Chapter 9
Surrogate Decision-Making

Romika Dhar and Aarti Gupta

Introduction

Current demographic trends are indicative of an aging population with the number of seniors in the United States expected to double in the next four decades [1]. The remarkable advancements in modern medicine have led to increased life expectancy on the one hand but potential for increased disease burden on the other. It is vital that as people age, individuals, families, and physicians engage in meaningful communication regarding an individual's health care and end-of-life care wishes. However, the current statistics are

R. Dhar (✉)
Department of Medicine, West Virginia University School of Medicine, Morgantown, WV, USA
e-mail: romika.dhar@hsc.wvu.edu

A. Gupta
Yale University School of Medicine, New Haven, CT, USA

M. Balasubramaniam et al. (eds.), *Psychiatric Ethics in Late-Life Patients*, https://doi.org/10.1007/978-3-030-15172-0_9

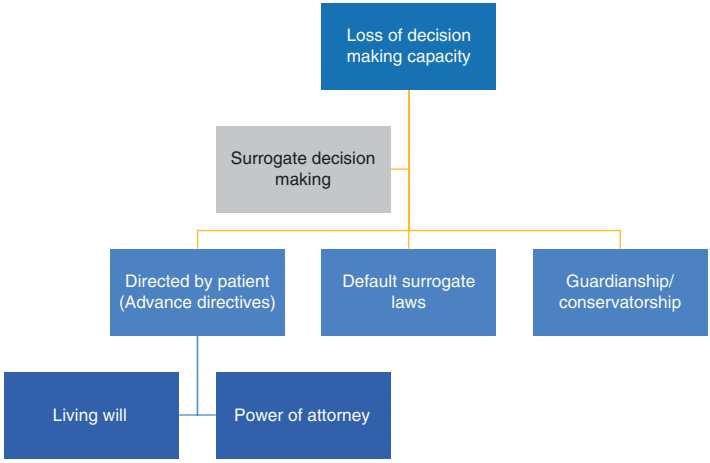

FIGURE 9.1 Different ways to appoint a surrogate decision-maker in absence of decision-making capacity

unpromising, two out of three US adults have not completed any advanced directive [2].

In the last few decades, the ethical standards for medical care have seen a paradigm shift from paternalism toward maintaining and protecting patient autonomy. Individuals can make decisions preemptively or choose a surrogate while they still have capacity through the process of advance health care planning and advance directives. In the absence of advance care directives, most individuals inadvertently rely on their state's default surrogate consent statutes. These statutes grant a person or particular class of people, usually in kinship priority, the default authority to make health care decisions for a loved one when that loved one loses decisional capacity (see Fig. 9.1).

Advance Directives

As detailed in the chapter "Advance Health Care Planning," individuals may make their own decisions preemptively and

choose their own surrogate while they still have decisional capacity. This is the best way of preserving autonomy, although this is limited by its own shortcomings. If no advance directives are in place, then the default surrogate laws are applicable.

Default Surrogate Statutes

Hierarchy Surrogate Consent Laws

Majority of states have adopted the hierarchical scheme for health care surrogate appointment if the individual loses capacity and does not have advance directives. Members of the individual's family fall within a priority list of potential surrogates who may act as surrogates. In most states, the following persons are designated to serve as surrogates. In descending order of hierarch, they are the spouse (unless divorced or legally separated); an adult child; a parent; and an adult sibling. Many states include adult grand-children [3], adult nieces and nephews [4], adult uncles and aunts [5], grandparents [6], and cousins [7].

Resolving Conflict Among Surrogates

Most states provide opportunities for resolution of differences when equal priority surrogates are unable to reach a consensus regarding health care decisions or when some interested party objects to the process or decision. The designation of a hierarchy is the primary strategy states use to avoid disputes, because those lower in the hierarchy cannot overrule the authorized surrogate without resorting to judicial proceedings.

The most common provision for dispute resolution among multiple surrogates at the same level of authority (typically adult children) is to allow clinicians to rely on a majority of the equally authorized surrogates. A second model for dispute resolution contained in two states' statutes (Delaware and Maryland) is the referral to and reliance on the recom-

mendation of an ethics committee. Although ethics committees can play a valuable role in improving policy and practice, committees are seldom quick or qualified enough to play a meaningful role in real-time, bedside decisions [8, 9]. In West Virginia and Tennessee, the health care provider can select a surrogate who appears to be best qualified based on reasonable inquiry [10, 11].

Even without an express provision for resolving disagreements, judicial intervention through the initiation of a guardianship or conservatorship is always available as a possible intervention by any interested party.

Pitfalls in Hierarchy Surrogate Consent Laws

Health care team may not look to a lower-ordered potential surrogate (e.g., sibling) if a higher-ordered potential surrogate (e.g., spouse) is available, capable, and is willing to serve as a surrogate. However, this order does not correlate with who will be the best qualified surrogate. Even in traditional family structures, the legal hierarchy may not reflect reality where families are geographically apart or complicated by divorce and remarriage, or where a friend has become the closest confidante and supporter. This supports the concept of the best qualified surrogate, who might be at the bottom of the hierarchical list, but the one that the health care team identifies as an "adult who has exhibited special care and concern for the individual, who is familiar with the individual's personal values, who is reasonably available, and who is willing to serve."

Some states have taken into account such factors in formulating laws regarding surrogate appointments. In Tennessee [12], the hierarchical list is simply something to which "consideration may be given in order of descending preference for service as a surrogate." The Tennessee statute provides five mandatory criteria for determination of the person best qualified to serve as the surrogate: (1) whether the proposed surrogate reasonably appears to be better able to make decisions either in accordance with the known wishes of the indi-

vidual or in accordance with the patient's best interests; (2) the proposed surrogate's regular contact with the individual prior to and during the incapacitating illness; (3) the proposed surrogate's demonstrated care and concern; (4) the proposed surrogate's availability to visit the individual during the individual's illness; and (5) the proposed surrogate's availability to engage in face-to-face contact with health care providers for the purpose of fully participating in the decision-making process.

Colorado and Hawaii have chosen an alternative to reliance on a hierarchy list by creating a single class of "interested persons" [13, 14]. In Hawaii, "interested persons" includes the individual's spouse (unless legally separated or estranged), a reciprocal beneficiary, any adult child, either parent of the individual, an adult sibling or adult grandchild of the individual, or any adult who has exhibited special care and concern for the individual and who is familiar with the individual's personal values.

At the time of writing this chapter, Missouri, Rhode Island, and Massachusetts do not have a default hierarchical list for the selection of surrogates. Any available next of kin is appointed as a surrogate, and if there is a dispute, judicial intervention is sought. In California, Kansas, New Jersey, and Oklahoma, the laws only apply for consenting to medical research. The surrogate consent statute in Wisconsin only applies to certain facility admissions.

Status and Recognition of Domestic Partner as Default Surrogate in Non-traditional Families

The surrogates list in a majority of the states fails to include domestic partners who are not legally married. While a same-sex partner would probably qualify as a "close friend" in some of these states, that category is usually listed only at the bottom of the surrogate list [15].

Only 15 states have an LGBTQ-inclusive surrogate selection statute. Because an individual's same-sex or domestic

partner often has greater knowledge of the individual's values than statutorily recognized decision-makers, such as estranged family, disregarding the partner's input is considered to be unethical [16].

Status of the Unbefriended

Fourteen states have enacted provisions for decisionally incapable individuals who have no living relative or friend who can be involved in the decision-making. This class of individuals is referred to as the "unbefriended" [17].

The unbefriended individual includes "persons who are decisionally incapacitated" and is made up of two main groups:

1. Those who had capacity and lost it, including frail elders in nursing homes and hospitals
2. Those who never had capacity, including persons with mental retardation or developmental disabilities.

In nine states, attending and primary physicians have been placed on surrogate priority lists for patients with no family or friend surrogates. These states typically seek to prevent unilateral decision-making by requiring physicians to consult an ethics committee or have the concurrence of a second physician before health care decisions are made for the unbefriended.

Given the vulnerable nature of this population, clinicians, health care teams, and ethicists must be diligent when formulating treatment decisions on their behalf. Public guardianship is often one of the avenues that is resorted to for this population. In the majority of US states, public guardianship programs are managed through a social service agency or county government public officials. However, this is less than ideal solution as it is unclear what caliber of decision-making guardians can provide. Another variation is the ability to apply for temporary and emergency guardianships when there is no time to conduct normal "plenary" or full guardianship hearings, which may take several weeks or months [18].

The American Geriatrics society has published a position statement on making medical treatment decisions for unbefriended older adults [19]. The statement proposes that the process of arriving at a treatment decision for an unbefriended older adult should be conducted according to the standards of procedural fairness and include capacity assessment, a search for potentially unidentified surrogate decision-makers, and a team-based effort to ascertain the unbefriended older adult's preferences by synthesizing all available evidence. Proactive preventive efforts are also needed to reduce older adults' risk of becoming unbefriended.

Guardianship

If no advance directives or qualified surrogates are available, or in the absence of default surrogate laws, a guardian is appointed through a legal due process. This step is used as one of last resort due to the vast delegation of powers to the guardian. Please refer to the chapter on Guardianship for more details.

Standards for Surrogate Decision-Making

Substituted Judgment Standard

In a majority of states, surrogates must make decisions in accordance with a substituted judgment standard [20]. Per this standard, the surrogates try to make the decision that the individual would have made if he or she were able to make decisions even if such wishes may not have been expressly conveyed.

The appeal of this standard is that it supports the individual's autonomy by leading us to the decision that the individual would have wanted. However, several authors have argued that substituted judgment does not succeed in meeting this goal due to several reasons [21–23].

Individuals' own preferences regarding life-sustaining treatment change over time. In one study, over half of individuals who initially said yes to a series of medical procedures changed their minds over the next 2 years [24]. However, individuals who had made advanced directives were less likely to change their wishes than those who do not [25]. Thus, the individuals who most need substituted judgment, because they lack a living will, are the ones for whom it is least likely to be accurate.

A meta-analysis of surrogate predictions found that that surrogates make different decisions than individuals would make for themselves in roughly one-third of cases [26]. Research also suggests that surrogates' own treatment preferences may influence their predictions of others' preferences. Evidence also indicates that surrogate predictions more closely resemble surrogates' own treatment wishes rather than the wishes of the individual that they were trying to predict [27]. Intense emotional distress and impaired information processing have been implicated in reducing a surrogate decision-maker's ability to formulate informed health care decisions for a critically ill patient [28].

The Best Interest Standard

The best interest standard seeks to implement one's best interests by reflecting upon the welfare or wellbeing of the individual [29]. If the individual's wishes cannot be ascertained or inferred in any way, the surrogate is obligated to make a decision consistent with what *most* people would decide for themselves under the same circumstances, or what would be best for the individual.

Dignity-driven decision-making is an important emerging concept based on respect for persons defined as "a process in which decisions about the patient's care emerge from a collaborative relationship developed over multiple encounters." This method favors patient autonomy and greater support for surrogate decision-makers [30]. Care that features dignity-driven decision-making involves balancing medical care with supportive services.

A shared decision-making model implemented early in treatment with surrogates and health care providers working together to effectively prepare for and tackle the multiple issues surrounding benefits and burdens of treatment to the individual is very important.

Special Considerations in Surrogate Decision-Making

To protect against the potential abuse of incapacitated adults, some states have placed limitations on surrogate decision-making. The District of Columbia has adopted a procedural limitation requiring that at least one witness be present whenever a surrogate grants, refuses, or withdraws consent on behalf of the individual [31].

About a dozen states permit surrogates to withhold life-sustaining treatment only if the individual has been certified to be in a terminal or permanently unconscious condition [32]. Many states impose stricter conditions to the withholding of artificial nutrition and hydration. Ohio prohibits withholding artificial nutrition and hydration unless there is a mandated court order [33].

Health care decisions statutes often treat artificial nutrition and hydration differently from other forms of life-sustaining medical treatment. Many states impose special additional conditions on surrogate decisions to withhold or withdraw artificial nutrition and hydration [34].

Conclusions

Surrogate decision-making is a crucial tool for delivering medical care to older adults lacking decisional capacity. In the absence of advance health care directives, default surrogate laws or guardianship are resorted to maintain the safety of the older adult. Default surrogate statutes of hierarchical order of surrogate selection are a helpful concept in the time

of need, but have some practical limitations that need to be addressed. There is need for flexibility in prioritizing interested persons who are familiar with the individual's personal values and care goals as opposed to choosing surrogates based on blood or marital relationships. Furthermore, these laws may need to be revamped to accommodate the increasingly common non-traditional family structures.

Surrogate decision-making, although currently widely utilized, is criticized for its inability to make accurate decisions for an incapacitated person. Though different models have been proposed over the years to circumvent the shortcomings of surrogate decision-making, some of the pitfalls are unavoidable. Shared decision-making, a collaborative process that allows individuals, their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the individuals' values, goals, and preferences if known, may help in dealing with this challenging problem. The next step is high-quality research trials studying the feasibility and impact of this intervention on older individuals, their families, and the health care system.

References

1. https://www.census.gov/prod/2010pubs/p25-1138.pdf. Accessed 17 Nov 2018.
2. Yadav KN, Gabler NB. Approximately one in three US adults completes any type of advance directive for end-of-life care. Health Aff. 2017;36(7):1244.
3. Del. Code. Ann., tit. 16 § 2507(b)(2)(e); Ga. Code Ann. § 31-9-2(a)(6)(E); 755 Ill. Comp. Stat. 40/25(a)(6); Me. Rev. Stat., tit. 18A§ 5-805(b)(5); Pa. Stat. Ann., tit. 20 § 5461(d)(1)(v); S.C. Code Ann. § 44-66-30(A)(6); S.D. Codified Laws § 34-12C-3(5); Utah Code Ann.§ 75-2a-108(1)(b)(ii)(D);Wis. Stat. Ann. § 50.06(3)(f); Wyo. Stat. §35-22-406(b)(vi).
4. Del. Code. Ann., tit. 16 § 2507(b)(2)(f); Ga. Code Ann. § 31-9-2(a)(6)(F); Me. Rev. Stat., tit. 18A § 5-805(b)(6); S.D. Codified Laws § 34-12C-3(6).
5. Ga. Code Ann. § 31-9-2(a)(6)(F); Me. Rev. Stat., tit. 18A §5-805(b)(7); S.D. Codified Laws § 34-12C-3(6).

6. Ga. Code Ann. § 31-9-2(a)(6)(D); N.M. Stat. Ann. §24-7A-5(B)(6); S.C. Code Ann. § 44-66-30(A)(6); S.D. Codified Laws § 34-12C-3(5); Utah Code Ann. § 75-2a-108(1)(b)(ii)(F); Wis.Stat. Ann. § 50.06(3)(e); Wyo. Stat. § 35-22-406(b)(iv).
7. S.D. Codified Laws § 34-12C-3(6).
8. Del. Code § 2507(b)(9).
9. Maryland Code, Health-Gen. § 5-605(b).
10. Tenn. Code Ann. § 68-11-1806(c).
11. W. Va. Code, § 16-30-8(b).
12. Tenn. Code Ann. § 68-11-1806(c)(3).
13. Hawaii Rev. Stat. §572-C-.
14. Colo. Rev. Stat. Ann. § 15-18.5-103(3).
15. Alaska Stat. § 47.24.016(a)(6); Ark. Rev. Stat. § 36-3231(A)(6); Del. Code Ann., tit. 16 § 2507(b)(3); Fla. Stat. Ann. § 765.401(1)(g); W. Va. Code § 16-30-8(a)(6).
16. Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in translation: the unintended consequences of advance directive law on clinical care. Ann Intern Med. 2011;154(2):121–8.
17. Karp N, Wood E. Incapacitated and alone: medical decision-making for the unbefriended elderly. Washington, DC: American Bar Association Commission on Law and Aging; 2003.
18. Cal. prob. code § 3208 (west 2016); Fla. prob. rule 5.900 (2017); O.C.G.A § 31-36a-7 (2016) (placement only); Ind. code § 16-36-1-8 (2016); N.J ct. rule 4:86-12 (2016) (special medical guardian); S.D. codified laws. § 34-12c-4 (2016); VA code ann. § 37.2-1101(b) (west2016), amended by s.b. 371, 2012 gen. assemb., reg. sess. (va. 2012).
19. Farrell TW, Widera E, Rosenberg L, Rubin CD, Naik AD, Braun U, et al. AGS position statement: making medical treatment decisions for unbefriended older adults. J Am Geriatr Soc. 2017;65:14–5.
20. Meisel A, Cerminara KL. The right to die: the law of end-of-life decision making. 3rd ed. New York: Aspen Publishers; 2004. p. 4.02(B)–3(B).
21. Bailey S. Decision making in health care: limitations of the substituted judgment principle. Nurs Ethics. 2002;9(5):483–9.
22. Dresser R. Precommitment: a misguided strategy for securing death with dignity. Tex Law Rev. 2003;81(7):1823–47.
23. Welie JV. Living wills and substituted judgments: a critical analysis. Med Health Care Philos. 2001;4(2):169–83.
24. Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. Ann Intern Med. 1994;120(7):567–73.

25. Weissman JS, Haas JS, Fowler FJ Jr, et al. The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. Med Decis Making. 1999;19(1):16.
26. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166(5):493–7.
27. Fagerlin A, Ditto PH, Danks JH, Houts RM. Projection in surrogate decisions about life-sustaining medical treatments. Health Psychol. 2001;20(3):166–75.
28. Hickman RL Jr, Pignatiello GA, Tahir S. Evaluation of the decisional fatigue scale among surrogate decision makers of the critically ill. West J Nurs Res. 2018;40(2):191–208.
29. Kopelman LM. The best interests standard for incompetent or incapacitated persons of all ages. J Law Med Ethics. 2007;35:187–96.
30. Vladeck BC, Westphal E. Dignity-driven decision making: a compelling strategy for improving care for people with advanced illness. Health Aff. 2012;31(6):1269–76.
31. DC Code § 21-2210.
32. Ala. Code § 22-8A-11(a)(2); Del. Code. tit. 16 § 2507(b)(6); Iowa Code Ann. § 144A.7(1); Me. Rev.Stat. tit. 18-A § 5-805(a); Mont. Code Ann. § 50-9-106(1)(a); Nev.Rev. Stat. § 449.626(1)(a); N.C. Gen. Stat. § 90-322(a)(1a); Ohio Rev.Code § 2133.08(D)(2).
33. Ohio Rev. Code Ann. § 2133.09.
34. Seiger CE, Arnold JF, Ahronheim JC. Refusing artificial and hydration: does statutory law send the wrong message? J Am Geriatr Soc. 2002;50(3):544–50.