternalistic decision making, the patient plays a passive role, while in consumerist decision making, the patient is more active.

Although shared decision making with one's health care team bears similarities to interdependent decision making with one's family and friends, we find it useful to distinguish them. Whereas accounts of shared decision making specify how physicians or other clinicians should participate in medical decisions in light of their professional and fiduciary obligations, accounts of interdependent decision making characterize the participation of individuals who are *not* part of the care team and are not bound by such obligations. Family and friends doubtlessly have ethical obligations, but they are not always well characterized.

Shared decision making is nevertheless compatible with interdependent decision making. For instance, a study of cancer patients found that the patient, patient's family, and oncologist were often involved in decision making.<sup>35</sup> Moreover, clinicians may have various roles facilitating interdependent decision making. For instance, they can elicit patients' preferences for the involvement of others.<sup>36</sup> When appropriate, clinicians ought to engage in *triadic communication*, including both the patient and others identified by the patient in conversations about treatment or goals of care. Clinicians might monitor interdependent decision making to ensure coherence with ethical norms (e.g., to ensure an absence of coercion). They could use their knowledge of interdependent decision making to ensure that patients with marginal capacity are appropriately involved in making decisions about their health and health care.<sup>37</sup> Or, they might document the presence of conditions that activate surrogate decision making under a health care power of attorney. As individuals renegotiate their roles in decision making to account for changes in context and capacity, clinicians can provide guidance, even in the mere specification of the kinds of decision-making approaches that patients and families might use. For example, families may not be aware of supported decision making, which is still relatively new in the law; clinicians could advocate for supported decisions, if appropriate, in lieu of recommending guardianship. Additional research is needed to identify best practices, such as how to engage in triadic communication and address decisional conflict.

### **When, if ever, is wholly independent decision making desirable?**

Even if a person is capable of making decisions wholly independently, we would argue that, in most cases, patients ought to favor interdependent decision making. Decisions may be interdependent due to collaboration in the process, shared interest in the outcome, or both. For reasons of process and outcome, there is good reason to involve others.

First, the process of collaborative decision making may lead to better decisions. There is evidence that medical decisions can vary when encouraging the decision maker to think about the problem from alternate perspectives.<sup>38</sup> When a patient receives input from others,

it may result in an improved understanding of tradeoffs. Similarly, in the political science literature, studies suggest that diverse groups reach better decisions and more effective work processes by enlarging the pool of information available to address a problem.<sup>39</sup> As a potential indicator of decisional quality, evidence suggests that family involvement in decision making is associated with increased patient satisfaction, which is a quality-of-care indicator and is linked to important outcomes, such as treatment adherence.<sup>40</sup> Like Lincoln's "team of rivals," the biases of any one individual can be counterbalanced by those of others, thereby optimizing the deliberative process and increasing prudential value for the patient. A future direction for research is to investigate how interdependent decisions are negotiated and, under what conditions, they result in improved decisions.

Second, because humans are embedded in relationships, others are often entangled in and affected by the outcomes of medical decisions. Consider the following examples. A woman considering a knee replacement knows she will need assistance with her post-operative care. The schedule of her surgery will impact her adult daughter, whom she will depend upon during her recovery, and so she asks her daughter for input on scheduling. Similarly, a man diagnosed with prostate cancer solicits input from his husband to reach a decision about whether to undergo surgery or to pursue watchful waiting; this helps him think through treatment options in light of various relational details, including how decisions would impact his and his husband's lives together. These examples illustrate the mechanisms of "caring for" and "caring about" an individual who is ill.<sup>41</sup> "Caring for" denotes the physical labor required of caregivers, while "caring about" denotes the psychological connection family members have for one another during times of illness. When our health decisions are likely to impact others, it is reasonable to consult them and ask for advice, or if unable to seek their advice, to consider their interests. This shows that we "care about" the prospect of our loved one's "caring for" us. Indeed, if health decisions result in reasonably foreseeable harms to or burdens on others, soliciting others' opinions could even rise to an ethical duty, as failure to do so might show a disregard of our loved one's interests. This does not mean that patients must always acquiesce to the wishes of family or trusted others. Rather, it suggests that the strength of any trusting relationship is only as good as the faith and respect we show toward our loved ones when contemplating major medical decisions.

### **What are the appropriate roles for the parties to interdependent decision making?**

Patients have interests. So too do their family members and friends. For instance, patients might have an interest in preserving or regaining their health or in palliating symptoms. Family and friends often have congruent interests because they care about the patient. Yet, as just noted, family and friends may also have their own distinct needs and interests. These can interact with the patient's needs and interests in complex ways. Friends and family members may experience financial hardships (e.g., the forgone wages associated with informal caregiving) or may otherwise find the quality of their lives affected (e.g., if one's sexual partner pursues a treatment that has a side-effect of impotence).<sup>42</sup>

The patient may, from a place of care, endorse the interests of others. It will often be possible to reconcile these various needs and interests. But, in some cases, others' interests will problematically conflict with the patient's interests. A quotidian concern is that a family

member is indifferent or even neglectful. In an extreme example, it may be alleged that a family member wants to withdraw life-sustaining treatment from a critically-ill relative because he stands to benefit financially from the patient's death—not because withdrawal advances the patient's wishes or interests.<sup>43</sup> Concerns about conflicts of interest may become more prominent the more dependent the patient's decision-making is on others.

Clearly, there is value in considering how others are affected by medical decisions. Nonetheless, actively incorporating these interests into decision making raises questions. To what extent are others permitted to influence a patient's choice? It seems relevant not just *whether* and *to what extent* a patient's choice is influenced by others but *how* it is influenced. Some strategies for influencing a patient's decisions are plainly unacceptable and compromise voluntariness—these would include threats of harm or other forms of coercion and abuse. Yet, further work needs to be done to distinguish acceptable and unacceptable influence on a patient's decisions. As preliminary thoughts, such distinctions may turn on the patient's personal circumstances, cultural background, relational quality, or the import of the decision.<sup>44</sup> Moreover, it is important to think about how, if at all, to manage conflicts of interest.

### **What are the implications of interdependent decision making for bioethics?**

The idealized conception of the rational, independent decision maker suggests that our primary obligation in medical decisions is to remove obstacles to free choice. Yet, when we re-envision decision making as largely interdependent, a positive obligation emerges: to provide patients with means that enable decision-making and affirm their choices. This suggests we must identify new ways to enhance self-determination for individuals who might otherwise be marginalized in making decisions about their health care and their own lives.

To illustrate this point, consider decision making for persons living with neurodegenerative diseases like Alzheimer's disease. Overreliance on the capacity/incapacity binary obscures an important fact: capacity often erodes gradually in individuals with neurodegenerative diseases.<sup>45</sup> During this period of gradual decline, a majority of individuals with dementia wish to participate in decision making about their care,<sup>46</sup> and many are able to make their own medical decisions.<sup>47</sup> As dementia becomes more severe, care partners' decision-making role evolves: they report making the "final" decision more often.<sup>48</sup> Yet, this prolonged period of declining, or marginal, capacity and the accompanying transition of decision-making authority within the dyad, often remains unacknowledged by clinicians and bioethicists.

Exploration of interdependent decision making provides new insights into how to handle decision-making in Alzheimer's disease and other conditions that fundamentally impact autonomy. Here, we offer four examples. First, the concept of "geriatric assent"—the involvement of older adults in medical decision making—was developed by drawing on the pediatric assent literature.<sup>49</sup> Unfortunately, geriatric assent has not been widely adopted in clinical care, but bioethicists should advocate for this, as adoption of partial involvement strategies can prolong the period in which individuals are (appropriately) engaged in decisions about their health care.

Second, advance directives are ill-suited for individuals in the lacuna between capacity and incapacity because advance directives envision a period of incapacity—of total dependence on a surrogate—that is typically brief and immediately preceding death.<sup>50</sup> Yet, following a dementia diagnosis, people live eight or more years (on average); this period is typified by marginal capacity and navigating through it requires countless medical decisions. Appeals to interdependent decision making could inform development of new decision-making tools or adoption of relatively underutilized tools, like supported decision-making agreements, to supplement advance directives.

Third, explicitly acknowledging that many people—of all abilities—rely on others in making decisions could help to destigmatize reliance on others by persons living with dementia by revealing such reliance to be a difference in degree rather than in kind. This is important, as stigma, or negative attitudes, can result in denial of need by the patient and baseless contempt from others, as well as delayed access to care and exacerbated caregiver burden.<sup>51</sup>

Fourth, interdependent decision making can help us conceptualize the particular psychological labor of dementia caregivers. If, for example, we see the caregiver as an extension of the mind—or cognitive prosthesis—for persons living with dementia, there would be an attendant set of policy prescriptions. This would draw our attention, for instance, to the moral importance of regarding the presence of caregivers at the patient's bedside as an essential accommodation for an individual with disabling cognitive and functional impairments. They are not mere “visitors.”<sup>52</sup>

Bioethicists will doubtlessly face other questions when considering the implications of interdependence. For example, some individuals—sometimes referred to as “unbefriended” or “unrepresented”—lack natural supports. They have no readily identifiable family members or friends and can be particularly vulnerable in the health care system.<sup>53</sup> Care will be needed to determine how to support their decisions, rather than wresting decision-making authority away.<sup>54</sup> It will also be necessary to think about transition points between the different kinds of interdependent decision making, how to assess capacity when there are multiple parties to decision making and, and how policies and practices of informed consent might be adapted to facilitate interdependence.

## Conclusion

The strong conceptual linking of capacity to independence, and also the binaries of capacity/incapacity and independent/dependent, reflect simplifying assumptions: it is often easier to have a bright line rule than to rely on standards, which can be fuzzy and require complicated decision making. Nevertheless, they are oversimplifications. Almost anyone who has ever made an important decision, medical or otherwise, knows that incorporating the wisdom and advice of others in deliberation is typical and often advantageous for reasons of process and outcome.

Here, we have distinguished the patient's capacity from the parties to decision making as two axes that reveal interdependent approaches to decision making, in which a patient

engages with one or more persons to reach a decision. Recognizing the ubiquity of interdependence may help wrest decision-making power back for patients, but there are critical questions for bioethicists to address in future scholarship.

## Funding:

Dr. Largent is supported by the National Institute on Aging (K01-AG064123 and R01-AG077111) and a Greenwall Faculty Scholar Award. Dr. Grill is supported by the National Institute on Aging (P30 AG066519). Dr. Karlawish is supported by the National Institute on Aging (P30-AG-010124 and R01-AG077111). Dr. Stites is supported by the National Institute on Aging (K23AG065442). Dr. Peterson is supported by the National Institute on Aging (R21AG069805 and R01-AG077111) and a Greenwall Faculty Scholar Award. The funders had no role in the design and conduct of the study; collection, management, analysis, or interpretation of the data; preparation or approval of the manuscript; and decision to submit the manuscript for publication.

## References

1. Walter JK and Ross LF, "Relational Autonomy: Moving Beyond the Limits of Isolated Individualism," *Pediatrics* 133, no. Supplement 1 (2014): S16–23. [PubMed: 24488536]
2. Largent EA, "Consent to Trainee Involvement in Pediatric Care," *The New England Journal of Medicine* 383, no. 12 (2020): 1097–99. [PubMed: 32937042]
3. Mann H and Reyes M, "Identifying the Human Research Subject in Cluster Randomized Controlled Trials," *IRB: Ethics & Human Research* 30, no. 5 (2008): 14–18; S.-J. Blakemore and T. W. Robbins, "Decision-Making in the Adolescent Brain," *Nature Neuroscience* 15, no. 9 (2012): 1184–91.
4. Tymula A et al. , "Like Cognitive Function, Decision Making across the Life Span Shows Profound Age-Related Changes," *Proceedings of the National Academy of Sciences* 110, no. 42 (2013): 17143–48.
5. Hirschman KB et al. , "How Does an Alzheimer's Disease Patient's Role in Medical Decision Making Change Over Time?," *Journal of Geriatric Psychiatry and Neurology* 17, no. 2 (2004): 55–60. [PubMed: 15157344]
6. Appelbaum PS, "Assessment of Patients' Competence to Consent to Treatment," *New England Journal of Medicine* 357, no. 18 (2007): 1834–40. [PubMed: 17978292]
7. Longmore PK, "Medical Decision Making and People with Disabilities: A Clash of Cultures," *Journal of Law, Medicine & Ethics* 23, no. 1 (1995): 82–87.
8. Agich GJ, "Reassessing Autonomy in Long-Term Care," *The Hastings Center Report* 20, no. 6 (1990): 12; P. E. Osamor and C. Grady, "Autonomy and Couples' Joint Decision-Making in Healthcare," *BMC Medical Ethics* 19, no. 1 (2018): 3.
9. Appelbaum, "Assessment of Patients' Competence to Consent to Treatment."
10. Dworkin G, "The Nature of Autonomy," *Nordic Journal of Studies in Educational Policy* 2015, no. 2 (2015): 28479; B. A. Ackerman, *Social Justice in the Liberal State*, Nachdr. (New Haven, Conn.: Yale Univ. Press, 2009); S. Hampshire and R. Dworkin, *Public and Private Morality*, 1991.
11. Francis LP, "Understanding Autonomy in Light of Intellectual Disability," in *Disability and Disadvantage*, ed. Brownlee K and Cureton A (Oxford University Press, 2009), 200–215.
12. Dworkin R, "Autonomy and the Demented Self," *The Milbank Quarterly* 64, no. Suppl. 2 (1986): 4–16. [PubMed: 11649885]
13. Buchanan A and Brock DW, "Deciding for Others," *The Milbank Quarterly* 64 (1986): 17. [PubMed: 11649884]
14. Christman J, "Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves," *Philosophical Studies: An International Journal for Philosophy in the Analytic Tradition* 117, no. 1/2 (2004): 143–64; M. A. L. Oshana, "Personal Autonomy and Society," *Journal of Social Philosophy* 29, no. 1 (1998): 81–102; C. Mackenzie and N. Stoljar, eds., *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: Oxford University Press, n.d.).



15. Osamor and Grady, "Autonomy and Couples' Joint Decision-Making in Healthcare"; Brown RCH and Savulescu J, "Responsibility in Healthcare across Time and Agents," *Journal of Medical Ethics* 45, no. 10 (2019): 636–44. [PubMed: 31221764]
16. Kwak J and Haley WE, "Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups," *The Gerontologist* 45, no. 5 (2005): 634–41; J. Benbassat, D. Pilpel, and M. Tidhar, "Patients' Preferences for Participation in Clinical Decision Making: A Review of Published Surveys," *Behavioral Medicine* 24, no. 2 (1998): 81–88; L. A. McLaughlin and K. L. Braun, "Asian and Pacific Islander Cultural Values: Considerations for Health Care Decision Making," *Health & Social Work* 23, no. 2 (1998): 116–26. [PubMed: 16199398]
17. Öhlén J et al. , "The Influence of Significant Others in Complementary and Alternative Medicine Decisions by Cancer Patients," *Social Science & Medicine* 63, no. 6 (2006): 1625–36. [PubMed: 16725245]
18. Rawls J, *A Theory of Justice*, Rev ed (Cambridge, Mass: Belknap Press of Harvard University Press, 1999).
19. Francis, "Understanding Autonomy in Light of Intellectual Disability."
20. Kukla R, "Conscientious Autonomy: Displacing Decisions in Health Care," *Hastings Center Report* 35, no. 2 (2005): 34–44.
21. Francis LP and Silvers A, "Liberalism and Individually Scripted Ideas of the Good: Meeting the Challenge of Dependent Agency," *Social Theory and Practice* 33, no. 2 (2007): 311–34; M. Bratman, *Shared Agency: A Planning Theory of Acting Together* (New York, NY: Oxford University Press, 2014).
22. Peterson A, Karlawish J, and Largent E, "Supported Decision Making With People at the Margins of Autonomy," *The American Journal of Bioethics*, 2020, 1–21.
23. National Resource Center for Supported Decision-Making, "In Your State," accessed May 3, 2021, at <http://supporteddecisionmaking.org/states>.
24. Jenny Hatch M, Crane SA, and Martinis JG, "Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship," *Inclusion* 3, no. 2 (2015): 65–74.
25. Kohn NA, Blumenthal JA, and Campbell AT, "Supported Decision-Making: A Viable Alternative to Guardianship?," *Penn State Law Review* 117, no. 4 (2013): 1111–58.
26. Peterson, Karlawish, and Largent, "Supported Decision Making With People at the Margins of Autonomy"; Kohn, Blumenthal, and Campbell, "Supported Decision-Making: A Viable Alternative to Guardianship?"
27. Peterson A, Mintz K, and Owen AM, "Unlocking the Voices of Patients with Severe Brain Injury," *Neuroethics* 15, no. 1 (2022): 9.
28. McCarthy AM and Howard D, "Supported Decision-Making: Non-Domination Rather than Mental Prosthesis," *AJOB Neuroscience*, 2021, 1–11.
29. Bartholome WG, "A New Understanding of Consent in Pediatric Practice: Consent Parental Permission, and Child Assent," *Pediatric Annals* 18, no. 4 (1989): 262–65; "Informed Consent, Parental Permission, and Assent in Pediatric Practice. Committee on Bioethics, American Academy of Pediatrics," *Pediatrics* 95, no. 2 (1995): 314–17; A. L. Katz, S. A. Webb, and COMMITTEE ON BIOETHICS, "Informed Consent in Decision-Making in Pediatric Practice," *Pediatrics* 138, no. 2 (2016): e20161485. [PubMed: 2755734]
30. Dickert NW et al. , "Reframing Consent for Clinical Research: A Function-Based Approach," *The American Journal of Bioethics* 17, no. 12 (2017): 3–11.
31. Sehgal A et al. , "How Strictly Do Dialysis Patients Want Their Advance Directives Followed?," *JAMA* 267, no. 1 (1992): 59–63. [PubMed: 1489360]
32. Charles C, Gafni A, and Whelan T, "Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or It Takes at Least Two to Tango)," *Social Science & Medicine* 44, no. 5 (1997): 681–92. [PubMed: 9032835]
33. Blumenthal-Barby J et al. , "Potential Unintended Consequences Of Recent Shared Decision Making Policy Initiatives," *Health Affairs* 38, no. 11 (2019): 1876–81; S. N. Whitney et al., "Beyond Shared Decision Making: An Expanded Typology of Medical Decisions," *Medical Decision Making* 28, no. 5 (2008): 699–705. [PubMed: 31682503]



34. Emanuel EJ and Emanuel LL, "Four Models of the Physician-Patient Relationship," *JAMA: The Journal of the American Medical Association* 267, no. 16 (1992): 2221. [PubMed: 1556799]
35. Laidsaar-Powell R et al. , "Family Involvement in Cancer Treatment Decision-Making: A Qualitative Study of Patient, Family, and Clinician Attitudes and Experiences," *Patient Education and Counseling* 99, no. 7 (2016): 1146–55. [PubMed: 26873544]
36. Hobbs GS et al. , "The Role of Families in Decisions Regarding Cancer Treatments," *Cancer* 121, no. 7 (2015): 1079–87. [PubMed: 25708952]
37. Laidsaar-Powell RC et al. , "Physician–Patient–Companion Communication and Decision-Making: A Systematic Review of Triadic Medical Consultations," *Patient Education and Counseling* 91, no. 1 (2013): 3–13. [PubMed: 23332193]
38. Zikmund-Fisher BJ et al. , "A Matter of Perspective: Choosing for Others Differs from Choosing for Yourself in Making Treatment Decisions," *Journal of General Internal Medicine* 21, no. 6 (2006): 618–22. [PubMed: 16808746]
39. Landemore H, "Deliberation, Cognitive Diversity, and Democratic Inclusiveness: An Epistemic Argument for the Random Selection of Representatives," *Synthese* 190, no. 7 (2013): 1209–31.
40. Wolff JL, "Hidden in Plain Sight Medical Visit Companions as a Resource for Vulnerable Older Adults," *Archives of Internal Medicine* 168, no. 13 (2008): 1409; M. R. DiMatteo, "Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis.," *Health Psychology* 23, no. 2 (2004): 207–18. [PubMed: 18625921]
41. Lin JL et al. , "Intergenerational Decision Making: The Role of Family Relationships in Medical Decision Making," *MDM Policy & Practice* 6, no. 2 (2021): 238146832110394.
42. Hardwig J, "What about the Family?," *The Hastings Center Report* 20, no. 2 (1990): 5–10.
43. Mulgrew I, "Brain Injured Man at Centre of Legal Battle over Whether to Remove Feeding Tubes," *Vancouver Sun*, 2012.
44. Hobbs et al., "The Role of Families in Decisions Regarding Cancer Treatments."
45. Okonkwo OC et al. , "Medical Decision-Making Capacity in Mild Cognitive Impairment: A 3-Year Longitudinal Study," *Neurology* 71, no. 19 (2008): 1474–80. [PubMed: 18981368]
46. Hirschman KB et al. , "Do Alzheimer's Disease Patients Want to Participate in a Treatment Decision, and Would Their Caregivers Let Them?," *The Gerontologist* 45, no. 3 (2005): 381–88. [PubMed: 15933278]
47. Kim SYH, Karlawish JHT, and Caine ED, "Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons," *The American Journal of Geriatric Psychiatry* 10, no. 2 (2002): 151–65. [PubMed: 11925276]
48. Hirschman et al., "How Does an Alzheimer's Disease Patient's Role in Medical Decision Making Change Over Time?"
49. Molinari V et al. , "Geriatric Assent," *The Journal of Clinical Ethics* 15, no. 3 (2004): 261–68. [PubMed: 15630869]
50. Gaster B, Larson EB, and Curtis JR, "Advance Directives for Dementia: Meeting a Unique Challenge," *JAMA* 318, no. 22 (2017): 2175. [PubMed: 29114779]
51. Agich, "Reassessing Autonomy in Long-Term Care."
52. Applebaum AJ, "I Was Never Just a Visitor," *Hastings Bioethics Forum*, March 9, 2022, at <https://www.thehastingscenter.org/i-was-never-just-a-visitor/>.
53. Chamberlain SA et al. , "Characteristics and Unmet Care Needs of Unbefriended Residents in Long-Term Care: A Qualitative Interview Study," *Aging & Mental Health* 24, no. 4 (2020): 659–67. [PubMed: 30676088]
54. Schweikart, "Who Makes Decisions for Incapacitated Patients Who Have No Surrogate or Advance Directive?," *AMA Journal of Ethics* 21, no. 7 (2019): E587–593. [PubMed: 31333174]

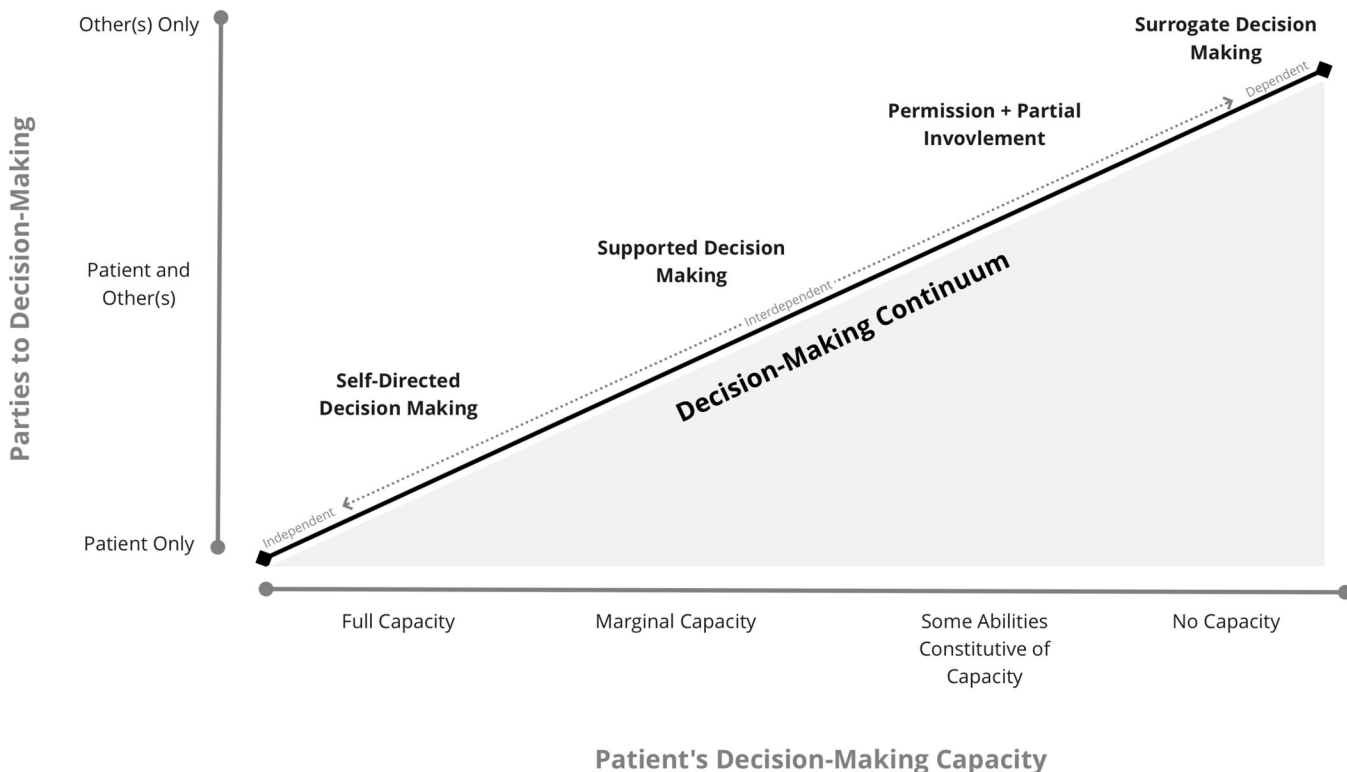
## WORKS CITED

- Ackerman BA *Social Justice in the Liberal State*. Nachdr. New Haven, Conn.: Yale Univ. Press, 2009.
- Agich GJ "Reassessing Autonomy in Long-Term Care." *The Hastings Center Report* 20, no. 6 (1990): 12. doi:10.2307/3563417.

- Appelbaum PS “Assessment of Patients’ Competence to Consent to Treatment.” *New England Journal of Medicine* 357, no. 18 (2007): 1834–40. doi:10.1056/NEJMcp074045. [PubMed: 17978292]
- Applebaum AJ “I Was Never Just a Visitor.” *Hastings Bioethics Forum*. <https://www.thehastingscenter.org/i-was-never-just-a-visitor/>.
- Bartholome WG “A New Understanding of Consent in Pediatric Practice: Consent Parental Permission, and Child Assent.” *Pediatric Annals* 18, no. 4 (1989): 262–65. doi:10.3928/0090-4481-19890401-09. [PubMed: 2755734]
- Benbassat J, Pilpel D, and Tidhar M “Patients’ Preferences for Participation in Clinical Decision Making: A Review of Published Surveys.” *Behavioral Medicine* 24, no. 2 (1998): 81–88. doi:10.1080/08964289809596384. [PubMed: 9695899]
- Blakemore S-J, and Robbins TW “Decision-Making in the Adolescent Brain.” *Nature Neuroscience* 15, no. 9 (2012): 1184–91. doi:10.1038/nn.3177. [PubMed: 22929913]
- Blumenthal-Barby J, Opel DJ, Dickert NW, Kramer DB, Tucker Edmonds B, Ladin K, Peek ME, Peppercorn J, and Tilburt J “Potential Unintended Consequences Of Recent Shared Decision Making Policy Initiatives.” *Health Affairs* 38, no. 11 (2019): 1876–81. doi:10.1377/hlthaff.2019.00243. [PubMed: 31682503]
- Bratman M *Shared Agency: A Planning Theory of Acting Together*. New York, NY: Oxford University Press, 2014.
- Brown RCH, and Savulescu J “Responsibility in Healthcare across Time and Agents.” *Journal of Medical Ethics* 45, no. 10 (2019): 636–44. doi:10.1136/medethics-2019-105382. [PubMed: 31221764]
- Buchanan A, and Brock DW “Deciding for Others.” *The Milbank Quarterly* 64 (1986): 17. doi:10.2307/3349960. [PubMed: 11649884]
- Chamberlain SA, Duggleby W, Teaster P, and Estabrooks C “Characteristics and Unmet Care Needs of Unbefriended Residents in Long-Term Care: A Qualitative Interview Study.” *Aging & Mental Health* 24, no. 4 (2020): 659–67. doi:10.1080/13607863.2019.1566812. [PubMed: 30676088]
- Charles C, Gafni A, and Whelan T “Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or It Takes at Least Two to Tango).” *Social Science & Medicine* 44, no. 5 (1997): 681–92. doi:10.1016/S0277-9536(96)00221-3. [PubMed: 9032835]
- Christman J “Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves.” *Philosophical Studies: An International Journal for Philosophy in the Analytic Tradition* 117, no. 1/2 (2004): 143–64.
- Dickert NW, Eyal N, Goldkind SF, Grady C, Joffe S, Lo B, Miller FG, et al. “Reframing Consent for Clinical Research: A Function-Based Approach.” *The American Journal of Bioethics* 17, no. 12 (2017): 3–11. doi:10.1080/15265161.2017.1388448.
- DiMatteo MR “Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis.” *Health Psychology* 23, no. 2 (2004): 207–18. doi:10.1037/0278-6133.23.2.207. [PubMed: 15008666]
- Dworkin G “The Nature of Autonomy.” *Nordic Journal of Studies in Educational Policy* 2015, no. 2 (2015): 28479. doi:10.3402/nstep.v1.28479.
- Dworkin R “Autonomy and the Demented Self.” *The Milbank Quarterly* 64, no. Suppl. 2 (1986): 4–16. [PubMed: 11649885]
- Emanuel EJ, and Emanuel LL “Four Models of the Physician-Patient Relationship.” *JAMA: The Journal of the American Medical Association* 267, no. 16 (1992): 2221. doi:10.1001/jama.1992.03480160079038. [PubMed: 1556799]
- Francis LP “Understanding Autonomy in Light of Intellectual Disability.” In *Disability and Disadvantage*, ed. Brownlee K and Cureton A, 200–215. Oxford University Press, 2009. doi:10.1093/acprof:osobl/9780199234509.003.0008.
- Francis LP, and Silvers A “Liberalism and Individually Scripted Ideas of the Good: Meeting the Challenge of Dependent Agency.” *Social Theory and Practice* 33, no. 2 (2007): 311–34.
- Gaster B, Larson EB, and Curtis JR “Advance Directives for Dementia: Meeting a Unique Challenge.” *JAMA* 318, no. 22 (2017): 2175. doi:10.1001/jama.2017.16473. [PubMed: 29114779]
- Hampshire S, and Dworkin R *Public and Private Morality*, 1991. <http://site.ebrary.com/id/10897775>.
- Hardwig J “What about the Family?” *The Hastings Center Report* 20, no. 2 (1990): 5–10.

- Hatch, Jenny M, Crane SA, and Martinis JG “Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship.” *Inclusion* 3, no. 2 (2015): 65–74. doi:10.1352/2326-6988-3.2.65.
- Hirschman KB, Joyce CM, James BD, Xie SX, and Karlawish JHT “Do Alzheimer’s Disease Patients Want to Participate in a Treatment Decision, and Would Their Caregivers Let Them?” *The Gerontologist* 45, no. 3 (2005): 381–88. doi:10.1093/geront/45.3.381. [PubMed: 15933278]
- Hirschman KB, Xie SX, Feudtner C, and Karlawish JHT “How Does an Alzheimer’s Disease Patient’s Role in Medical Decision Making Change Over Time?” *Journal of Geriatric Psychiatry and Neurology* 17, no. 2 (2004): 55–60. doi:10.1177/0891988704264540. [PubMed: 15157344]
- Hobbs GS, Landrum MB, Arora NK, Ganz PA, van Ryn M, Weeks JC, Mack JW, and Keating NL “The Role of Families in Decisions Regarding Cancer Treatments.” *Cancer* 121, no. 7 (2015): 1079–87. doi:10.1002/cncr.29064. [PubMed: 25708952]
- “Informed Consent, Parental Permission, and Assent in Pediatric Practice. Committee on Bioethics, American Academy of Pediatrics.” *Pediatrics* 95, no. 2 (1995): 314–17. [PubMed: 7838658]
- Katz AL, Webb SA, and COMMITTEE ON BIOETHICS. “Informed Consent in Decision-Making in Pediatric Practice.” *Pediatrics* 138, no. 2 (2016): e20161485. doi:10.1542/peds.2016-1485. [PubMed: 27456510]
- Kim SYH, Karlawish JHT, and Caine ED “Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons.” *The American Journal of Geriatric Psychiatry* 10, no. 2 (2002): 151–65. doi:10.1097/00019442-200203000-00006. [PubMed: 11925276]
- Kohn NA, Blumenthal JA, and Campbell AT “Supported Decision-Making: A Viable Alternative to Guardianship?” *Penn State Law Review* 117, no. 4 (2013): 1111–58.
- Kukla R “Conscientious Autonomy: Displacing Decisions in Health Care.” *Hastings Center Report* 35, no. 2 (2005): 34–44. doi:10.1353/hcr.2005.0025.
- Kwak J, and Haley WE “Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups.” *The Gerontologist* 45, no. 5 (2005): 634–41. doi:10.1093/geront/45.5.634. [PubMed: 16199398]
- Laidsaar-Powell R, Butow P, Bu S, Charles C, Gafni A, Fisher A, and Juraskova I “Family Involvement in Cancer Treatment Decision-Making: A Qualitative Study of Patient, Family, and Clinician Attitudes and Experiences.” *Patient Education and Counseling* 99, no. 7 (2016): 1146–55. doi:10.1016/j.pec.2016.01.014. [PubMed: 26873544]
- Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, Jansen J, et al. “Physician–Patient–Companion Communication and Decision-Making: A Systematic Review of Triadic Medical Consultations.” *Patient Education and Counseling* 91, no. 1 (2013): 3–13. doi:10.1016/j.pec.2012.11.007. [PubMed: 23332193]
- Landemore H “Deliberation, Cognitive Diversity, and Democratic Inclusiveness: An Epistemic Argument for the Random Selection of Representatives.” *Synthese* 190, no. 7 (2013): 1209–31. doi:10.1007/s11229-012-0062-6.
- Largent EA “Consent to Trainee Involvement in Pediatric Care.” *The New England Journal of Medicine* 383, no. 12 (2020): 1097–99. doi:10.1056/NEJMp2004237. [PubMed: 32937042]
- Lin JL, Lipstein EA, Wittenberg E, Tay D, Lundstrom R, Lundstrom GL, Sediqzadah S, and Wright DR “Intergenerational Decision Making: The Role of Family Relationships in Medical Decision Making.” *MDM Policy & Practice* 6, no. 2 (2021): 238146832110394. doi:10.1177/23814683211039468.
- Longmore PK “Medical Decision Making and People with Disabilities: A Clash of Cultures.” *Journal of Law, Medicine & Ethics* 23, no. 1 (1995): 82–87. doi:10.1111/j.1748-720X.1995.tb01335.x.
- Mackenzie C, and Stoljar N, eds. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press, n.d.
- Mann H, and Reyes M “Identifying the Human Research Subject in Cluster Randomized Controlled Trials.” *IRB: Ethics & Human Research* 30, no. 5 (2008): 14–18. [PubMed: 18953772]
- McCarthy AM, and Howard D “Supported Decision-Making: Non-Domination Rather than Mental Prosthesis.” *AJOB Neuroscience*, 2021, 1–11. doi:10.1080/21507740.2021.1973147.

- McLaughlin LA, and Braun KL “Asian and Pacific Islander Cultural Values: Considerations for Health Care Decision Making.” *Health & Social Work* 23, no. 2 (1998): 116–26. doi:10.1093/hsw/23.2.116. [PubMed: 9598394]
- Molinari V, McCollough LB, Workman R, and Coverdale J “Geriatric Assent.” *The Journal of Clinical Ethics* 15, no. 3 (2004): 261–68. [PubMed: 15630869]
- Mulgrew I “Brain Injured Man at Centre of Legal Battle over Whether to Remove Feeding Tubes.” *Vancouver Sun*, 2012. <https://vancouver.sun.com/news/metro/brain-injured-vancouver-man-at-centre-of-legal-battle-over-whether-to-remove-feeding-tubes>.
- National Resource Center for Supported Decision-Making. “In Your State.” Accessed May 3, 2021. <http://supporteddecisionmaking.org/states>.
- Öhlén J, Balneaves LG, Bottorff JL, and Brazier ASA “The Influence of Significant Others in Complementary and Alternative Medicine Decisions by Cancer Patients.” *Social Science & Medicine* 63, no. 6 (2006): 1625–36. doi:10.1016/j.socscimed.2006.03.050. [PubMed: 16725245]
- Okonkwo OC, Griffith HR, Copeland JN, Belue K, Lanza S, Zamrini EY, Harrell LE, et al. “Medical Decision-Making Capacity in Mild Cognitive Impairment: A 3-Year Longitudinal Study.” *Neurology* 71, no. 19 (2008): 1474–80. doi:10.1212/01.wnl.0000334301.32358.48. [PubMed: 18981368]
- Osamor PE, and Grady C “Autonomy and Couples’ Joint Decision-Making in Healthcare.” *BMC Medical Ethics* 19, no. 1 (2018): 3. doi:10.1186/s12910-017-0241-6. [PubMed: 29325536]
- Oshana MAL “Personal Autonomy and Society.” *Journal of Social Philosophy* 29, no. 1 (1998): 81–102. doi:10.1111/j.1467-9833.1998.tb00098.x.
- Peterson A, Karlawish J, and Largent E “Supported Decision Making With People at the Margins of Autonomy.” *The American Journal of Bioethics*, 2020, 1–21. doi:10.1080/15265161.2020.1863507.
- Peterson A, Mintz K, and Owen AM “Unlocking the Voices of Patients with Severe Brain Injury.” *Neuroethics* 15, no. 1 (2022): 9. doi:10.1007/s12152-022-09492-0.
- Rawls J *A Theory of Justice*. Rev ed. Cambridge, Mass: Belknap Press of Harvard University Press, 1999.
- Schweikart. “Who Makes Decisions for Incapacitated Patients Who Have No Surrogate or Advance Directive?” *AMA Journal of Ethics* 21, no. 7 (2019): E587–593. doi:10.1001/amajethics.2019.587. [PubMed: 31333174]
- Sehgal A, Galbraith A, Chesney M, Schoenfeld P, Charles G, and Lo B “How Strictly Do Dialysis Patients Want Their Advance Directives Followed?” *JAMA* 267, no. 1 (1992): 59–63. [PubMed: 1489360]
- Tymula A, Rosenberg Belmaker LA, Ruderman L, Glimcher PW, and Levy I “Like Cognitive Function, Decision Making across the Life Span Shows Profound Age-Related Changes.” *Proceedings of the National Academy of Sciences* 110, no. 42 (2013): 17143–48. doi:10.1073/pnas.1309909110.
- Walter JK, and Ross LF “Relational Autonomy: Moving Beyond the Limits of Isolated Individualism.” *Pediatrics* 133, no. Supplement 1 (2014): S16–23. doi:10.1542/peds.2013-3608D. [PubMed: 24488536]
- Whitney SN, Holmes-Rovner M, Brody H, Schneider C, McCullough LB, Volk RJ, and McGuire AL “Beyond Shared Decision Making: An Expanded Typology of Medical Decisions.” *Medical Decision Making* 28, no. 5 (2008): 699–705. doi:10.1177/0272989X08318465. [PubMed: 18556639]
- Wolff JL “Hidden in Plain Sight Medical Visit Companions as a Resource for Vulnerable Older Adults.” *Archives of Internal Medicine* 168, no. 13 (2008): 1409. doi:10.1001/archinte.168.13.1409. [PubMed: 18625921]
- Zikmund-Fisher BJ, Sarr B, Fagerlin A, and Ubel PA “A Matter of Perspective: Choosing for Others Differs from Choosing for Yourself in Making Treatment Decisions.” *Journal of General Internal Medicine* 21, no. 6 (2006): 618–22. doi:10.1111/j.1525-1497.2006.00410.x. [PubMed: 16808746]



**Figure 1.** The decision-making continuum spans from wholly independent self-directed decision making to wholly dependent surrogate decision making. Patients are not required to make decisions along the frontier, although doing so would let them exercise their full decision-making abilities. Patients might, for instance, delegate a decision to others; for a patient with full capacity, this would move them to the upper left corner – that is, full capacity, other(s) only. The gray area is null.