Title: A Novel Tool to Assess the Capacity of People with Dementia to Designate a Surrogate

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Abstract:

Background and Objectives: As their cognitive function declines, people with dementia often lose decision-making capacity (DMC) for choosing certain medical treatments, but some retain the capacity to designate a surrogate decision maker. There is currently no tool for assessing the capacity to designate a surrogate (CDS). The purpose of this study is to validate a novel capacity assessment tool for evaluating CDS for people with a clinical diagnosis of dementia. **Research Design and Methods**: A concurrent mixed-methods design was used to evaluate 52 participants' ability to (1) consistently name a surrogate, (2) understand the role of the surrogate, and (3) provide a rationale for why they chose their surrogate. A basic difference of means was used to test differences in CDS scores between participants who had and did not have DMC. Thematic analysis was applied to the narrative data on reasons for the participants' choice of surrogate. **Results**: The CDS instrument demonstrated high interrater reliability and evidence of validity. On every dimension, the CDS tool identified participants who otherwise lacked DMC who nonetheless had full understanding of the need, process, and role of a surrogate. Thematic analysis of the rationale section of the CDS tool revealed thirty-three unique reasons participants chose their surrogate, which were then grouped into three overarching themes. **Discussion and**

Implications: The CDS tool shows that there are patients who may otherwise lack DMC but who can validly designate a surrogate. The CDS tool may be a highly useful instrument to promote patient-centered care among vulnerable patients deemed to lack capacity for treatment decisions.

Keywords: Dementia, capacity, evaluation, measurement

A Novel Tool to Assess the Capacity of People with Dementia to Designate a Surrogate

Background and Objectives

Dementia has been shown to seriously impair a person's decision-making capacity as the disease progresses. For this reason, many assume that persons with dementia lack the ability to make decisions by virtue of having the illness (Kleinfeld et al., 2019; Ganzini et al., 2003). A more specific inferential error occurs when physicians assume that patients who lack the capacity to make certain medical treatment decisions also lack other capacities relevant to other kinds of decision making, including the capacity to designate a surrogate (CDS) decision maker (Navin et al., 2022). It is not uncommon for physicians to make these kinds of overly broad judgments about patients' capacities, particularly when they are not using formal assessment tools (Wilkinson and Fower, 2020; Barstow, Shahan, Roberts, 2018; Sessums, Zembruzuska, Jackson, 2011). This leads to disallowing patients with the relevant capacities for some kinds of decisions (e.g., surrogate appointment) from exercising their autonomy and making important decisions for themselves (Fetherstonhaugh et al., 2013). Bioethical and clinical literature has long agreed, however, that decision-making capacity (DMC) should be understood as domain-specific, meaning capacity should be assessed for the decision-at-hand, but this is rarely done well and does not account for the qualitative differences across decisional domains (e.g., choosing among treatments versus choosing among surrogates) (Kleinfeld et al., 2019; Buchanan and Brock, 1989; Ganzini et al., 2003).

Many researchers, professional groups, and state laws endorse the idea that the threshold level of competence for designating a surrogate should be lower than that required for making medical treatment decisions (Appel, 2023; Kim et al., 2011; Kim and Appelbaum, 2006; Mezey et al., 2000; Moye et al., 2013). When a person completes a legal document pertaining to medical decision-making (e.g., a Living Will, Medical Power of Attorney, Durable Power of Attorney for Health Care, or Advance Care Plan), witnesses are asked only to verify that the person filling out the document is “of sound mind” and not under duress. There is empirical evidence to suggest that people with mild to moderate dementia retain significant decision-making abilities, including the ability to consistently identify persons they want to make decisions for them as well as the ability to understand the role of a surrogate decision maker (Gaubert and Chainay, 2021; Karlawish et al., 2001; Kim et al., 2011; Mezey et al., 2000). A surrogate-decision maker whom the patient chooses is expected to “represent their values, goals and wishes” to the medical team when the patient can no longer speak for him or herself (Levi et al., 2024). In other words, surrogate decision makers act as spokespersons for the patient’s preferences. Informed consent for medical treatment decisions requires that patients understand the medical information being provided to them, reason logically about that information, appreciate the consequences of pursuing or foregoing medical interventions, and that they can communicate their decision, all of which can be difficult for persons with dementia as their disease progresses (Van Duinkerken et al., 2018). Since the cognitive demands for appointing a surrogate are much lower than informed consent for medical treatment, there is good reason to believe that the abilities needed to appoint a surrogate might be preserved even after the patient loses the capacity for informed consent to treatment (Kleinfeld et al., 2019; Sachs, 1994).

At present, however, there are no guidelines or instruments for assessing patients' CDS in the clinical context. Some advances have been made for enrolling persons with dementia into research protocols, where a substantial proportion of people who cannot consent to participate in research retain the capacity to appoint a research proxy (Kim et al., 2011; Swan et al., 2024). Considering this, it may also be the case that many people with dementia who lack the capacity to provide informed consent to medical treatment retain the capacity to appoint surrogates to make their medical decisions.

There are weighty reasons to identify appropriate means for assessing CDS that are both ethical and pragmatic. It is important not to deny patients their voice when it comes to significant health care decisions. Designating a health care surrogate extends a person's autonomy, ensuring that if an individual no longer has the capacity to make medical decisions, a trusted individual can do so on their behalf. Health care teams also demonstrate respect for patients' personhood and personal liberty when they allow patients with capacity to appoint surrogates.

Additionally, identifying patients who lack DMC who nonetheless retain CDS has significant practical implications for health care institutions and families in terms of financial and emotional costs. When patients have not designated a surrogate, it falls upon clinicians and clinical ethicists to identify the surrogate. Often, state laws enumerate a next of kin statutory hierarchy that health care institutions are obligated to follow, but many people do not want their next of kin making decisions on their behalf. Others do not have a living relative willing to make decisions for them. Moreover, many states' hierarchy places multiple people on the same level (e.g., two adult parents or several adult children) without guidance on how to adjudicate disputes between surrogates. These situations often lead to the appointment of a commercial guardian, and this can be costly, time-consuming, and can delay treatment initiation and increase poor outcomes (Moye et al., 2013). The process of choosing a surrogate or going to court can also be stressful and anxiety-provoking for families and caregivers and may result in the appointment of a surrogate that the patient would not have selected while capacitated or with whom they have ongoing conflict (Hirschel and Smetanka, 2022).

A reliable assessment of CDS will be useful to hospitals, long-care facilities, and outpatient clinics that have patients with dementia as they seek to maximize the ability of patients to stay engaged in their care. The population is also aging, with cases of AD expected to reach almost 13 million by 2050 (Alzheimer's Association, 2024). This underscores the need to create more robust mechanisms for promoting ongoing engagement with people with dementia and other cognitive impairments. A well-designed and validated assessment tool would do precisely this, ensuring that patients with capacity are empowered to choose a surrogate whom they trust to make medical decisions on their behalf, even when they might lack DMC for certain medical treatment decisions. If, as we hypothesize, there are some persons who lack DMC but nonetheless retain CDS, clinicians need a way to assess this specific capacity. Failure to accurately assess CDS may result in denying vulnerable patients the right to exercise their autonomy.

The objectives of this pilot study were twofold:

1. Design a survey tool specifically constructed to assess the capacity of participants to designate a surrogate (CDS).

2. Evaluate the CDS Tool, including statistical assessment of its reliability and validity and a robust narrative analysis of the kinds of reasons proffered for surrogate selection.

Method

Research Design

This study employed a mixed-method design that quantitatively evaluates the capacity of participants to choose a surrogate and understand the role of a surrogate and qualitatively evaluates their narrative rationales for their choices (see Appendix 2). In the first phase of the research, we developed and refined the CDS interview scoring tool. The CDS tool developed for this project is based on: (1) a problem commonly described by clinicians and ethicists at our test sites, (2) an assessment type that physicians are familiar with, (3) ethical norms commonly accepted in the medicine (i.e., respect for persons, self-determination, and shared-decision-making) and (4) normative considerations surrounding respect for persons with limited decisional capacity.

Conceptual Framework

The CDS tool was designed within particular conceptual parameters that reflect its underlying conceptual distinctiveness from DMC assessment tools. For example, DMC requires patients to understand a set of medical facts about their condition, various treatment options, and the risks and benefits of each, the risks of forgoing treatment, and how their current medical condition will impact their future (Lo, 2015, 79). Our tool is based on the conceptual framework of Navin et al. (2022), which specifies that an instrument used to determine CDS should be based on two criteria: the ability of a person to express a choice about a preferred surrogate consistently, and the person demonstrates a basic understanding of what a surrogate does.

Unlike DMC, CDS does not require patients to demonstrate a capacity for means-end reasoning about their preferences for surrogates. The selection of a surrogate, on the other hand, “is commonly a matter of affection, of existing relationships, or of identification and trust (Navin et al., 2022).”

Phase 1: Design and Pretesting of the CDS Tool

The research team designed a structured survey instrument with questions clustered into three sections: (1) expression of a choice, (2) knowledge of surrogacy, and (3) rationale (see Appendix 1). The first two sections were scored with ordinal response choices using an assessment rubric (See Appendix 2). Section 1 checked whether the participant could name a surrogate consistently, including the use of a test-retest consistency check separated by 90 seconds of unrelated conversation (see Appendix 1 for more detail). Section 2 asked a series of questions to assess the understanding of surrogacy, including the conditions under which the participant might need a surrogate decision maker, how they would designate a surrogate, and the role and expectations of a surrogate. The third section was designed to elicit narrative rationales for a surrogate selection using the open-ended prompt, “Can you tell me in your own words why you selected [surrogate’s name here] as the person who would make medical decisions for you if you can’t make them for yourself?”

After designing the CDS survey questions and scoring sheet, the research team recorded five mock interviews with actors playing subjects. One researcher interviewed each subject using the CDS tool and recorded the interviews. Then the original interviewer and three additional researchers scored each interview and compared notes. This process led to several refinements of the interview questions, including several additional prompts and explanatory material (see

Appendix 1) and elaboration of criteria (e.g., the difference between “Some” versus “Full” capacity; see Appendix 2).

Phase 2: Recruitment and Data Collection

Participants were recruited from one outpatient clinic and four nursing homes in Waco, Texas, between September 2023 and March 2024. All participants were at least 18 years old, had a clinical diagnosis of ADRD, spoke English, and could carry on a conversation (as determined by a member of the patient’s clinical care team). After each participant’s interview, a researcher asked a member of the participant’s clinical team (either a physician or director of nursing) whether the participant could make any important medical decisions independently. Participants were coded as either having decision-making capacity, if the clinician responded “yes” or not having decision making capacity, if the clinician responded “no.”

One evaluator conducted, audio-recorded, and scored all fifty-two interviews, and a second evaluator independently scored each interview based on those recordings. Both reviewers were blinded to the participants’ decision-making capacity as evaluated by their clinical team. Because people with mild to moderate dementia often have waxing and waning capacity due to the nature of their illness, researchers avoided conducting interviews in the late afternoon and early evening when many people with dementia “sundown.” Raters were blinded to each other’s evaluations. Inter-rater reliability scores were calculated using Kappa (where -1.0 is perfect disagreement and 1.0 is perfect agreement). Differences of means on both individual items and composite measures between the group with DMC and the group without DMC were assessed using one-way analysis of variance (ANOVA). Given that this is a pilot study, the alpha was set *a priori* at .10.

Because this study operated from the presumption, grounded in the normative literature described above, that the kinds of reasoning employed in the selection of a surrogate were not necessarily similar as those employed in treatment decision-making around which most DMC assessment tools had been built, we approached the qualitative data using analytic techniques common to grounded theory and other thematic analysis methods (Charmaz 2014; Lofland, Snow, Anderson, and Lofland 2022; Wasserman, Clair, and Wilson 2009). This allowed for kinds of reasons which could not be forecasted to enter the analysis, nonetheless. Evaluators first wrote down verbatim each subject's response to why they chose their surrogate. Each evaluator then coded these responses line by line using an open-coding strategy where codes were intended to distill the key concepts expressed in the narrative response. The two evaluators then met to raise the codes into axial codes as a liminal step between open coding and categorization (Strauss and Corbin 1998). A second iteration of distillation into higher order categories then ultimately gave rise to three overarching emergent themes motivating participants' surrogate decision rationales: 1) the surrogate's care for and knowledge of the subject, 2) the surrogate's positive qualities, and 3) the relationship between the surrogate and participant.

Results

In all, fifty-two participants completed the interview, and twenty-four declined the interview. Twenty-two of the participants were coded as having DMC ("Yes" in Table 1) and thirty as not having DMC ("No" in Table 1) as determined by their primary care physician, the attending physician, or the director of nursing at their long-term care facility. The median age of our participants was 80, which is slightly younger than the national average for nursing home patients (Lendon et al., 2024), but our sample included clinic patients with a clinical diagnosis of dementia as well. Female participants were slightly overrepresented, comprising 79% of our participants, while females comprise 62% of same-age US adults overall and 69.2% of nursing home residents in the US (US Census 2020; Caffrey et al., 2020). 69% were White, non-Hispanic, (compared to 61.6% in the US population and 74% of US nursing home residents), 26.9% were African American, (compared to 12.1% of the US population and 15.7% of US nursing home residents), and 3.8% were Hispanic (compared to 18.7% of the US population and 5% of US nursing home residents) (US Census 2020; Lendon et al., 2024).[1] Interview times ranged from two to eighteen minutes, with an average time of six minutes and fifty-three seconds.

[Table 1 Demographic Characteristics of Participants]

Quantitative Findings

Analysis of the tool showed strikingly high inter-rater reliability on survey items related to expressing a surrogate choice (section 1) and knowledge of surrogacy (section 2). Kappa statistics on the items in these domains ranged from a low of .709 (p<.001) to 1.00 (p<.001) (Table 2). Further supporting the validity of the CDS instrument, participants who had been judged by their residential institution's healthcare team to lack DMC performed slightly worse on average than those with DMC, as one would expect (see Table 3). Importantly, however, a substantial proportion of those lacking DMC otherwise were able to perform as well as those with DMC in terms of capacity to designate a surrogate. In fact, there was no statistically significant difference between patients with and without DMC in terms of expressing a choice of surrogate and being consistent in that choice.

[Table 2 Interrater Reliability]

[Table 3 Difference of Means Tests]

In terms of understanding the conditions under which one needs a surrogate, the process of designating a surrogate, and a formal and substantive understanding of the role of a surrogate, those lacking DMC scored lower than those with DMC (F-statistic range 5.35 to 24.16; $p<.05$ to $p<.001$) (Table 3). Nonetheless, on every dimension of understanding, the CDS tool identified some participants who lacked DMC, but who nonetheless had full understanding of the need, process, and role of a surrogate.

Qualitative Findings

Overall, 92.3% of participants were able to supply reasons for their surrogate decision. Researchers used thematic analysis to find common themes among responses (Table 4). This section describes the emergent themes related to the reasons for surrogate selection, the constitutive categories that substantiate each theme, and provides representative narrative examples for each.

[Table 4 Emergent Theme and Categories]

Theme 1: The choice was motivated by the surrogate's prior care for and knowledge of the patient. The two primary categories substantiating this theme included 1) having assisted the patient currently or in the past, and 2) knowledge of the patient themselves.

With respect to past and present participation in caregiving, axial codes included helping with medical decisions in the past, helping with caregiving or medical decisions in the present. For example, Participant 49 described how her son had recently taken her to several rehabilitation appointments after she injured her hip. When she was dissatisfied with the rehabilitation therapist, they discussed alternative centers and practitioners. Participant 41 offered that her daughter “picked up all her medications” and “ensured she always had enough adult diapers to get through the day.”

Axial codes comprising the knowledge of the patient included understanding or their medical needs or history, and knowledge of their wishes generally, and knowledge of their medical wishes in particular. Participant 22, for example, pointed out that her surrogate “knows what I can and can’t do” and went on to describe the various physical and cognitive limitations that made her life difficult. Others explicitly stated that they have had conversations about their end-of-life wishes with their surrogate. Participant 52 noted that her chosen surrogate mediated conversations with her physician, and if there is a problem, “he repeats it to me.” Some participants said that their chosen surrogate understood their wishes more generally without specifically mentioning their medical wishes. For example, Participant 44 reported, “She’s my daughter and she knows what I want. She comes to visit, and we talk. She knows a lot about what I like, and I trust her.

Theme 2: The choice was motivated by the surrogate’s positive qualities. When explaining why participants chose their given surrogate, nearly all mentioned positive qualities that the surrogate possessed. Three kinds of primary categories related to positive qualities emerged: intellectual qualities, character attributes, and social role.

Within the general category of intellectual qualities, reasons falling into the subcategories of decision-making capability, intelligence, and knowledge of medicine or healthcare were frequently described. In this category, the most common reason given had to do with the chosen surrogate being a good or capable decision maker in other aspects of their lives. Participants said things like, “she’s good at making decisions” (Participant 3), “he is very capable” (Participant 1), or described them as “level-headed” (Participant 17).

Many participants referenced positive character attributes as they explained why they selected their surrogate. Within this category, subcategories frequently cited included being an assertive advocate, being dependable or reliable, or being caring. As participant 40 put it, "He is always there when I need him." Participant 47 described his reason for choice of surrogate as including "[she's] aggressive for getting things done." Other kinds of reasons included moral attributes such as honesty, wisdom, having a strong moral compass, or religious values. These kinds of justifications included the surrogate being a "Christian" (Participant 11), a "good father" (Participant 32), "compassionate" (Participant 5), and the like.

Finally, for others, the social role their surrogate occupied was important. This included familial as well as occupational kinds of social roles. The latter often intersected with the knowledge category in ways that were difficult to distinguish. Two participants noted that their chosen surrogate was a nurse, insinuating relevant occupational and knowledge justifications. Participant 36 noted that her surrogate "knew everyone in the family from head to toe" and so was the obvious medical decision maker. Others described that their surrogate held another important occupation, such as a teacher or banker. While it was somewhat unclear why such occupations qualified a person to be a medical decision maker, it was clear that they represented some kind of social value to the participant. Some emphasized the relative ages of their surrogates, such as specifically having chosen an older or younger sibling. These also appeared to convey some value associated with the person chosen (beyond the relationship itself, described in theme three). For example, the older sibling may be viewed as a family leader, while a young sibling may be viewed as more physically or mentally capable of caring for older family members.

Theme 3: The choice was motivated by the patient's relationship to their selected surrogate. The primary categories comprising this theme involved 1) availability, 2) emotional bond, and 3) kinship or relation.

Axial codes related to availability included geographic proximity and frequency of interaction. Many chose their surrogate because that person had made themselves available through frequent contact or because the surrogate lived geographically close to the participant. This was a common reason why many subjects said they chose one child or grandchild over another. Participants said things like, "I have three children, but he lives here" (Participant 43) or "He's my neighbor, and I've known him for years and years" (Participant 34). Such reasons are important to an individual's medical team inasmuch as surrogates must be reasonably available to act in that capacity.

Axial codes related to emotional connection or bond included affection, trust, and (emotional) closeness. Participants, for example, articulated trusting relationships with the surrogate or stated straightforwardly that they loved their surrogate. Participant 5 said of her surrogate, "She's the darling of my heart and I trust her with my life." Some participants noted they were very close with their surrogate and could talk with them openly.

Finally, axial codes related to kinship or relation involved not only kinship itself, but the statements about the proximal nature of the kinship relationship (i.e., how closely related they were), as well as how long they had known the surrogate. Many participants chose a surrogate they described as related to them, either biologically or through marriage; only two participants chose a surrogate who was a friend rather than a relative, even though both participants acknowledged they had a living family member. Many described their kinship relationships with their chosen surrogate and often this would be accompanied by a description of the associated quality of the relationship. Participant 15, for example, noted, "she's the only daughter I have, and I see her every day." Ten people noted that the person they chose was their only living family member. Sometimes this was said to acknowledge no one else could make decisions for them, while others insinuated that this was the only living relative who they trusted to make decisions. For example, one participant stated, “he is my only family left,” (Participant 51) while another described, “I only have the one sibling” (Participant 37).

Discussion

If CDS is substantively distinct in its constituent facets from DMC, then we should be able to identify individuals who lack DMC but possess CDS. Our measurement tool for CDS demonstrated interrater reliability (as noted above) and some initial evidence of validity. The former is demonstrated by the high Kappa statistics. The latter is supported by the face validity of the instrument, as well as the structure of the results across subgroups, which, for example, demonstrate lower rates of CDS among those who lack DMC as one would expect. Thus, the initial results of this study suggest that the CDS tool can identify individuals who possess CDS, even when they lack DMC. Indeed, there were some participants who were determined by their healthcare provider to lack decision making capacity for nearly all medical treatment decisions but received a maximum score on the quantitative portion of our scoring tool and were able to supply reasons for their choice of surrogate. This finding is consistent with research that suggests that people with dementia maintain decision-making capacities for some decisions while losing their capacity for other types of decisions, depending upon the complexity and type of the decision, as well as the context of that decision (Kleinfeld et al., 2019).

Our study provides initial indication of reliability and validity, as well as support for the concern that there are people who possess CDS but may be precluded from exercising that right because they lack DMC. This conclusion is supported by other dementia researchers who are concerned that global capacity assessments are not useful in the clinical domain, because they fail to assess decisions in their context and without regard to risk (Amaral et al., 2024; Wilkinson and Flower, 2020) However, important normative considerations about the CDS tool remain. These include:

- identifying a threshold score for CDS
- further interrogating what kinds of understanding are essential for CDS within the healthcare context (e.g., whether understanding that one needs to notify their physician of their surrogate selection is an important feature of the tool within the hospital context, where a physician would likely be conducting the assessment)
- whether understanding the notion of substituted judgment is essential, particularly in cases where patients may reject that standard in favor of more family-centered kinds of views about surrogacy
- differentiating reasonable rationales (which would be indicative of CDS) versus unreasonable rationales (which would be indicative of lacking-CDS)

Along with further validating the instrument in larger and more diverse populations, these kinds of questions will need to be addressed in the normative literature.

This study did not formally ask participants if they already had a legally designated surrogate or whether the person they chose fell outside of the next of kin hierarchy. Texas (where all interviews took place) relies upon a statutory next of kin hierarchy for patients who lack DMC and do not have a legally designated surrogate (Tex. Health & Safety Code § 313.004). The order is spouse, adult children, parents, siblings. Nine of our subjects independently mentioned that they had a living family member within that hierarchy that Texas would give priority to, but they chose a person lower on the hierarchy. For example, two participants said they had sons, but would prefer that their daughter-in-law make their medical decisions. Another four participants mentioned that they would choose one family member over another who were on the same level of the hierarchy. For example, one participant had twin granddaughters but relied upon one over the other to help her with medical decisions. Since most healthcare facilities will ask an incapacitated patient's next of kin to make medical decisions, it is noteworthy that so many of our participants made decisions to appoint a surrogate that did not comport with that hierarchy. Subsequent studies should ask explicitly about other living family members to give a better assessment of how many subjects explicitly choose a surrogate outside of the default hierarchy.

Limitations

This study has several limitations. The sample size was comparatively small, though tolerable for the analyses utilized. Additionally, the scoring system relies to some extent on subjective judgment. While the domains were operationalized clearly for the scorers, there will inevitably be variation in their impressions and, therefore, some variation in their scores. This is not, however, unlike the challenges implicit in other screening tools, including the common instruments used to screen for DMC. Moreover, the double-blind scoring and assessment of the same interview demonstrated high interrater reliability, giving some confidence that when properly operationalized, the constructs in the survey can be reliably assessed by different users

Additionally, researchers did not assess DMC and CDS concurrently but instead relied upon the participant's physician or director of nursing's determinations of DMC. DMC assessments are notoriously fraught, and so there is some risk that these determinations of DMC by which we sorted our analytic groups may be unreliable. Standardizing the DMC assessment and conducting it concurrently with the CDS assessment in future research may attenuate some of these issues. These concerns, however, are mitigated by several factors. First, physicians and nurses are typically legally empowered to determine DMC. Thus, the conditions of our study reflect the real-world conditions under which the tool would be deployed. Second, the clinicians determining DMC of the participants interacted with them longitudinally. They were thus arguably *better* positioned to assess DMC than a single point-in-time measure that we might have deployed for the study itself.

Another limitation of the study was that the interviews were not conducted by a person known to the participant, and so it was not always clear whether a participant did not understand a question or was merely hesitant to answer. In the comments section of CDS scoring tool, evaluators noted six such instances. Similarly, some participants did not want to engage questions of future surrogate decision makers because they currently were able to make their own medical decisions. In some of these cases, it was unclear if they lacked the capacity to imagine such a future or if they simply did not want to discuss the hypothetical. If the researcher had been a trusted clinician, this obstacle may have been mitigated. However, this situation also reflects real-world conditions where those evaluating capacity, particularly in an inpatient hospital setting, are not known to the patient.

Conclusion and Next Steps

One might argue that DMC, while an imperfect proxy for surrogacy selection decisions, is nonetheless sufficient. This is both a philosophical and a practical question. It is philosophical where it suggests there is a tolerable rate of error when it comes to misidentifying a patient's capacity to engage in an activity to which they have a legal and ethical right. It is practical where we might wonder how much error is needed to motivate the deployment of an entirely new screening tool, in light of the costs of doing so (including the time it takes to administer). Additionally, research shows that many clinicians do not know how to assess patients' capacity, and they lack confidence in their capacity assessments (Young and Davison, 2018). These are questions and considerations that reach beyond the scope of this paper, but it seems important to note that deployment of the tool is quick, with the average interview lasting seven minutes, and the costs of provoking surrogacy conflict or court intervention is high.

If the CDS tool can identify any individuals who are capable of selecting their own surrogates, the offsetting savings in terms of time and resources may be quite large. Beyond those sorts of consequentialist calculations, we might remember that underestimating a patient's capacity can have serious repercussions for their independence (Morris, 2020). Inasmuch as selecting one's own surrogate is a right of those with the capacity to do so, assessing CDS might be properly understood as a moral duty irrespective of the cost. Moreover, there is good reason to suspect that family members of people with dementia, even those acting as their caretakers, do not accurately predict their preferences (Dening et al., 2016; Carpenter et al., 2006).

If individuals can lack DMC but possess CDS, then we must have a specific way of identifying the latter. Failure to do so risks the rights of these vulnerable patients to choose their own surrogate, amplifies conflict and distress in clinical situations (particularly during the end of life), and is costly where judicial intervention becomes required. Moreover, involving people with dementia in decision making helps them to feel less marginalized and improves their well-being (Miller et al., 2018; Bonds et al., 2021; Mitoku and Shimanouchi, 2014). Our data suggest that relying on a DMC determination to allow or restrict a patient from choosing a surrogate is not sufficient and our CDS tool appears to be a viable mechanism for amplifying the ability of patients to participate in one of the most critical decisions related to their medical care.

Future empirical and normative research can expand on the work in this study. Future studies should compare scores between people with dementia residing in different types of facilities, compare scores between persons with various stages of dementia or different cognitive assessment scores, or even populations with cognitive limitations beyond dementia. Additional studies could also investigate why patients chose surrogates other than their legal next-of-kin.

Researchers should also consider the threshold score necessary for determining that a patient has CDS as well as which rationales provided are reasonable or unreasonable.

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Conflicts of Interest

We have no conflicts of interest to declare.

Data Availability

This study is not pre-registered. Original data is not available due to IRB and confidentiality concerns. The full survey tool is included in Appendices 1 and 2.

NOTES

1. These statistics closely mirror the racial and ethnic makeup of Waco, TX, where the interviews took place, according to the US census.

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Tables

Table 1. Demographic Characteristics of Participants

Characteristic	Median (Range)	n (%)
Age (years)	80 (64-94)	
Sex		
Female		41 (79)
Male		11 (21)
Race/Ethnicity		
White/non-Hispanic		36 (69)

African American	14 (27)
Hispanic	2 (4)
Location	
Home (Clinic Patient)	11 (21)
Long-Term Care Facility	41 (79)
Decision Making Capacity	
Yes	22 (42)
No	30 (58)

Table 2. Interrater Reliability

Item	Kappa	p
Expressed a choice of a surrogate decision maker at any point during the interview	1.000	<.001
Choice was consistent when revisited. (If multiple surrogates named, patient settled on one and named that person twice)	0.766	<.001
Selected different surrogate at consistency check but was aware of the change and had a rationale.	0.847	<.001
Understands conditions under which they need a surrogate decision maker.	0.709	<.001
Understands how to designate a surrogate decision maker.	0.821	<.001
Formal Understanding	0.800	<.001
Substantive Understanding	0.783	<.001

Table 3. Difference of Means Tests

Item		N	Mean	Std. Dev.	F	p
Expressed a choice of a surrogate decision maker at any point during the interview	No DMC	30	0.90	0.305	2.350	0.132
	DMC	22	1.00	0.000		
Choice was consistent when revisited. (If multiple surrogates named, patient settled on one and named that person twice)	No DMC	30	0.80	0.407	2.634	0.111
	DMC	22	0.95	0.213		
Selected different surrogate at consistency check but was aware of the change and had a rationale.	No DMC	30	0.10	0.305	0.517	0.476

	DMC	22	0.05	0.213		
Understands conditions under which they need a surrogate decision maker.	No DMC	30	0.83	0.791	13.252	<.001
	DMC	22	1.59	0.666		
Understands how to designate a surrogate decision maker.	No DMC	30	1.07	0.828	2.737	0.104*
	DMC	22	1.41	0.590		
Formal Understanding	No DMC	30	1.03	0.928	9.754	0.003
	DMC	22	1.73	0.550		
Substantive Understanding	No DMC	30	0.73	0.640	11.055	0.002
	DMC	22	1.55	0.510		
*Mean difference was significant on this item for Reviewer 2						

Table 4. Emergent Themes and Categories

Theme 1: Choice motivated by the surrogate's prior care for and knowledge of the subject	**Theme 2: Choice motivated by the surrogate's positive qualities**	**Theme 3: Choice motivated by the relationship between the subject and surrogate**
Past or Present Assistance	*Intellectual Qualities*	*Availability*
- Helped with medical decisions in past	- Capable decision-maker	- Geographically close
- Helps with current decisions/caregiving	- Intelligent	- Frequent interactions or contact
Knowledge of the Subject	- Knowledge of medicine/healthcare	*Emotional Bond*
-Knows subject	*Character Attributes*	- Emotionally close
- Understands medical needs or history	- Assertive/advocate	- Affection for surrogate
- Knows subject's wishes	- Dependable or reliable	- Trusted
- Knows subject's medical wishes	- Caring	*Kinship/Relation*
- Know subject's abilities	- Responsible	- Only living kin

	- Available	- Close kin relation
	- Moral person	- Kin relation
	- Religious values	- Long-time acquaintance
	- Honest	
	- Good listener	
	- Wise	
	- Mature	
	Social Role	
	- Occupation (implied intelligence, education, or social status)	
	- Healthcare worker	
	- Older	
	- Family leader	
	- Younger	

Appendix 1

Capacity to Designate a Surrogate Interview Questions

Section 1A (Expression of a Surrogate Choice)

"I'm going to ask you some questions about who might make medical decisions for you if you were not able to make them for yourself. "

A. "Is there someone you would like to make medical decisions for you if you were not able to make them for yourself?"

Section 2 (Knowledge about Surrogacy)

A. Can you tell me why you might need someone to make medical decision for you in the future?
    a. Follow-up prompts if necessary:
        i. What sort of things might come up that would make it necessary for someone else to make your medical decisions for you?
        ii. What might happen that would make it so that you need someone else to make decisions for you?

B. Once you decide on who your surrogate (decision maker) is, who would you tell that choice to?
    a. Follow-up prompts if necessary:
        i. What might you need to tell them about your choice?

C. Can you tell me what your decision maker would do?
    a. Follow-up prompts if necessary:
        i. What kinds of decisions would this person make?
        ii. How would the person you selected go about making those decisions?

*If the patient is unable to articulate a valid response to any of the above items, please provide the explanations below. Afterward, please revisit the questions above that they previously could not answer and reassess. Then proceed to the next section.

Explanatory material (if necessary):

- Sometimes, when people are not able to understand their medical conditions, or are not able to think clearly enough to make decisions, they select someone who can do that for them. This person is called a 'surrogate'. ***(*Have you ever heard of that?)***
- A surrogate decision maker should be someone who understands what you would want to do in different situations, so that they can make the same decisions you would have made. ***(*Does that make sense?)***
- This person will have the responsibility for making most, if not all, of the medical decisions that you can no longer make. ***(*Have you ever talked about this with someone?)***
- To designate a person to make decisions for you, you should tell your physician or another health care provider and ask them to document that in your medical record. You should also tell the person you chose that you want them to make medical decisions for you in the future. ***(*Does that make sense?)***

Section 1B (Consistency)

B1. Who would you like to make medical decisions for you if you are not able to make them for yourself?"

- If the person named in response to this question is not the same as the person originally named, then proceed with the following questions:

C1. "So, have you changed your mind from before about [person originally named]? Can you tell me why?"

Time delay (use any of the following):

- Can you tell me a little bit about your condition?
- Can you tell me a little bit about yourself?
- Can you tell me where you grew up?

After at least 90 seconds have passed:

B2. "Can you tell me again, who you would like to make medical decisions for you if you are not able to make them for yourself?"

- If the person named in response to this question is not the same as the person originally named, then proceed with the following questions:

C2. "So, have you changed your mind from before about [person originally named]?"
[If yes,] "Can you tell me why?"

Section 3 (Rationale)

“Can you tell me in your own words why you selected [surrogate’s name here] as the person who would make medical decisions for you if you can’t make them for yourself?”

- a. Follow-up prompts if necessary:
  - i. Why did you pick [surrogate’s name]?
  - ii. What do you think will make [surrogate’s name] a good decision maker for you?

Appendix 2
Capacity to Designate a Surrogate Scoring Tool

1. EXPRESSION OF A CHOICE			
	Item	**Score**	**Notes**
A	**Expressed a choice of a surrogate decision maker at any point** during the interview	0 No 1 Yes	
B	**Choice was consistent when revisited.** If multiple surrogates named, patient settled on one and named that person twice	0 No 1 Yes	
C	**Selected different surrogate at consistency check but was aware of the change and had a rationale.**	0 No 1 Yes N/A (B=1)	

2. KNOWLEDGE OF SURROGACY			
	Item	**Score**	**Notes**
A.	**Understands conditions under which they need a surrogate decision maker**. • Some: names only 1 scenario • Full: names at least 2 distinct scenarios (ex. fully unconscious, confused)	0 No 1 Some 2 Full	

B	**Understands how to designate a surrogate decision maker.** • Some: knows to tell EITHER health care team OR surrogate OR wants to tell others WITHOUT a clear rationale • Full: knows to tell BOTH health care team AND surrogate OR wants to tell others but WITH a clear rationale	0 No 1 Some 2 Full	
C	**1a. FORMAL UNDERSTANDING** • Some: Understands surrogate will make decisions but does not connect decisions directly with healthcare or medicine makes vague comments that may or may not be medical (ex: “decides if I live or die”) • Full: Understands surrogate will make medical decisions or mentions a nursing home or other health care facility in connection with decisions	0 No 1 Some 2 Full	
	1b. SUBSTANTIVE UNDERSTANDING • Some: Understands surrogate will make decisions based on what the surrogate thinks is good for them but does NOT reference what the patient herself would have wanted (ex: “decides if I live or die”) • Full: Understands surrogate will make decisions based on what the surrogate thinks is good for them and what the patient herself would have wanted	0 No 1 Some 2 Full	

3. RATIONALE

Notes:

Distillation of Reason to around 6 words: