

Systematic Review: Individuals' Goals for Surrogate Decision-Making

Brenna Kelly, JD, MPH,* Annette Rid, MD,^{†‡} and David Wendler, PhD[‡]

OBJECTIVES: To determine to what extent current practice promotes the goals of individuals who did not designate a surrogate while competent with respect to decision-making during periods of decisional incapacity.

DESIGN: Systematic literature search for studies published in English and listed in PubMed, Scopus, Embase, CINAHL, or PsycINFO. Studies were eligible if they provided quantitative or qualitative empirical data on how adults want treatment decisions to be made for them during periods of incapacity.

SETTING: Primarily United States, with six other countries.

PARTICIPANTS: Fourteen qualitative articles, representing 11 distinct data sets, and 26 quantitative articles, representing 25 distinct data sets, providing data on the views of 22,828 individuals, met the inclusion criteria. Most of the respondents were elderly or seriously ill.

MEASUREMENTS: Quantitative surveys and qualitative interview studies assessing individuals' goals.

RESULTS: The majority wanted close family members to act as their surrogate. The most common reason for preferring family members was the belief that they know which treatments the patient would want. Individuals also wanted to reduce the burden on their families. There was significant variation in the extent to which respondents wanted their surrogates to have leeway when making treatment decisions.

CONCLUSION: Individuals have three primary goals with respect to making treatment decisions for them during periods of incapacity: involve their family, treat them consistently with their own treatment preferences, and reduce the burden on their family. Unfortunately, prior systematic reviews have found that family members often are not able to determine which treatment patients want, and family members frequently experience substantial distress when

acting as surrogates. These findings suggest that current practice frequently fails to promote individuals' primary goals for treatment decision-making. Future research should evaluate ways to better promote individuals' goals. In the meantime, clinicians should be aware of these findings and should encourage patients to document their own goals, including their treatment preferences and their preferences regarding how they want decisions to be made for them during periods of decisional incapacity. *J Am Geriatr Soc* 60:884–895, 2012.

Key words: surrogate; end of life; decision-making; incapacity; goals; preferences; values

Respect for autonomy implies that individuals should be allowed to make their own treatment decisions, typically in consultation with a clinician. Yet many people, including the majority of those at the end of life, are not able to make decisions.^{1–3} Moreover, the majority of individuals do not complete an advance directive or otherwise leave clear instructions for how they want to be treated during periods of decisional incapacity.⁴

Designated surrogates make decisions for incapacitated individuals who completed a durable power of attorney while competent. For incapacitated individuals who did not designate a surrogate while competent, the next of kin makes treatment decisions. Surrogates, whether patient designated or next of kin, are instructed to make decisions based on the substituted judgment standard, making the treatment decision they think the individual would have made if he or she were capable.^{5,6} Proponents argue that this approach extends individual autonomy by allowing individuals' preferences and values to guide how they are treated, even when they are not able to make their own decisions.

No systematic analyses have attempted to identify individuals' goals with respect to treatment decision-making during periods of incapacity. As a result, it is unclear to what extent current practice promotes individuals' goals. In the absence of an advance directive, how do individuals want treatment decisions to be made for them? Does current practice of relying on the next of kin, and

From the *University of Michigan Law School, Ann Arbor, Michigan; [†]Institute of Biomedical Ethics, University of Zurich, Zurich, Switzerland; and [‡]Department of Bioethics, National Institutes of Health Clinical Center, Bethesda, Maryland.

Address correspondence to David Wendler, Department of Bioethics, NIH Clinical Center, Building 10, Room 1C118, Bethesda, MD 20892. E-mail: dwendler@nih.gov

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instructing them to use the substituted judgment standard, promote individuals' goals? To assess these questions, a systematic review of the empirical literature was conducted to evaluate how individuals want treatment decisions to be made for them during periods of decisional incapacity.

METHODS

Data Sources and Searches

PubMed, Scopus, Embase, CINAHL, and PsycINFO were searched for studies published in English that provide quantitative or qualitative empirical data on how adults want treatment decisions to be made for them during periods of decisional incapacity. Studies were eligible if they were indexed before August 2, 2010. The search combined Medical Subject Headings in three inclusion categories: end-of-life care, attitudes, and family or surrogate. (See Appendix for the specific terms used.)

Study Selection

The systematic search identified 6,551 articles, and the authors identified seven additional articles. (See Figure 1 for the selection process.) Two authors independently reviewed the titles of the articles and categorized them as ineligible, of unclear eligibility, possibly eligible, or probably eligible. Categorization was performed while blinded to the articles' authors and affiliations. Articles were judged to be ineligible only if the reviewer was confident, based on the title, that the article would not satisfy the inclusion criteria of providing quantitative or qualitative empirical data by surveying adults regarding how they want treatment decisions to be made for them during periods of decisional incapacity. Titles that both authors agreed clearly failed to satisfy these criteria were eliminated, leaving 273 potentially eligible studies.

The same two authors read the abstracts (or first pages of articles without abstracts) of the 273 articles and

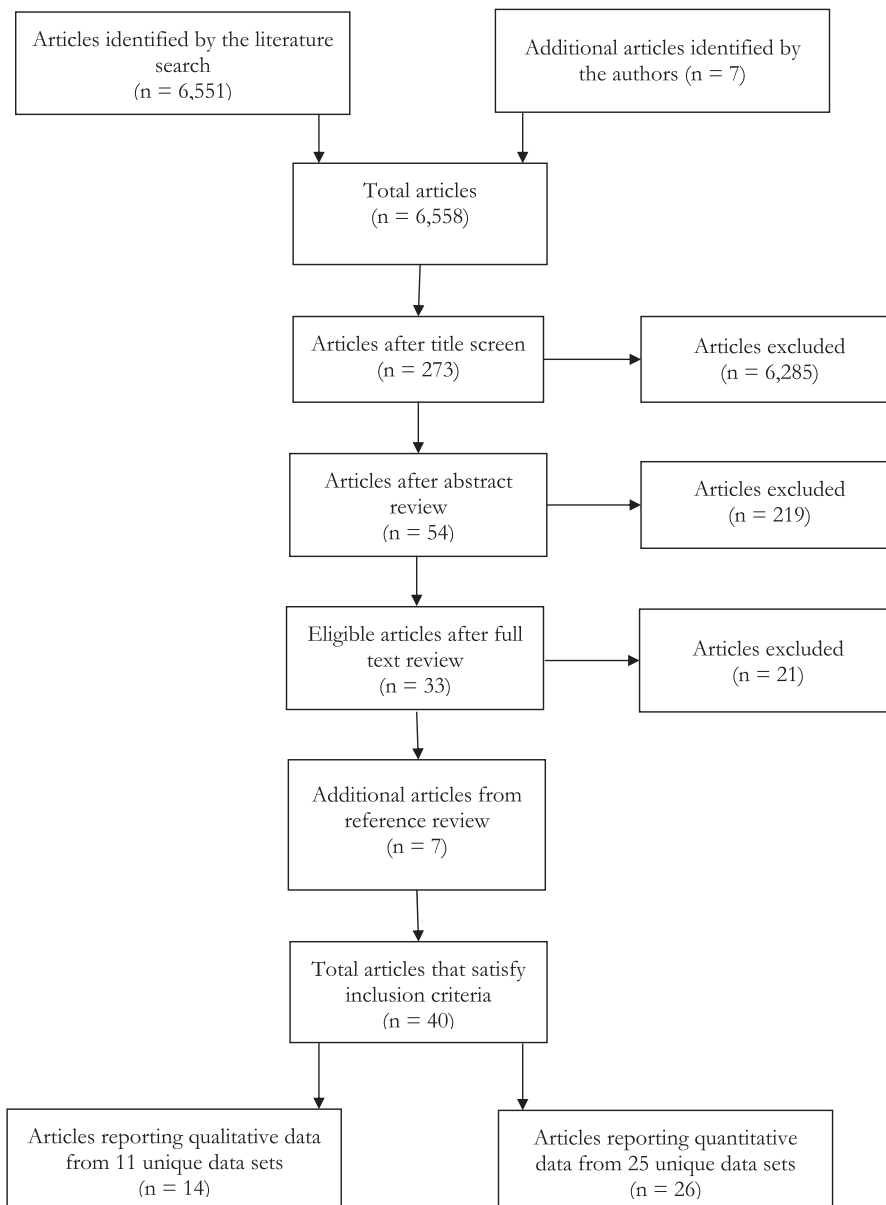


Figure 1. Literature search and selection.

ranked them as ineligible, of unclear eligibility, or likely eligible. This process identified 54 articles as being of unclear eligibility or likely eligible. Both authors independently read the full text of these 54 articles and identified 33 articles that satisfied the inclusion criteria. Review of the references of the 33 eligible articles yielded four additional eligible articles. The references of these four articles were reviewed, yielding no additional eligible articles.

To determine whether the systematic search missed any eligible articles, the two authors evaluated the references of a related systematic review, which evaluated the effect of making treatment decisions on surrogates.⁷ This review identified three additional eligible articles. Review of the references of these three articles yielded no additional eligible articles. Finally, five researchers in the field were contacted to determine whether they were aware of any eligible articles that had been missed, yielding no additional eligible articles. Thus, in total, 40 articles met the inclusion criteria.

Data Extraction and Quality Assessment

Two authors independently read the 40 eligible articles and extracted data on study location, number and type of respondents, response rate, methods, main findings, and limitations. When the extracted data from two different articles appeared to be related, the corresponding authors were contacted to determine whether the two articles were based on the same data set.

Two authors assessed the methodological strength of the eligible articles by giving them one point for each of 12 criteria that they satisfied. (See Table 1 for specific criteria.) When a criterion was not mentioned in the article, it was regarded as not satisfied. The final strength score is intended to reflect the extent to which the articles provide valid data relevant to the inclusion criteria used in the present review.

The quantitative articles used a range of different instruments, making it impossible to conduct formal statistical analyses on the aggregate results. The reviewed data are thus presented as a narrative summary.⁸

RESULTS

Identified Studies

The literature search identified 40 articles published in English before August 2, 2010, that met the inclusion criteria.⁹⁻⁴⁸ These articles provided data from 36 distinct data sets. The number of individuals evaluated in the articles ranged from 12 to 8,000, for a total of 22,828 individuals evaluated. Twenty articles reported the views of elderly individuals, typically aged 65 and older,^{14,15,17,18,20-24,26,27,29-31,33,36-38,42,44} nine reported the views of terminally or seriously ill patients,^{14,16,19,28,34,37,42,45,46} Ten articles focused on the views of particular patient or ethnic groups.^{9,25,29,30,32,35,40,41,47,48} Only six articles surveyed a larger cross-section of a given population.^{10-13,39,43}

The articles focused on whom individuals wanted to be their surrogate if they could no longer make decisions for themselves. Thirteen articles also evaluated why individuals preferred a particular surrogate; nine evaluated

Table 1. Strength Criteria (Adapted from Ref. 7)

Quantitative studies	
For each of the following criteria satisfied, a point was given	
1.	Trained interviewers
2.	Interviewers independent of the care team
3.	Selected a representative sample
4.	Performed measures to ensure the reliability of the data
5.	Performed measures to ensure the validity of the data
6.	Evaluated why respondents selected a particular person or process for end-of-life decision-making
7.	Reported respondents' sociodemographic characteristics
8.	Response rate exceeded 50%
9.	Reported the raw number or percentage of respondents for each reported theme or result
10.	Specified the number of participants needed to reach statistical significance
11.	Reached the specified number of participants
12.	Statistical analysis of the findings
Qualitative studies	
For each of the following criteria satisfied, a point was given	
1.	Trained interviewers
2.	Interviewers independent of the care team
3.	Selected a representative sample
4.	Performed measures to ensure the reliability of the data
5.	Performed measures to ensure the validity of the data
6.	Evaluated why respondents selected a particular person or process for end-of-life decision-making
7.	Reported respondents' sociodemographic characteristics
8.	Response rate exceeded 50%
9.	Reported the raw number or percentage of respondents for each reported theme or result
10.	Reported theme saturation
11.	Recorded verbatim answers
12.	Coded findings in a blind and independent manner

how much leeway individuals thought that their surrogate should have when making treatment decisions.

The first article was published in 1987; 22 articles were published in 2000 or later. Twenty-nine of the articles surveyed individuals in the United States; three surveyed individuals in Canada; two each in France and Japan; one each in Sweden, Australia, and Singapore; and one in Japan and the United States. Twenty-six articles reported quantitative data from 25 distinct data sets, and 14 reported qualitative data from 11 unique data sets (Tables 2 and 3). The quantitative articles used a range of instruments. Most of the qualitative articles used semi-structured interviews. The qualitative articles reported data using direct quotations, as well as general descriptors of the results, such as a lot, some, and a little.

Who Individuals Want to Make Decisions for Them

The identified articles indicated that the vast majority of respondents wanted close family members to make treatment decisions for them during periods of decisional incapacity (Tables 2 and 3). In six articles, most respondents preferred their spouse to make decisions.^{11,13,18,36,37,44} Twelve articles reported that most respondents preferred that their adult children act as surrogates.^{14,15,20-24,26,27,31,37,42} In one of these articles, individuals preferred their adult children as decision-makers because they assumed that their spouses would predecease them.⁴² A minority of

Table 2. Qualitative Studies on Individuals' Surrogate Decision-Making Preferences

Study, Year (Reference)	Country	Strength Score ^a	N (RR)	Method	Population	Scenario	Preferred Surrogate	Reasons for Preferred Surrogate	Surrogate Leeway
Elliott and Oliver, 2007 (16)	Australia	7	28 (NR)	Semistructured interviews	Individuals with terminal cancer	End of life	Most: family Some: MDs	Some: family best qualified to know patients wishes, family too emotional to make decisions	Some: follow AD Others: family consider effect on themselves
Seairight and Gafford, 2005 (40)	United States	6	12 (NR)	Focus groups	Recent Bosnian immigrants	Life-threatening illness	Family and MD	NR	NR
Moore et al., 2003 (33)	United States	7	30 (NR)	Semistructured interviews	Community dwelling adults aged ≥ 60	Coma	Adult child, spouse	33% care about family burden	Substituted judgment: 50% Surrogate decide: 33% Best interest: 17%
Rosenfeld et al., 2000 (38)	United States	9	21 (NR)	Semistructured interviews	Elderly adults with chronic conditions	Range of illnesses	Family and MD ^b	Family cares; MD expert	NR
Waters, 2000 (48) and 2001 (47)	United States	7	27 (NR)	Focus groups	African Americans	End of life	Family: 79% Providers: 8%	Some: family knows preferences	NR
Aikman et al., 1999 (9)	Canada	6	124 (59%)	Evaluation completed ADs	Human immunodeficiency virus positive	Dementia, coma, terminal illness; disability, dementia	NR	NR	Some: full Some: none
Terry et al., 1999 (46)	United States	10	300 (75%)	Semistructured interviews	Individuals with terminal illness	Coma	NR	34% trust in relationship	Substituted judgment: 54% Follow AD: 46%
Patterson et al., 1993 (36)	United States	5	53 (47%)	Structured interviews	Senior citizens	Incapacity	Spouse: 57% ^c Adult child: 25% ^c Other: 19% ^c	NR	NR
Shawler et al., 1992 (42)	United States	6	43 (NR)	Semistructured interviews	Hospitalized elderly adults	Incapacity	Adult child: 56% Spouse: 28% Other relative: 9% Sibling: 2% Doctor: 2%	Family knows preferences	NR
Sloan, 1990 (44)	Canada	2	20 (NR)	Structured interviews	Elderly adults	Incapacity	Spouse: 35% ^d MD best interest judgment: 25% ^d Adult child: 20% ^d Other: 20% ^d	NR	NR
High, 1987 ^e (21), 1988 ^e (20), and 1990 (22)	United States	6	71 (NR)	Semistructured interviews	Elderly adults	Incapacity	Adult child: 32% Spouse: 21% Doctor: 18% Other family: 7% Close friend: 7%	Trust family; Have no family	NR

RR = response rate; NR = not reported; AD = advance directive; MD = doctor.

^a Out of a possible 12 points.

^b Shifts to family as the patient's prognosis becomes "grim."

^c Includes only respondents who did not have a durable power of attorney.

^d Response to the question of whom the respondent would appoint as their substitute decision-maker.

^e The 1987 and 1988 articles report data from a subset (N = 40) of the 71 respondents in the 1990 article.

Table 3. Quantitative Studies of Individuals' Surrogate Decision-Making Preferences

Study, Year (Reference)	Country	Strength Score ^a	N (RR)	Method	Population	Scenario	Preferred Surrogate	Reasons for Preferred Surrogate	Surrogate Leeway
Carr and Khodyakov, 2007 (13)	United States	6	3,838 (37%)	Telephone interview and mailed survey	Wisconsin high school graduates	Incapacity	Spouse: 30% ^b Child: 18% ^b Other: 4% ^b Sibling: 1% ^b	NR	NR
Sulmasy et al., 2007 (45)	United States	8	147 (47%)	In-person survey	Terminally ill	Unconscious	NR	22% follow own wishes; 9% follow what loved ones think best; 27% equal weight own wishes; 26% follow own wishes after considering what loved ones think best; 13% do what loved ones think best after considering patient's wishes	NR
Heyland et al., 2006 (19)	Canada	9	440 (79%)	In-person survey	End-stage cancer; Advanced illness; Inpatients	CPR	Family: 42% Family and MD: 26% MD: 21%	NR	NR
Miyata et al., 2006 (32)	Japan	8	418 (61%)	Self-administered questionnaire	Middle-aged adults	Dementia; Irreversible coma; Temporary illness	NR	NR	5% follow strictly; 58% follow as much as possible; 33% use as reference; 3% do not care if wishes followed
Hawkins et al., 2005 (18)	United States	6	337 (84%)	In-person survey	Elderly outpatients	End of life	Spouse: 62% Daughter: 23% Son: 7% Other: 8%	NR	None 9% Little 37% A lot 28% Complete 24% NR
Kim and Kjervik, 2005 (28)	United States	4	362 (NR)	In-person survey ^c	Seriously ill patients with pain	Resuscitation	Family and MD: 77% ^d Previously expressed wishes: 23% ^d	NR	NR
Nolan et al., 2005 (34)	United States	8	130 (45%)	In-person survey	Terminally ill	Unconscious	Weigh family and MD equally: 48%; More family: 33% More physician: 19% ^e	NR	NR
Norris et al., 2005 (35)	United States	10	229 (est. 76%)	In-person survey	Homeless	CPR and mechanical ventilation	Family: 64% ^f Physician: 16% ^f Friend: 8% ^f	NR	NR

(Continued)

Table 3. (Contd.)

Study, Year (Reference)	Country	Strength Score ^a	N (RR)	Method	Population	Scenario	Preferred Surrogate	Reasons for Preferred Surrogate	Surrogate Leeway
Akabayashi et al., 2003 (10)	Japan	7	425 (76%)	Mailed survey	General public	Acute illness	NR	NR	11% follow AD absolutely; 55% follow AD as much as possible; 9% use AD as reference
Azoulay et al., 2003 (11)	France	9	8,000 (99%)	Telephone survey	General public	Incompetent and admitted to intensive care unit	Spouse: 61% Parents: 15% Children: 14% Other family: 6% Friends: 2% Family physician: 1%	NR	NR
Beck et al., 2002 (12)	United States	7	735 (59%)	Mailed survey	Older health maintenance members in randomized controlled trial for ADs	Life-sustaining treatment	No AD: Family: 88% MD: 40% Have AD: Family: 69% MD: 34%	Family understands patient's wishes; MD knows wishes	NR
Matsumura et al., 2002 (30)	Japan, United States	8	539 (92%)	Self-administered survey	Elderly English-speaking Japanese Americans	Life-threatening illness	Shared: 75% Single family member: 16% Physician: 9%	NR	NR
			340 (82%)	Self-administered survey	Elderly Japanese-speaking Japanese Americans	Life-threatening illness	Shared: 57% Single family member: 25% Physician: 18%	NR	NR
			304 (91%)	Self-administered survey	Elderly Japanese	Life-threatening illness	Shared: 69% Single family member: 19% Physician: 12%	NR	NR
Hopp, 2000 (26)	United States	6	137 (who completed an AD) (NR)	Survey	Community-dwelling adults aged > 70	Incapacity	Child or grandchild: 68% Spouse: 18% Other relative: 8% Friend: 3% Physician or lawyer: 3%	NR	NR
Low et al., 2000 (29)	Singapore	7	43 (70%)	Semistructured interview	Elderly Chinese	Mentally incompetent	MD: 53% Family member: 35% Of those who chose a family member: Son: 14% Daughter: 12% Spouse: 5% Other Family: 5%	Family members know patient the best; MDs know patients' interests, most qualified	NR

(Continued)

Table 3. (Contd.)

Study, Year (Reference)	Country	Strength Score ^a	N (RR)	Method	Population	Scenario	Preferred Surrogate	Reasons for Preferred Surrogate	Surrogate Leeway
Puchalski et al., 2000 (37)	United States	7	513 (42%)	In-person survey	HELP study: older inpatients	Resuscitation decisions	Prefer family/MD: 71% Surrogate: Child: 53% Spouse: 20% Other: 22% None: 5%	NR	NR
			646 (29%)	In-person survey	SUPPORT study: seriously ill adult inpatients	Resuscitation decisions	Prefer family/MD: 78% Surrogate: Spouse: 48% Child: 26% Other: 22% None: 4%	NR	NR
Roupie et al., 2000 (39)	France	8	1,089 (54%)	Self-administered survey	Noncritical patients in the emergency department	Coma	Family member: 66% MD: 29% Friend: 4%	NR	NR
Hines et al., 1999 (25)	United States	5	400 (77%)	In-person survey	Dialysis patients	Critical illness	Family member: 93%	NR	NR
Stokvist et al., 1999 (43)	Sweden	8	771 (64%)	Mailed survey	General public	Ventilator when incompetent	Family and MD: 73% Family only: 19% MD only: 5% Uncertain: 3%	NR	NR
Hornung et al., 1998 (27)	United States	5	1,193 (NR)	Chart review	Frail elderly adults	NR	Child: 12% ^g Other relative: 4% ^g Spouse: 2% ^g	NR	NR
Meier et al., 1997 (31)	United States	7	331 (95%)	Physician-administered survey	Geriatric outpatient clinic patients	End of Life	Daughter: 45% ^h Son: 18% ^h Other relative: 13% ^h Sibling: 8% ^h Grandchild: 6% ^h Spouse: 5% ^h Friend: 4% ^h	NR	NR
High, 1993 (23) and 1993 (24)	United States	8	293 (85%)	Telephone survey	Elderly	End of life	Adult child: 61% Spouse: 29% Physician: 15% Sibling: 13% Friend: 6% Others: 6% Attorney: 4%	NR	NR

(Continued)

Table 3. (Contd.)

Study, Year (Reference)	Country	Strength Score ^a	N (RR)	Method	Population	Scenario	Preferred Surrogate	Reasons for Preferred Surrogate	Surrogate Leeway
Sehgal et al., 1992 (41)	United States	10	150 (51%)	In-person survey	Individuals undergoing dialysis	Develop Alzheimer's disease	Most: family	NR	None 39% Little 19% A lot 11% Complete 31% NR
Cohen-Mansfield et al., 1991 (15)	United States	7	103 (73%)	In-person survey	Residents in Jewish long-term care facility	NR	Adult child: 64% Other relative: 15% Sibling: 10% Nonrelative: 10% Spouse: 2%	Closest relative: 33% Know patient best: 26% Proximity: 17% Other reasons: 16%	NR
Cohen-Mansfield et al., 1991 (14)	United States	10	97 (71%)	In-person survey	Hospitalized elderly	NR	Adult child: 33% Spouse: 29% Sibling: 10% Friend: 10% Other: 10% Other relative: 9%	Personality traits: 24% Knows patient: 23% Next of kin: 20% Proximity: 9% Other reasons: 24%	NR
Gamble et al., 1991 (17)	United States	6	75 (NR)	In-person survey	Elderly	Terminal illness	Other family: 78% Spouse: 15% Physician: 7%	NR	NR

RR = response rate; NR = not reported; AD = advance directive; CPR = cardiopulmonary resuscitation; HELP = Hospitalized Elderly Longitudinal Project.

^a Out of a possible 12 points.

^b Of respondents who completed a durable power of attorney.

^c Based on a secondary analysis of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) II study.

^d Of those who expressed a clear resuscitation preference.

^e Of respondents who would weigh family and physician (MD) input equally.

^f Data based on an N of 226 (not 229).

^g Of those who had a documented surrogate.

^h Of those who had not appointed a proxy previously but did so during the study (N = 147).

respondents in the various articles preferred that a non-family member and nonphysician make treatment decisions.^{11,14,15,20-24,26,31,35,39} This preference sometimes reflected the fact that the respondent did not have any immediate family.^{20-22,26} In other cases, individuals did not want their family members to be involved in making decisions because of disagreements or conflicts they had with their family.^{9,46}

Fifteen articles, reporting the findings of 12 data sets, found that the majority of respondents wanted their family members to make decisions together.^{11,18-22,28,30,34,38,42,43,45,47,48} One respondent identified as his preferred decision-maker: "My wife, my son, and daughter. I am a firm believer that these are joint decisions."²⁰ Another stated that decisions should be made by "My three daughters together.... They'd make them together. They'd just stick together."⁴² Most respondents wanted their family members to consult with their clinicians during the decision-making process.

Reasons for Surrogate Preference

Fourteen articles, reporting the findings of 11 data sets, evaluated why respondents preferred a particular surrogate.^{12,14-16,20-22,29,33,38,42,46,47,48} Eleven of these articles found that most individuals wanted a family member to be their surrogate because the respondent assumed that family members would know their treatment preferences.^{12,16,20-22,29,33,42,46,47,48} For example, one respondent explained the preference for her daughter on the grounds that "My daughter would choose what I would do in the situation."⁴⁶ In some cases, respondents' confidence in their family's ability to determine their own treatment preferences was based on previous discussions between the patient and family member: "I have talked to my son and daughter. In all probability I'll predecease them, so I thought that was good enough."²²

Seventeen articles provided quantitative data regarding whether respondents had any discussion with someone else regarding end-of-life decision-making; none quantified the frequency, length, or depth of discussion.^{14,15,17,19,20,22-26,30-32,41,42,45,46} Of these 17 articles, 11 found end-of-life discussion rates of lower than 50%.^{14,15,17,19,26,30,32,41,42,45,46} An additional five articles found rates lower than 70%.^{20,22-25} Only one reported discussion rates higher than 70%.³¹

Ten articles found that respondents preferred family members as surrogates based on trust.^{14,20-22,33,38,42,46-48} Some respondents trusted their family members to implement their wishes. For example, one respondent stated: "You need someone you have confidence in to carry out your wishes."⁴⁷ Others trusted their family members to protect their interests: "My daughter would have my best interest at heart."⁴⁶

How Much Leeway Do Individuals Want to Grant Their Surrogates

Nine articles evaluated how much leeway individuals thought their surrogates should have when making treatment decisions for them.^{9,10,16,18,32,33,41,45,46} One of these articles explicitly defined "leeway" as "freedom to do

what they think is best for you."⁴¹ Another used the term "leeway" without defining it.¹⁸ Two articles incorporated some explanation of leeway in the question.^{9,10} For example, one asked respondents: "How much leeway do you want to give your proxies in interpreting your wishes?"⁹ The remaining five articles evaluated the concept without using the term "leeway."^{16,32,33,45,46} For example, one article reported respondents' views regarding "to what extent their proxy should respect their treatment preferences."³²

These nine articles found that the preferred amount of leeway varied widely. One quantitative article reported that 58% of respondents wanted their surrogates to have none or a little leeway, whereas 42% wanted their surrogates to have a lot or complete leeway.⁴¹ Another quantitative article found that 63% of respondents wanted their surrogates to follow their advance directives strictly or as much as possible, whereas 33% wanted their surrogates to use their advance directives as a reference only, and 3% did not care if their wishes were followed.³² The qualitative articles, which found that some respondents "granted permission to proxies to freely interpret their written preferences," whereas others insisted that their surrogates "follow their instructions precisely," supported these findings.⁹

The reasons why respondents wanted their surrogates to have leeway or not also varied. Many respondents who wanted their wishes followed simply wanted to have some treatments and avoid others. Others regarded the following of their wishes as a way to avoid burdening their family.^{9,10,18} One respondent stated: "follow my directions to the T, because I do not want anyone to feel guilty that they made the wrong decision."⁹ Other respondents felt that giving their surrogate leeway would allow the surrogate to make treatment decisions that better promoted the patient's interests.^{9,10,18}

Study Strength

The median strength score of the identified articles was 7 out of 12 (range 2-10); 33 of the 40 articles scored 8 points or less. Several of the deficiencies are of particular importance. For example, 15 articles did not report a response rate, and five had response rates below 50% (Tables 1-3).

Limitations

The present findings are subject to at least five important limitations. First, the strength of the identified articles was low, with a median strength score of 7 out of 12. Second, only 13 articles, reporting the findings of 10 data sets, asked respondents why they preferred a particular surrogate or a particular method for making treatment decisions. Third, the studies were conducted in a range of groups in different countries around the world. Thus, the present data are not robust enough to detect significant differences in views between groups and in different countries. Similarly, the wide range of survey instruments used precludes subgroup analyses of the data. Fourth, the nine articles that assessed leeway relied on different understandings of the concept. Some understood leeway as flexibility

in interpreting the individual's stated preferences; others understood leeway as the flexibility to make decisions that were not consistent with the individual's stated preferences. Fifth, most respondents were older, very ill, or both. Although this group of individuals represents those for whom decisional incapacity is most likely, it may have failed to detect differences based on age or generational cohort.

DISCUSSION

Systematic review of the published data on more than 22,000 respondents from 36 unique data sets suggests that individuals have three primary goals with respect to how treatment decisions are made for them during periods of decisional incapacity. First, the vast majority of individuals want their close family members to make treatment decisions, typically in consultation with the individual's doctors. Second, individuals want to be treated consistently with their own preferences and values; most believe that relying on their family to make decisions will promote this goal. Third, many individuals want to minimize the burden on their families.

In the absence of an advance directive, current practice relies on the next of kin to make treatment decisions for incapacitated individuals. Yet prior systematic reviews have found that family members often do not know patients' treatment preferences,⁴⁹ and family members often experience substantial burden when acting as surrogates.⁷ The present findings, when combined with those of these prior systematic reviews, suggest that current practice is promoting only one of individuals' three primary goals with respect to decision-making during periods of incapacity. Current practice realizes individuals' primary goal that close family members make treatment decisions for them. Yet the way families currently make decisions likely undermines individuals' two other primary goals: receiving treatments they want and avoiding burden on their families.

Implications for Future Research

Future research should assess whether modifications to current practice, or alternative approaches, might better promote individuals' goals. In particular, future research will be needed to assess whether it is possible to involve family members in the decision-making process in ways that reduce the burdens on them and also increase the chances that individuals are treated consistent with their own preferences and values.⁵⁰

One approach that has gained considerable support is shared decision-making, which involves family members and clinicians making decisions together.^{51,52} Clinicians may be able to help clarify the circumstances and options and take on some responsibility for the ultimate decision. Unfortunately, data suggest that clinicians may be less able than family members to predict their patients' treatment preferences.^{53–55} Thus, greater involvement of clinicians in the decision-making process may help to promote individuals' goal of reducing the burden on their family⁷ while undermining their goal of being treated consistently with their own preferences.

A second approach that has been proposed is to provide family members with predictions for what treatment course the individual would want based on the individuals' sociodemographic characteristics.^{56,57} Future research will be needed to evaluate whether this approach increases the chances that individuals are treated consistently with their preferences; whether it reduces the burden on their families; and what patients think about this approach.

In addition to evaluating ways to promote all three of individuals' primary goals, future research should consider how individuals prioritize these goals. Do individuals care more about having their family involved in the decision-making process, about reducing the burden on their families, or about receiving the treatments they want? Answering this question will be especially important if future research fails to identify approaches that successfully promote all three goals.

Implications for Clinical Practice

What implications do the present findings have for clinical practice? First, clinicians should be aware that individuals often assume that their family members know their treatment preferences. Given that this often is not the case,⁴⁹ clinicians should encourage individuals to discuss their preferences with their designated surrogates and document them using an advance directive. These steps may increase the chances that at least individuals who have specific treatment preferences are treated consistent with them.³ In addition, the presence of an advance directive often reduces the burden on surrogate decision-makers.⁷

Second, in addition to specific treatment preferences, clinicians should encourage individuals to use their advance directives to document any preferences they have regarding how treatment decisions are made for them. To what extent is the individual concerned primarily with the treatments they receive versus who makes decisions for them versus the effect on their families? This information will help surrogate decision-makers to better respect individuals' preferences.

Third, some commentators have argued that current practice inappropriately directs surrogates to make the decision they think the individual would have made if capable.⁵⁸ These commentators argue that surrogates should instead have leeway to take into account considerations other than the individual's treatment preferences, including the effect of the treatment options on the family. Although the present findings suggest that many individuals want their surrogates to have substantial leeway, many others do not. In addition, those who want their surrogates to have substantial leeway often assume that this approach is more likely to result in their receiving the treatments they want. In contrast, some respondents who are concerned about the effect on their families want their advance directives to be followed strictly because they assume that this approach will reduce the burdens on their family.

These findings suggest that it is not possible to develop an unequivocal recommendation regarding how much leeway surrogates should have. In addition, simply asking individuals to specify the amount of leeway they want their surrogates to have may lead to confusion regarding

the individual's ultimate goals. To address this concern, individuals could be encouraged to document their most important goal with respect to making treatment decisions for them during periods of decisional incapacity. Individual also might document how much leeway they want their surrogates to have and the reasons for granting their surrogates leeway or not.

CONCLUSION

Review of the published literature suggests that individuals have three primary goals with respect to treatment decision-making during periods of decisional incapacity: involve their family, being treated consistently with their own preferences and values, and minimize the burden on their family. In the absence of an advance directive, current practice attempts to promote individuals' goals by relying on family members to make treatment decisions using the substituted judgment standard. Yet previous reviews show that family members often do not know the individual's treatment preferences⁴⁹ and often experience substantial burden when acting as surrogates.⁷ Clinicians should be aware of these findings and encourage individuals to discuss and document their own goals, including any specific treatment preferences and their preferences regarding how they want decisions to be made for them. Future research should consider whether modifications to current practice or alternative approaches might better promote all three of individuals' primary goals with respect to decision-making during periods of incapacity.

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APPENDIX

SEARCH TERMS

The search terms were: Advance care planning [Medical Subject Headings] or advance directives [Medical Subject Headings] or advance directive adherence [Medical Subject Headings] or resuscitation orders [Medical Subject Headings] or withholding treatment [Medical Subject Headings] or treatment refusal [Medical Subject Headings] or Critical Care [Medical Subject Headings] or Intensive Care [Medical Subject Headings] or Life Support Care [Medical Subject Headings] or Palliative Care [Medical Subject Headings] or Terminal Care or resuscitation [Medical Subject Headings] or “end-of-life” [tw] AND Proxy [Medical Subject Headings] or legal guardians [Medical Subject Headings] or third-party consent [Medical Subject Headings] or family [major] or caregivers [Medical Subject Headings] or surrog* [tw] or mental competency [Medical Subject Headings] or “durable power of attorney” [tw] AND Choice* [Title] or prefer* [Title] or goal* [Title] or desire* [Title] or wish* [Title] or attitude* [Title] or values [Title] or communication [Medical Subject Headings] or decision-making [Medical Subject Headings].