

Kate Robins-Browne, Kelsey Hegarty, Marilys Guillemen, Paul Komesaroff, and Victoria Palmer, "The Role of Relational Knowing in Advance Care Planning," *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 122-34.

The Role of Relational Knowing in Advance Care Planning

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ABSTRACT

Medical decision making when a patient cannot participate is complicated by the question of whose voice should be heard. The most common answer to this question is that "autonomy" is paramount, and therefore it is the voice of the unwell person that should be given priority. Advance care planning processes and practices seek to capture this sentiment and to allow treatment preferences to be documented and decision makers to be nominated. Despite good intentions, advance care planning is often deficient because it is unable to facilitate a relational approach to decision making in cases when the patient's competence is reduced. In this article we present findings from a study of the ways in which older people and their significant others understand decision making in such circumstances. Critical to the participants' understanding was the emergent concept of "relational knowing," a concept that is poorly articulated in the advance care planning literature. Our findings suggest that the dominant understanding of decision making in

conditions of impaired competence is incomplete and obscures much of what matters to people. We conclude that, having recognized a broader set of ethical concerns, it is necessary to develop a relational and narrative based approach that applies in appropriate settings.

INTRODUCTION

The question of how to facilitate medical decision making when someone's ability to participate is diminished or absent has long been a cause of perplexity in the bioethics literature. The issue hinges largely on whose voice should be heard, and is commonly connected with the protection of "autonomy."¹ Documentation of treatment preferences, through written directives and nomination of preferred surrogate decision makers through enduring medical powers of attorney documents, are ways to

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protect autonomy by ensuring the unwell person continues to have input into decisions. This approach, often referred to as “advance care planning,” is widely promoted as a solution to the problem of decision making when an unwell person’s competence is diminished.

Advance care planning has been utilized in the United States for more than 40 years,² and in the past few decades has also gained traction in the United Kingdom³ and Australia.⁴ It is popular because it provides a response to the challenges faced by patients, families, and healthcare professionals in circumstances when an unwell person cannot fully participate in decision making. The approach has increasingly been seen as central to “ethical care” in such settings. However, advance care planning rests on a particular ethical framing of decision making in conditions of incompetence that gives precedence to the concept of autonomy, and therefore to particular definitions of how competence and incompetence are perceived and enacted in medical settings, and this framing is often not clearly recognized. This unexamined assumption, which underlies advance care planning theory and practice, creates an ethical tension that requires critical examination.

Advance care planning is underpinned by the ethical theory known as the principle-based perspective or “principlism.”⁵ Viewed from the perspective of principlism, being unable to decide (often referred to as “incompetence”) is a threat to “autonomy” (itself narrowly conceived) that is best addressed by efforts to retain control over decision making by affected individuals. The approach of principlism suggests an individualized conception of personhood in which identity is conceived (albeit perhaps unintentionally) as independent of one’s relationships. From this perspective, a person’s identity and interests are considered separate from those of her or his loved one, and to know what the other person would want depends upon that person’s having engaged in purposive and specific communication regarding her or his preferences. As a result, formal documentation of the intentions and desires of an individual is seen as superior to decisions made on his or her behalf by a surrogate. Documentation is preferred because it is seen as transparent and objective evidence of the unwell person’s preferences, whereas there is a concern that a surrogate could conflate her or his own interests with the patient’s interests and make decisions that reflect the surrogate’s preferences alone. This individualistic notion of personhood constrains the roles of significant others, excludes discretionary decision making, and re-

duces the ideal surrogate to no more than a conduit for the patient’s wishes.

Empirical research has raised questions regarding the principle-based construction of “relationships” and “knowing” and the roles assigned to the surrogates. Individuals and their surrogates often indicate that a surrogate’s decision-making role is an extension of the surrogate’s broader caring role.⁶ Furthermore, a surrogate’s knowledge of the unwell person evolves, as the person moves from merely being unwell to actually dying. A surrogate obtains knowledge of a loved one’s preferences through multiple means, including hearing, seeing, and interacting with the person.⁷ This more complex conceptualization of a surrogate’s role and of the ways that a surrogate can come to know a loved one’s preferences is not readily accommodated either by principlism or by advance care planning approaches that are founded on principlism.

In this article we provide further evidence of the limitations of current advance care planning approaches and the emphasis on autonomy, showing how together they undervalue the importance of relational knowing. We argue that what matters to people when they think about future debility is not so much the question of determining their preferences, but rather knowing who will decide and how this will be respected, encapsulated in the term “relational knowing.” Our findings emerged from a study that explored how older people and their significant others understand decision making when the former cannot participate. Since advance care planning is fundamentally concerned with decision making, how people understand this and what matters to them when they imagine being unable to decide requires detailed examination. Our findings reveal the centrality of the concept of relational knowing to people’s understandings of decision making when reduced competency is experienced, and highlight the need for alternative ethical approaches to decision making.

Current Ethical Framing of Advance Care Planning

The substantial body of empirical research regarding advance care planning has largely focused on issues such as barriers and facilitators to advance care planning, the accuracy of decisions made by surrogates, and the impact of advance care planning approaches.⁸ Most studies have taken for granted the relevance and applicability of the principle-based approach in framing the problem.

The most contentious and vigorously debated aspect of the principle-based approach is the concept of “respect for autonomy.”⁹ Respect for auto-

my has a central role in bioethics both because autonomy is considered a good in itself¹⁰ and because the freedom to choose is often seen to give meaning to a person's life.¹¹ Within healthcare, people who are described as being "autonomous" are assumed to possess a degree of freedom that is not available to those who are deemed to be non-autonomous.¹² While an autonomous person is free to accept or refuse medical treatment, a person who is non-autonomous, or "incompetent," is perceived as being in a more precarious position in which treatment decisions might be made without the person's involvement and might not accord with her or his wishes. This is one of the key problems that advance care planning is intended to address.

The principle-based approach to conditions of incompetence consists of a three-tier hierarchy in which a patient's documented preferences take precedence over all else, followed by adoption of his or her undocumented specific and relevant preferences, and, finally, if specific and relevant preferences cannot be established, his or her putative "best interests."¹³ A surrogate's emotional attachment to the patient is considered to be problematic, and therefore the surrogate's involvement is restricted, and healthcare professionals are encouraged to monitor the surrogate's decision making.¹⁴ Advance care planning programs propagate this view by encouraging people to think that if an unwell person has not explicitly communicated her or his wishes, then loved ones will not know what the person wants, implying that, if surrogates are allowed to use their own judgement, they will invariably make poor decisions.¹⁵

Limitations on discretionary decision making by surrogates are justified, in part, by the numerous empirical studies that have concluded that surrogates do not consistently predict the patient's preferences.¹⁶ Yet multiple empirical studies have failed to demonstrate that surrogates' accuracy is improved by access to patients' advance directives or by prior discussion of patients' preferences.¹⁷ It is also assumed that people want and expect their surrogates to replicate their exact preferences, which is, again, contrary to the evidence of numerous studies that have found that a large proportion of people do not want their surrogates to adhere strictly to their documented preferences.¹⁸ Indeed, several studies report that both patients and surrogates see the surrogate in broader terms as someone who is close to and cares for a person in need,¹⁹ and that when people consider their own future incompetence, they are concerned at least as much with protecting their loved ones as with their own autonomy.²⁰

METHODS

Study Population and Design

A qualitative study was conducted that included older people and, when possible, their significant others. "Older people" were aged 65 years or over, and lived in the community. Older people were excluded if they were terminally ill or receiving palliative care, if they resided in a residential aged care facility, if their general practitioner felt their competence was reduced to an extent that would prohibit participation, and if their general practitioner believed they did not speak English well enough to allow them to participate in an interview. "Significant others" were nonprofessional people identified by the older people as those whom they thought would be involved in decision making if they experienced reduced competence and became unable to participate in making decisions.

Recruitment was guided by a sampling frame that included the variables of age and gender, identified by three prior literature reviews as having an effect on preferences regarding involvement in decision making when competent.²¹ Within the frame, we sought maximum diversity of participants by purposively selecting people with different religious backgrounds, socioeconomic backgrounds, and marital status, when possible.²²

Recruitment began with a convenience sample recruited by a research assistant who approached people in the waiting room of a single general medical practice located in a major city in Australia. Reception staff identified all those aged 65 years and older. The research assistant provided these people with written information regarding the project and scheduled a tentative time for an interview. The first author made follow-up phone calls confirming the participants' willingness to be interviewed. The research assistant approached 10 potential participants, eight women and two men, all of whom agreed to be interviewed.

The sample was extended through a purposively designed survey to examine knowledge of and attitudes towards advance care planning. This was mailed from five general practices located in the same Australian city, with one general practitioner from each practice participating. A list of all of the patients aged 65 years and older who had attended this practitioner in the last year was generated by the practice, and the list was reviewed by the general practitioner to exclude participants who did not meet the entry criteria. If fewer than 200 names remained, all of these people were sent a survey; if more than 200 names remained, the names were ran-

domized, and the first 200 were sent the survey. The survey was mailed to 445 people; 230 returned completed surveys (a 52 percent return rate), with 100 of the 230 respondents expressing interest in an interview. The first author reviewed the returned surveys to determine which of the respondents would best diversify the existing sample. In particular, we sought more male participants, participants aged between 65 and 74 years, and participants who indicated that they did not have a significant other. We selected 14 potential participants. The first author telephoned these people to explain the project and ascertain their interest in an interview. Four never answered the phone, one appeared confused, and one's daughter refused on his behalf, leaving nine additional participants.

Significant others were recruited through the older participants, who were given a written invitation to pass on to the significant other. Approximately a week after the interview, the older people were contacted to establish if they had passed the form to their significant other and if the significant other had indicated an interest in further information. Significant others could also return a form directly that expressed their interest in participating.

Interview Procedures

All interviews were conducted by the first author. Interviews were semi-structured and explored the older participants' past and present health, experience of medical decision making for self and others, and their understanding of decision making when reduced competence might be experienced. All but one interview was conducted face-to-face. The interviews were audio recorded and transcribed verbatim. The first author transcribed the first 10 interviews, with the remainder being transcribed by a professional transcribing service. All transcripts were checked for quality and accuracy against the audio files. Interviews with older participants averaged 55 minutes in length (range 22 to 92 minutes), and interviews with significant others averaged 61 minutes in length (range 51 to 72 minutes).

Ethics approval was granted by the University of Melbourne Human Research Ethics Committee. In what follows, participants are referred to by self-selected pseudonyms and their ages; all other potentially identifying information has been removed.

Analytical Procedures

The analysis was informed by our need to gain an appreciation of the breadth and complexity of people's understandings of decision making when an older person cannot participate. It began with an

inductive analysis using the *Listening Guide (LG)* developed by Gilligan, Brown, and colleagues,²³ which was extended by a theoretical analysis following Walker's²⁴ and Nelson's²⁵ concepts of moral self-definition.

The *LG* was originally designed for analysis of narratives regarding real-world moral decision making,²⁶ so it appeared to be a suitable method for looking at the central topics in the interviews. The *LG* involves four analytical steps: (1) listening for plot, which includes a reflexive response; (2) creating and analyzing "I-poems"; (3) listening for contrapuntal voices; and (4) generating a summary.²⁷ The first step familiarizes the researcher with the participant's story and encourages the researcher to acknowledge his or her own subjectivity.²⁸ The second step allows the researcher to hear the participant's voice and changes in this voice over the course of the interview.²⁹ The third step draws attention to the multiple voices expressed by a single participant. Because the *LG* explicitly acknowledges that these voices can be in harmony or conflict with one another, it avoids the need to hear, and present, a single harmonious story.³⁰ The final step turns the researcher's attention back to the research questions and the broader context in which people's stories take place.³¹

Overall, the I-poem analysis enabled an examination of identity information expressed by participants, in particular, what was termed "health-related identity," but it did not get to the heart of decision making. Thus, we applied the theoretical framework of moral self-definition to better understand and illuminate the relationship between identity and decision making.³² Moral self-definition legitimizes particularity and partiality in moral reasoning, in contrast to the emphasis placed by mainstream bioethical approaches, including principlism, on objectivity and partiality.³³ It also highlights the extent to which decisions are tied to, and arise from, identity-related experiences and questions, rather than being the product of purely rational analytical analysis. This combined methodological approach provided insight into the connections between decision making and identity for these participants.

Moral Self-Definition Explained

Hilde Lindemann Nelson described three forms of moral self-definition: "non-moral," "weak moral," and "strong moral."³⁴ Non-moral self-definition occurs when a person identifies an attribute as part of his or her identity without attaching any moral weight to it: for example, a person might describe him- or herself as left handed without providing

further explanation or seeming to attach significance to the description. Weak moral self-definition takes place when a person recognizes certain general moral precepts without individualizing them: for instance, a person might explain her or his actions by stating “it is wrong to lie” without personalizing this adage or indicating that honesty is integral to his or her moral identity. By contrast, strong moral self-definition occurs when a person uses backward-looking stories to review her or his values, affirms or rejects these values, and then presents a forward-looking story guided by the values that the person has affirmed.³⁵ Strong moral self-definition requires that a person recognize certain values as essential elements of her or his moral identity, so that to act contrary to these values would damage the person’s identity. Decisions made in accordance with strong moral self-definition oblige a person to undertake certain future actions and decisions, because it is only by living the values the person has affirmed that the person can demonstrate commitment to them. For example, a person with an unwell family member might elect to take time off work to care for the relative, on the grounds that the person has consistently prioritized family over work, but for this to constitute strong moral self-definition, the person would actually have to provide the care.

RESULTS

Participants’ Characteristics

The final sample consisted of 19 older people (seven men and 12 women), ranging from 65 to 93 years old, and six significant others (all female). Five of the significant others were the child of a participating older person, ranging in age from 39 to 44 years, and one significant other, aged 68 years, was married to an older participant. The findings presented below pertain to both the older people and the significant others, except when otherwise stated.

Relational Knowing

The participants’ understandings of decision making when the older person could not participate involved the interweaving of three major themes. These were the role of significant others, the role of documentation, and the role of the doctor. Underpinning all of these themes was the concept of relational knowing.

The inductive analysis resulted in the discovery of relational knowing as an important concept. Relational knowing was described as a feature of long-standing relationships, as implicit and explicit, and as dynamic. It could be evident in any relation-

ship and was not limited to family members: for example, some people talked about the importance of being known by their family doctor. Relational knowing was, however, the crux of the relationship between the older person and the significant other, and, for many participants, constituted the basis of the significant other’s authority. In part, this was related to the duration of the relationship between the older person and the significant other, which, even in the presence of conflict, had a long history and the possibility of a shared future.

Relational knowing was commonly described as implicit. For example, in speaking about health-related decision making, Anthony (73 years) said, “When you’re living closely with somebody and you’re deciding on a major issue and you discuss it and you come to a conclusion, you know instinctively whether you have their support.” Here, relational knowing rests upon an “instinctual” sense of being supported and the way people come to know one another over time. Similarly, Casey (74 years) said, “I expect J [partner], after 20 years of looking after one another, to see that I get to a hospital and that I’m reasonably well looked after.” Casey’s confidence in her partner was informed by an overarching assessment of their relationship as one of mutual care and by specific experiences such as the kindness and respect with which her partner had treated Casey’s father during his final illness. She said, “I live with a lady who was very fond of my father and she could see him suffering. He was living in a hostel, and he was a great walker, and he was very upset at having things wrong with his feet and he didn’t want to be a burden. And it was she, not the doctor, that confronted him with the idea, ‘Do you want to have treatment? Did he want to have the treatment or did he just want to be left in peace?’”

As well as evolving from an instinctual understanding over time, relational knowing was also described as dynamic and responsive to changes within relationships. For example, in the case of Elizabeth (42 years), a significant other for Pam (75 years), there was an indication that their relationship had improved over the years: “She’s a lot easier in the last 10 years to manage, but also in the last 10 years or so I’ve matured a fair bit.” By contrast, Judy (68 years) described how the relationship between her husband (Ernie, 68 years) and their daughter had deteriorated over the years, so that the daughter who once “idolized” Ernie was now estranged from both of them. Similarly, Claire (40 years) said that her brother and her mother (Ada, 70 years) had been “Really close, but he has distanced himself from a lot of people in his life.” Relational knowing was

diminished in relationships that had become more distant, in that the significant other was believed to have less insight into what mattered to the older person. It was assumed that involvement in decision making would be proportionate to the quality of the relationship between the older person and the significant other. Thus, Claire believed that her brother would not play a major role in decision making for Ada, because he had decreased his involvement in her life, and this meant he knew less about what she was experiencing, and hence what she would want. Similarly, Ernie and Judy both stated they no longer wanted their daughter involved in decision making.

The concept of relational knowing was central to the participants' understanding of the significant other's role and the role of documentation. This article focuses on these aspects of the participants' understanding. The doctor's role, which was complicated by the participants' desire for involvement in decision making, is only touched upon.

The Significant Other's Role

Within the relationship between the older person and the significant other, "knowing" was described as reciprocal, in that the older people believed they knew their significant others, and their significant others knew them. The older person's knowledge of her or his significant other was crucial to the person's confidence in the significant other's ability to perform that role. For example, Joe (78 years) said that he had formally nominated his son as his surrogate decision maker because "He's strong enough to [decide], he's quite as pigheaded as I am." Similarly, Ethel (80 years) described her family as "wonderful," and, as a result, she was confident that even if she were unable to participate, she would be "well nurtured in every way."

The older people indicated that a significant other's character could be inferred from past behavior. As discussed above, Casey (74 years) expressed this when she spoke of her partner's past behavior towards her father, and other participants, such as Nancy (78 years), shared these ideas. Nancy reported that when her daughter visited she would surreptitiously check what washing was on the line and whether there was milk in the fridge, which Nancy interpreted as a sign that her daughter cared for her and would take care of her should the need arise. In some cases, a significant other's prior behavior undermined the older person's trust. For example, Ernie and Judy (both 68 years) said that their daughter's past decisions had eroded their confidence in her decision making and her character, and as a result

they did not want her to be involved in decision making.

Like the older people, the significant others saw their individual characteristics as aiding or hindering their ability to perform the role of significant other. Thus Rosie (39 years) believed her history of active engagement in decision making and her ability to articulate her opinions meant she would be a good significant other. Similarly, Claire (40 years) explained that she and her sister Jan (44 years) were able to act as their mother's significant others because they liked to "talk things through," whereas their siblings did not "communicate very well."

Significant others were seen as knowing the older person. This encompassed knowing of the older person's past experiences, knowing his or her values, and knowing the person holistically. Knowledge of past experiences was important to the older people because their preferences, the product of their lived experiences, were seen as more genuine than preferences that arose from abstract considerations. Therefore, knowledge of influential experiences was believed to facilitate recognition of the authenticity of a person's preferences. The long-standing nature of the relationship between the older person and the significant other meant that the significant other had often shared experiences that shaped the older person's understanding. A distinction was made between being present during formative experiences and hearing about them after the fact.

The importance of shared experiences was demonstrated by Mary (73 years), whose preferences were heavily influenced by her mother's final years, and who placed particular emphasis on her significant other's knowledge of these events. Mary had completed a written directive, but she was unsure if it "would make any difference," as she viewed a directive as readily dismissed by someone who was unaware of the experiences that informed it. By contrast, she had great confidence in her significant others because they had been present during these events: ". . . anybody who knows me would realize that there's no way that I wish to be preserved as a shell, I don't think that would ever come up. I have been too outspoken with my family and they know exactly how I had to cope [with my mother's illness]. So I don't think there would be any doubt that they would keep me as a shell."

Other participants shared Mary's respect for knowledge of an older person's past experiences. For instance, Claire (40 years) said that even though her mother (Ada, 70 years) had never "come straight out and said" what she wanted, she had picked up "bits and pieces," particularly regarding Ada's response

to her own mother's time in a nursing home. Similarly, Jazz (41 years) said that if she were acting as her mother's (Jenny, 66 years) significant other, she would be influenced by the conversations they had after Jenny's mother-in-law developed dementia and entered residential care. Of note, Jenny indicated that if she were unable to participate in decision making, she would expect her family to reflect on this experience.

Knowledge of the older person's values was another important element of the significant others' knowing of the older person. Participants indicated that there is often a commonality of values between people in intimate relationships, and that a person's values could be inferred from how they lived. Casey (74 years) expressed the former understanding in speaking about her partner and her partner's family: "Their values are the same as mine." She went on to say, "The people you love have a similar standard to the one you have." Similarly, when Jazz (41 years) was asked how she would know what her mother (Jenny, 66 years) would want, she said, "Just from knowing her so long, just the relationship we have, her values have sort of become our values."

Casey and Jazz spoke of values that are known because they are held in common; however, other participants believed values could be known even if they were not shared. Elizabeth (42 years) said that even though she and her mother (Pam, 75 years) had "opposite" religious values, if she were required to act as Pam's significant other, she would "continue the process of how she [Pam] has lived, the way she likes to do things, because I think that would be better for her." Elizabeth indicated that her knowledge of Pam's values was the product of "the relationship you have built up with her [Pam] as well, like a daughter, but [also] as a friend." During her interview, Pam stressed the importance of her religious beliefs and her desire to live in accordance with these, suggesting that Elizabeth was correct in her estimation of what mattered to Pam.

The participants also spoke of a holistic knowing that occurs within intimate relationships. This was informed by knowledge of a person's experiences and values, but also by the passing of time. Anne (93 years) captured this when she said, "I think my son knows me well enough to know what I would want." She did not describe this knowing as the product of specific past experiences or known values, but as the result of a relationship that had endured a lifetime. Similarly, David (66 years) said, "I believe they [family] know me well enough to actually make a decision that they believe I would make if I was well." Interestingly, David's daughter (Rosie,

39 years) did not think she knew David's specific preferences, but she believed she knew how he would want the decision made. She explained that this knowledge was informed by his response to decisions she had made for her own health:

I feel like intuitively I know that [how David would want decisions made]. And I think it's probably as a result of me discussing with him how I've made decisions about other things. I have actually personally had a health crisis and so I guess along that journey I shared with my parents the ways in which I was making decisions about having treatment and in some instances not having treatment. And so I think there are elements in that process where I have a sense that my dad really respected the way that I was making those decisions and the decisions I made, but I also have a sense that there were some decisions that I made that he was not comfortable with. I think that I have perhaps a more radical approach than what he does and I would definitely be taking that into account.

The emphasis the participants placed on knowing an older person's past experiences and values, and on knowing the person holistically, informed the way they approached documentation. Because documentation is official and seemingly objective, it is the cornerstone of advance care planning. But viewed through the prism of relational knowing, documentation takes on a different appearance.

The Role of Documentation

The participants described documentation both as beneficial, as it allowed them to retain control over decision making and lessened the significant others' burden, and as problematic. Documentation was valued by older participants who wished to retain control of decisions. For example, Anthony (73 years) spoke of his written directive "as far as I can go in controlling my own destiny." Anthony trusted his own assessment of what was right for him, and he saw his preferences as fixed and certain: "There's no way that I would change my mind." Older participants who wished to retain control over decision making still expressed relational concerns. For instance, as discussed above, Mary (73 years) had firm preferences regarding her future treatment and had documented them, yet she also believed that the people who understood the events that informed her documented preferences were more likely to respect those preferences.

Documentation was also seen as potentially beneficial by older participants who wanted to lessen

the burden placed on their significant other, an outcome that could be achieved in two ways. First, some believed that outsiders, including doctors, would view documentation as objective evidence of their significant other's right to involvement and grant them surrogate decision-making authority. For example, when Susan (86 years) debated the merits of completing a power of attorney, she said, "I appreciate that in the long run it's easier for them [daughters] if they can present something nominating them as authorized to make the decisions." Second, some thought their significant other would be comforted by a written directive. These participants viewed documentation as guiding, rather than as binding. For instance, even though Ethel (80 years) had completed a written directive, she said, "They [the family] know if I'm not able to make a decision they make it for me and I know it'll be right."

Documentation was seen as problematic in three distinct ways. First, there were those who thought that formally nominating someone as a surrogate decision maker constituted an undue burden. Thus, although Susan (86 years) thought formally nominating her daughters might ease their interactions with outsiders, like healthcare professionals, she was also concerned that it conferred a "very, very great responsibility" that might be unduly onerous. Second, there were those who were concerned about the fixed nature of documentation. These participants viewed their preferences as fluid and changeable. For example, Bridget (77 years) said that although she would prefer to avoid life-prolonging treatment, she was reluctant to document this preference because "I might say that now, but when the time comes for me to shuffle over the other side I might change my mind."

Finally, there were those who were concerned that documentation could disrupt relationships and existing patterns of decision making. For instance, Rosie (39 years) spoke of decision making for her father (David, 65 years) as "very important" to her, and she tied her role in decision making to her identity within their family and to her relationship with David. Rosie thought a written directive might be a "fracturing document" in that her brother would see a directive as "factual," and seek to strictly adhere to it, whereas she would rather make decisions by "drawing on past conversations and impressions." David echoed this sentiment, explaining that Rosie's role would be greater than his son's because "she's the one that my wife talks to, that I talk to, about any health issues."

Documentation mattered more to participants like Anthony (73 years) and Mary (73 years) who

sought more control over decision making. Older people's desire for control over decision making was related to their understanding of the doctor's role in making decisions about their care.

The Doctor's Role

The doctor's role was complicated both by the extent to which participants wanted and expected to be involved in decision making, and by whether the doctor was known, such as their family doctor, or unknown, such as an intensive care specialist. Participants who expected the doctor to take responsibility for making decisions assigned less importance to the role of values in medical decision making and were therefore less concerned with being known by the doctor. By contrast, participants who wanted information and guidance from the doctor consciously recognized the need to weigh medical advice about risks and benefits in the context of what mattered to them, which meant they were uncomfortable with the idea of a doctor who did not know them making a decision without input from their significant others. Some participants saw the family doctor as having a distinctive role conferred by their knowledge of the person as a whole and the relationship they had built.

DISCUSSION

Our findings indicate that relational knowing is central to the understanding of decision making in reduced competence. The current emphasis on the problem of autonomy obscures the importance of relational knowing and the complexity with which people approach end-of-life decision making. When relational knowing is overlooked, the ethical terrain around advance care planning becomes curiously flat. The goal becomes that of protecting autonomy; enactment of prior wishes becomes the means by which this is achieved; and a stranger equipped with a written directive becomes as qualified (or more qualified) to undertake this role than an unwell person's loved ones. When relational knowing is accorded its proper place, a more nuanced topography of decision making in impaired competence becomes apparent.

Relational knowing arises from an understanding of identity as formed and maintained within relationships. In this case, persons whose competence is impaired are less autonomous, but they also have a limited capacity to sustain their relationships, and therefore their identity, which is supported by their relationships. This is consistent with Lindemann's assertion that the real role of significant others is

not to preserve unwell persons' autonomy, but to hold onto their identity.³⁶ From this perspective, surrogates are not people who convey static preferences, but are people who use their knowledge of an unwell person, as a unique individual, to make a decision that is both contemporaneous and meaningful. Decision making in such cases is a form of ethical work that is best performed by people who know and are emotionally engaged with the unwell person.

Relational knowing draws attention to the importance of the process of decision making. Advance care planning seemingly resolves the question of process, as it implies that the only voice that matters is that of the patient, as captured by documented preferences. By contrast, relational knowing suggests not only that significant others' voices matter, but that hearing the significant others enables health-care professionals to hear the patient's voice more clearly.

The dominant model of decision making in settings of diminished competence emphasizes the point in time at which a decision is made; whereas relational knowing highlights that decisions are not about moments in time or specific preferences, but are about what has gone before, and what will come after. Relational knowing draws attention to the idea that significant others have to be able to live with their decision. Thus the older participants recognized that there are times when it may be difficult for family members to let go of a loved one, as a result of which they may opt to prolong a course of treatment; however, the older participants were willing to endure this because they saw themselves as having an ongoing interest in the well-being of their loved ones. This form of knowing also acknowledges that decisions can deeply affect relationships between significant others and the way they see themselves and their relationships with their older charges. These factors form part of the forward-looking story that might shape decision making.

Recognition of the relational complexity of decision making highlights the need for a more nuanced conception of the ethical responsibilities of decision makers. It is possible to deal with the autonomy of a person, in the individualistic sense implicit in principlism, while remaining detached from the person. Indeed, the principle-based approach to persons with diminished competency actively encourages purely rational and intellectual decisions, from which emotions are rigorously excluded.³⁷ By contrast, virtually all of the participants in this research recognized that unwell persons are vulnerable, not only to having their will disregarded,

but to relational abandonment. To guard against this, they understood that it is necessary to acknowledge it, and to respect the relationships that sustain them. In this approach, ethical decisions can be both respectful of an unwell person's autonomy and caring; they can involve both emotional work and a willingness to view unwell people as specific, concrete individuals.

Advance care planning relies heavily on a principle-based understanding of decision making in reduced competence, which itself is underpinned by an individualistic notion of identity. Feminist ethicists have challenged the individualistic image of identity, arguing that identity is inherently relational, in that it is formed and maintained within relationships.³⁸ From this perspective, we are necessarily interdependent.³⁹ Recognition of this interdependence allows relationships to be seen as supportive of, rather than a threat to, a person's identity. This fits with the importance that participants placed on knowledge of the experiences that shaped the unwell person's preferences. This knowledge was seen as conferring a meaning and weight that documentation alone did not carry.

Nelson and Nelson's family ethics,⁴⁰ which also utilizes a relational ontology, highlights the ethical importance of families and family relationships, and is therefore of particular relevance to advance care planning and to the concept of relational knowing. Although it is widely acknowledged that families care for their unwell members⁴¹ and that, barring instructions to the contrary, they will be involved in decision making if the unwell person cannot participate,⁴² most discussions currently view families in instrumental terms. By contrast, Nelson and Nelson illuminate the more intangible ethical value of families.⁴³ They remind us that families are a source of intimacy, which is a good in itself, that they have shared interests, and that they have collective stories that are distinct from the stories of individual family members.⁴⁴ They argue that family members cannot be replaced by better qualified decision makers, and that their emotional attachments and interwoven interests mean that they are uniquely qualified to make decisions on behalf of unwell family members. This formulation reverses the argument of Beauchamp and Childress that good surrogate decision making hinges on possession of a particular set of skills, including a capacity for "objectivity," rather than on particular relationships.⁴⁵ Nelson and Nelson's family ethics sits comfortably alongside the concept of relational knowing, which hinges on intimate relationships, rather than on a capacity for objectivity and rationality.⁴⁶ These dis-

tinct notions of the family, and therefore the surrogate, need to be accommodated within advance care planning.

In our study, participants' understandings were not binary, but encompassed both individualized and relational concerns. These concerns are necessarily in tension and each carries its own risks. In particular, if the unwell person's intimate relationships have been abusive or harmful, or if his or her significant other is motivated exclusively by self-interest, then the unwell person may be at risk of harm. Some of the participants in this research had experienced significant family conflict, and these conflicts shaped their understanding of how decisions would be made. Relational knowing remained important for these participants, in so much as it allowed them to make judgements regarding their family members' suitability for the role of significant other. For healthcare professionals, acknowledging relational knowing requires attention to the roles and responsibilities within families and consideration of how obligations have been created and distributed.⁴⁷ The moral rightness of the relationship between a patient and his or her significant other must be open to examination, and healthcare professionals should not dismiss their intuitions regarding these relationships. At the same time, healthcare professionals should not regard the patient's loved ones as suspect or presume that they, by virtue of their professional expertise, are better qualified to make decisions.⁴⁸

The empirical literature, discussed above, indicates that surrogates are unable to consistently replicate their loved one's preferences, that prior discussion and having access to an unwell person's written directive does not improve the accuracy of a surrogate, and that most people are willing to allow a surrogate leeway in decision making. Our findings support the idea that maybe surrogates' accuracy is not that important, in so much as almost all of the participants in our study were more concerned with the questions of *who* makes the decision and *how*, than with the decision itself. In particular, many older people wanted their significant other to take into account their past experiences and values, but also the needs of others. Thus, relational knowing supports contextual, contemporaneous decision making over "accurate" decision making.

Relational knowing is additionally valuable because many people will never complete an advance care plan. In the U.S., where advance care planning is more firmly established than in Australia, the use of advanced directives is still often less than expected. For instance, two large studies of nursing

home residents found that only 15 to 20 percent had completed a written directive, and 25 to 33 percent had a healthcare power of attorney form.⁴⁹ A study of 999 persons aged 65 years and older, who needed someone else to make decisions on their behalf at the end of life, found that 7 percent had a written directive, 21 percent had a healthcare power of attorney form, and 40 percent had both.⁵⁰ Beauchamp and Childress indicate that when there is no formal documentation and the unwell person has not expressed specific and relevant preferences, then the best interests of the unwell person should prevail.⁵¹ By contrast, relational knowing suggests that significant others might be well placed to make a decision by considering not just what they have been explicitly told, but by reflecting on what they know about the older person.

Our study has limitations. First, despite efforts to do so, we were unable to recruit socially isolated participants. Only one participant was unable to identify a significant other. Second, we recognize that older people might be less likely to utilize individualistic models of decision making,⁵² and that if this is the case, younger people may hold different understandings. Against this, the significant others in our sample also expressed relational understandings, and five of the six significant others were daughters of the older participants and were therefore from a younger generation. Third, it was difficult to recruit significant others, in part because older people were reluctant to pass on the invitation, usually on the grounds that their significant others were too busy or in poor health, but also because not all of the significant others who received an invitation agreed to participate. Fourth, all participating significant others were female, which is consistent with other studies of significant others,⁵³ even though older participants expected their male family members to be involved in decision making. For this reason, we are reluctant to draw conclusions about the attitudes and understandings of male significant others. Finally, the competence of the older people was not formally assessed. However, as stated in the "Methods" section of this article, participants were excluded if their general practitioner felt their competence would impact on their participation; the first author excluded one potential participant who appeared confused on the phone. The goal was to include older people who, at the time of the interview, were still able to make decisions for themselves, because these are the people who might be expected and encouraged to complete an advance care plan. Most of the older people had experienced periods of ill health in

which they were possibly less able to participate in decision making, and many had experience of caring for a loved one whose competence was decreased. They were encouraged to reflect on these experiences during the interview. However, it is possible that when a person's competence has diminished, his or her understanding of decision making changes, and thus we cannot comment of the understanding of older people whose competence is reduced.

CONCLUSION

This study suggests that the dominant model of decision making, which underpins advance care planning, may be partial and incomplete in cases of reduced competence. Individualized concerns are certainly of importance, but they are not all that matters to people who are faced with the significant challenges associated with an inability to make decisions about medical treatments. Recognition of relational knowing enables the development of an alternative understanding of decision making when a patient cannot fully participate. It allows us to shift the emphasis from protecting an unwell person's autonomy to a focus on developing an understanding of and maintaining a person's identity. This identity work is multifaceted; it incorporates the person's prior preferences, be they documented or undocumented, but it also requires the involvement of the people who supported the person's identity, who understand the experiences and values that shaped the person's preferences, and who can place contemporaneous decisions into the broader context of the person's narrative. It rests on a definition of identity as formed and sustained in relationships. In this approach, it becomes necessary to hear not just the unwell person's voice, but the voices of their significant others, whose relational knowing provides a potentially information-rich environment for decision making.

This approach to decision making, when a patient's ability to participate is impaired, requires a willingness to acknowledge the complexity of people's understandings and to address a breadth of moral concerns, including those pertaining to autonomy and those pertaining to relational knowing. When we ignore, oversimplify, or dismiss people's relational understanding as non-moral concerns, we communicate, albeit unwittingly, to unwell people and their loved ones that their understanding is incorrect or inferior. This, unfortunately, could serve to reinstate power imbalances and a paternalist approach that many have sought to transform in the

medical setting. Ethicists and clinicians appreciate the relational component of people's lives. However, acknowledging this and allowing it to be part of care and decision making is one of the greatest challenges faced in medical care.

PRIVACY

Older participants and significant others are referred to by their self-selected pseudonyms, and other identifying details, including names of people and places, have been removed.

ACKNOWLEDGMENTS

The survey that was used to recruit participants was funded by Family Medical Care, Education, and Research grant from the Royal Australian College of General Practitioners. The first author was supported by a National Health and Medical Research Council scholarship for the doctoral study from which this article arises.

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