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Autonomy and the Family as (In)Appropriate Surrogates for DNR Decisions: A Qualitative Analysis of Dying Cancer Patients' Talk

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INTRODUCTION

A fundamental premise of Western medical discourse and practice is that of patients' autonomy, holding that patients have a right to make decisions about their healthcare, including treatment at the end of life.¹ One such decision is to refrain from initiating cardiopulmonary resuscitation (CPR) following cardiac arrest in a terminally ill patient: a *do-not-resuscitate* (DNR) decision. The ascendance of patients' autonomy has led to increased promotion of advance directives, wherein patients state their preferences for their future treatment, including decisions about DNR.² Despite this, many if not most patients do not make such decisions in advance, and, as decisions about CPR are typically required when a patient is incompetent,³ decisional authority passes to another, to a surrogate decision maker. Debate continues, however, regarding standards of surrogate judgment, the criteria for the nomination of surrogates, the existence of competing models of autonomy, as well as dispute over the nature of decisions about DNR. Some identify these decisions as not simply a matter of personal choice, but as constrained by medical, social, legal, and economic concerns.⁴

AUTONOMY AND SURROGACY

Surrogacy is premised upon a presumption that the autonomy of patients is the dominant standard for decision making. When making decisions, a surrogate is presumed to apply particular standards. The dominant, legally accepted standards are *substituted judgment* and *best interest*.⁵ Substituted judgment is generally preferred, with the justification that it encodes and reflects patients' wishes, and thus best serves patients' autonomy.⁶ Family members are sometimes deemed to have a *prima facie* claim to surrogacy⁷ because they are likely to know about the patient's wishes due to their mutual long-standing intimate engagement, are most likely to care about the patient and the realization of her or his wishes,⁸ and to shape and share the values underpinning the patient's decisions.⁹ Finally, family members are patients' preferred and most-often

named surrogates,¹⁰ despite consistently reported discrepancies between a competent patient's preferences for treatment and a family member's assessment as a surrogate.¹¹ Differences between a surrogate's and a patient's judgments may be moot in many cases, as, when judgments differ, significant numbers of patients identify some deviation from their wishes as acceptable.¹²

The best-interest standard requires that surrogates consider only the patient's current state to make a decision in the patient's best interest.¹³ This standard is recommended as avoiding the emotional turmoil and conflict of interests that may be inherent in the more subjective standard of substituted judgment.¹⁴ Some have argued that emotional attachments between family members may interfere with a family member's ability to make a rational decision about a patient's preferences, and displays of emotion have been seen as potentially constituting grounds for disqualifying the judgment of family members,¹⁵ thus excusing them from the responsibilities of surrogacy, with the physician identified as a preferred, dispassionate decision maker.¹⁶ Such arguments draw upon a model of autonomy that values a process wherein an individual rationally and independently weighs up objective facts before arriving at a reproducible decision. Some claim, however, that this model is theoretically and empirically flawed, and recommend, rather, *relational autonomy*,¹⁷ which defines and locates an individual within a network of social relationships and moral obligations, and emphasizes the presence and effect of emotions in decision making.

Most debate about DNR and surrogacy cites practices and policies within the United States, with relatively little discussion or research within Australia.¹⁸ As in the U.S., however, when there is no documented decision regarding DNR, CPR is the default option for patients who experience a cardiac arrest within an Australian medical institution.¹⁹ Additionally, Australian legislation covering advance directives (which allow for naming a surrogate and encompass patients' preferences regarding DNR) has followed U.S. models.²⁰ Australian law and ethical debate pertaining to DNR decision making has confirmed patients' autonomy as paramount.²¹ Despite this, advance directives are rarely used,²² patients do not always discuss CPR with their doctor,²³ and some do not wish to do so.²⁴ Thus, doctors often make these decisions, deeming them to be medical decisions,²⁵ although some report that family members are typically enjoined or expected to make decisions on the patient's behalf.²⁶

The majority of medical discussion regarding DNR, decision making, and surrogacy reflects a professional perspective, and patients' perspectives about end-of-life decision making are correspondingly sparse.²⁷ Some qualitative studies have questioned medical professionals,²⁸ patients' families,²⁹ non-patients,³⁰ or cancer patients who are not approaching death,³¹ but the views of dying patients have been absent. One study featured interviews with terminally ill patients regarding their currently established DNR orders, but this was limited to discussions about their relevance during a perioperative period.³²

There has been less examination of patients' talk about surrogacy. Determining how patients justify their preferences regarding surrogate decision making would enable investigation or verification of the relevance of theoretical assumptions, recommended guidelines, or hospital policies.³³ In one qualitative study examining cancer patients' perspectives on DNR decision making, participants typically asserted that patients should state their preferences for future treatment, and named family members as appropriate surrogate decision makers.³⁴ Yet few had recorded their views or had named an appropriate surrogate. Furthermore, family members were identified as potentially or actually constraining patients' autonomy, or as unwilling or unable to undertake surrogate decision making. These patients were not currently dying, however, and many implied that these issues were relevant only for dying patients. This article focuses upon such patients, and is part of a larger study on issues surrounding dying patients' perceptions of DNR orders, some of which have been reported elsewhere.³⁵ Here we examine participants' responses to questions regarding surrogacy, particularly focusing on how family members featured in surrogacy.

METHOD

This study was conducted at the Royal Adelaide Hospital and was approved by the hospital ethics committee. Patients attending the oncology clinic who met inclusion criteria received an information sheet detailing the project, and were asked by their primary caregivers (including oncologists and palliative care

physicians) if they would be willing to participate in an interview. Inclusion criteria were that patients were older than 18 years with English as their first language, and had been assessed by their long-term attending medical oncologist as being capable of coherent discussion and as being emotionally stable. Of these patients, 28 participated (13 female, 15 male, average age 61), and all but four were in-patients. Patients' primary cancer sites varied, but all were currently in the final phase of their illness, assessed by their medical oncologist as likely to die within three months, and — critically — aware of their prognosis; most (23 of 28) died within three months of interview. Half of the subjects chose to have others (usually family members) present, who sometimes spoke during interview. These interjections provided valuable data, specifically demonstrating familial interaction around DNR decisions.

Recruitment ceased when subsequent interviews revealed no additional information. Signed consent was obtained prior to commencement of the interviews (25 to 75 minutes long); these were conducted by the first author, who was not part of the clinical team. To ensure anonymity, pseudonyms have been adopted. We asked open-ended questions to elicit patients' speech about the issues surrounding DNR decision making, but encouraged participants to discuss anything they considered relevant. Interviews were taped, then transcribed using standard grammatical convention to enhance readability and clarity.³⁶ Transcribed data were entered into the software package N6,³⁷ and, following the principles of discourse analysis (DA), coded into categories representing particular ways of talking about DNR orders, associated people, and events.

Discourse analysts argue that, in using language, individual speakers draw upon pre-existing ways of talking about things, using patterns of meanings that are culturally and historically specific. In so doing, speakers re-produce and collectively re-construct (rather than merely describe) their social world. Further, proponents of DA propose that talk is action-oriented — that people use language to different effect, to achieve different things. Thus an individual's account of a phenomenon — or different individuals' accounts of the same phenomenon — will exhibit variation according to the specific context within which the account is produced.³⁸

Two distinct strands of DA have been defined: *conversational analysis* examines sequential turns of talk in the immediate interactional context, determining what talk is doing at each moment. *Foucauldian* or *post-structuralist analysis* situates language within a wider societal context, noting that patterns of meaning (sometimes called *discourses*) carry with them particular power relations that enable and constrain what can be said and done.³⁹ One relevant concept within this approach proposes that individuals are allocated a position (are positioned) within a discourse, one that carries with it a set of rights and responsibilities that acts to delimit what they can do and say.⁴⁰

Some have recommended integrating these two strands, noting that while talk functions to achieve some specific action *in situ*, it must engage the social, cultural, and historical context in which the talk is produced, either reproducing or challenging available discourses.⁴¹ We used this "synthetic" approach⁴² to explore how participants drew upon commonly available discourses to support different conclusions about family members as surrogate decision makers, and to investigate the interactional implications of their talk, including how patients and family members were variously positioned, as well as how speakers discursively negotiated issues that may have been problematic. This was specifically relevant when family members were either the producers or referents of speech.

In the following, we describe how different aspects of autonomy were invoked to render family members as both appropriate and inappropriate surrogate decision makers. We then consider how, in interactive dialogue, patients and family members can re-present opposing positions, noting some implications of such conflict. We present results and discussion (data and analysis) together to facilitate readers' assessment of the credibility of our conclusions.⁴³

RESULTS AND DISCUSSION

FAMILY ARE APPROPRIATE SURROGATES

Participants' accounts of their own decision making lend support to models of decision making that presume autonomy to have a relational or social component.⁴⁴ Most participants held that DNR decisions

were theirs to make, but the involvement of some family members appeared to be taken for granted, although the nature and extent of this assumption varied.

Family Members Who Support the Patient

Most participants reported discussing the issue with various family members, suggesting that family members knew their wishes, and would support or agree with their decision.

Ross's wife Margie: I can understand the illness, and we've [she and Ross] already talked about it, and so the decision could be [up to] me. . . .

Ross: I've made the decision on the path that I'd like them to follow.

Uri: I've made my decision and my wife and I have talked about it, and we've just made the decision that if it comes to that point, that I've instructed her not to go ahead with it, and, so that's how we've made that thing go. . . . And that's my decision, that's how I feel anyhow.

These participants re-presented the conventional version of family members as literally and figuratively "there" for the patient, thereby best qualified to know and convey his or her wishes.⁴⁵ The involvement of family members in the decision-making process was taken as normal and appropriate, particularly in the role of providing support through participation in discussions.⁴⁶

Patients were nonetheless constituted as primary. Patients make the decisions, then speak to their family members, who then "follow" or are "instructed" accordingly. There is, however, a reciprocal implied obligation that the patient should actually make the decisions, most clearly articulated by Vera and her husband Ben.

Vera: But basically I guess I decided all myself. Didn't I, because you wanted me to do=

Husband Ben: =Well it was your decision=

Vera: =what I wanted to do.

Ben: That was my thinking on it. . . . That you had to make that decision, and then I'd support you and go along with it. But I think that that had to come from you. . . . I think the whole family sort of thought like that.

Thus, although the family might support Vera, she "had to make that decision. . . ." To assign the roles of decider and supporter is relatively uncomplicated in (most) cases, wherein the patient accepts responsibility for making the decision; but it is problematic if the patient does not accept the responsibility (see the sections "When Family Members Are Inappropriate Surrogates" and "When Family Members and Patients Are in Conflict," below). Participants also suggested, however, that familial discussion might fulfil other functions than establishing patients' decisions and family support.

Uri: To a point, you must discuss it first because, you know [your family] have got to have some point of intake too that you, that they can point out things that you might have overlooked on the way. . . .

Uri depicted family input as useful in aiding the patient to consider all relevant information, a further aspect of the support role,⁴⁷ simultaneously implying that the family's "point of intake" constituted relevant information for the patient. However, Uri, as did Scott and Tom below, presented such familial discussions as mandatory, using imperatives such as "must" and "should." This establishes inclusion of the family in the process as an obligation placed upon the patient, highlighting the decision as being both moral and social.

Scott: I discussed it with . . . me whole family. . . . If you don't [discuss with them], my opinion . . . they'll tend to think "Well he never discussed it with us, and he's left us out in the lurch" or whatever. And I think it's vital that they do talk it over with the family. Because . . . the final decision is up to you what you do. But the family will then have a good idea what you're doing. . . . Yeah, keep them in the know, yeah.

Tom: I can't see why anyone wouldn't wanna discuss it [with their family], I mean, if they didn't wanna discuss this, I think they'd be a pretty cold attitude of looking at the situation. . . . I think the more open it is, about the situation, the better. But when the time comes it's still a blow, but perhaps lightened, lightened the way by sort of talking. . . .

Here, failure to discuss DNR decisions with family members was negatively presented as insensitive and, conversely, keeping family members informed was positively presented as benefiting the family. Although others have noted that patients consider the consequences of their decisions upon family members,⁴⁸ this analysis suggests that participants also considered the consequences of including (or not) the family in the decision-making process. What featured as important were the consequences upon the family's emotional status, and discussing the issue with family further rendered both normative and a moral necessity for the patient.

Notwithstanding family member's entitlement to inclusion or consideration in the decision-making process, many asserted that ultimately the patient's "opinion" should hold sway, even in the face of potential disapproval or disagreement from family. The language used below, moreover, suggests that there may be some obligation laid upon family members to work to effect the patient's wishes.

Yves: I said to [my wife] before, "It's probably me being selfish in my views, but they're my views and that's what I want to happen. . . . I'd appreciate those things . . . being observed."

Opal: I suppose if I'd made the decision not to go along with [resuscitation] . . . that should apply. But I suppose the family also should have a right to say whether you can or not, I guess it'd be up to them as well. I don't know. No, the only thing I would feel is that if I told them definitely that I didn't want to be put on life-support then they wouldn't do it. They'd go along with what I wanted.

Family is here construed as appropriate surrogate decision makers on the grounds that they represent the patient's wishes and enact the patient's autonomy,⁴⁹ regardless of their own positions on the matter. Although John Hardwig has argued that patients' autonomy should not include a right to assert their values over those of their family,⁵⁰ this representation by the participants in our study mirrors claims that patients' consideration of their family members' dissent or disapproval constitutes another factor that patients might legitimately take on board while arriving at their own decision.⁵¹

Family Who Have a Stake in the Outcome

Participants most often nominated family members (or a specific family member) as surrogate decision makers when considering a situation when the patient's decision was not available at the time that a decision was needed (for example, at the moment of crisis), a point that has been noted by others.⁵² The common-law assumption that family members have "a presumptive right"⁵³ to be consulted in such circumstances, with appropriate explanation and justification required if they are not,⁵⁴ is evident in the following excerpts.

Wendy's husband Dennis: But doesn't it . . . come back to the next family member? . . . If you ask "Well do you want to resuscitate?" isn't it the mother, the son would be asked. I know that if she's too far gone to make a decision, they'd ask the next-of-kin surely, to make that decision for them, is what they'd do?

Yves: I mean it's different if a person is in a kind of comatose or vegetive [*sic*] state. It revolves [*sic*] to the next-of-kin then I should say. . . . If they won't make the decision, I think it's best off for the next-of-kin to make the decision that's best off for them.

We note that the terms *family* and *next-of-kin* may be problematic. Their use obscures the fact that the entity to which they refer is composed of individual members in different relationships to the patient (who is also part of that family), who have different sets of values, experiences, and needs. In nominating family members as surrogate decision makers, participants reproduce the construction of the family as a homog-

enous "superpersonality" that thinks and acts as one,⁵⁵ despite evidence to the contrary,⁵⁶ including within this research (see the sections "When Family Members Are Inappropriate Surrogates" and "When Family Members and Patients Are in Conflict," below).

The positioning of the patient and his or her family with respect to DNR decisions (including process and outcome) might usefully be characterized as points along a continuum. At one extreme — that emphasizes the personal, individualistic aspects of autonomy and of DNR decisions — patients may justifiably assert their views over that of their family members. At the other extreme — that emphasizes the social, relational aspects — family might be deemed as entitled to claim (or to be assigned) greater involvement in or responsibility for making decisions, even obliged to make decisions. Within this study, discussions with patients and family members are not depicted as a one-way street, wherein a patient considers her or his family members' views and then his or her decision. For example, in discussing one decision, Sally spoke of obtaining her family's views, then basing her decision upon their expectations of her.

Sally: [My family and I] all got together . . . and I said "This is it, it's up to us now what to do." And they all gave their opinions, I said I wasn't going to give my opinion at first. And they all gave their opinions on it. And they were all heartily agreeable that I should fight on. Do take the necessary precautions, the treatment that was being offered to me, and that. That they were behind me. And they spoke so nicely about it that I didn't answer them straight away, but I thought about it, and I thought "I cannot refuse them that, try, try it."

This excerpt conveys how Sally established and balanced her obligations to (1) take responsibility for a decision that is ultimately about her treatment and (2) consider others. She began by identifying the decision, not as hers, but as her family's ("it's up to us"). Nevertheless, her family's acquiescence that she not voice her views initially suggests some tacit acceptance of her authority to control the decision-making process. In addition (by her account), they construed the issue and potential future actions under review as hers (she "should fight on" et cetera), with themselves in a supportive role ("they were behind me"), further confirming her in the primary role.

Sally's description might be understood simply as reflecting a process of rational decision making, but her description also indicates the complexity of her situation and the decision she faces. It was not information conveyed by the family that Sally identified as the relevant factor in accounting for her decision, but the "nice" way that they presented it. "Nice" carries an evaluative and emotional connotation, which works to stress the emotional as an important element in this process.⁵⁷ Furthermore, Sally's presentation of herself as obliged to responding positively to a family request ("I cannot refuse them") indicates that her decision has social and moral import.

Nonetheless, Sally's authority to make the decision is implicit in her statement that she "didn't answer them straight away, but I thought about it." This represents her as weighing up her family's requests, with an implied ultimate right to accept or decline their preferences. Thus, decisions about an individual were re-established as fundamentally personal.

Although this leaves unanswered the question of whether Sally's actions might represent some degree of coercion by her family members, or simply Sally's autonomous decision to engage and accept her family members' viewpoints, or even some amalgamation of the two, it reveals that although it may be difficult to separate the interests of family members and patients, patients can manage to value both while maintaining the supremacy of the patient's choice.

WHEN FAMILY MEMBERS ARE INAPPROPRIATE SURROGATES

There were instances wherein participants identified family members as inappropriate surrogate decision makers, most often in descriptions of their experiences as the patient approached death.⁵⁸ For example, some participants indicated that the inevitability and imminence of a patient's death were difficult for some family members, manifested in some form of denial.

Pete: I guess it [responsibility for DNR decision] depends where there's acceptance of where they're going, you know, (. . .) the family stuff. I know with my neighbor, she stood by her husband's bed day and night saying all the time "Don't you dare leave me, don't you dare leave me." And (. . .) how could he die? . . . she never wanted to talk about it.

Opal: Although he [Opal's husband] knows it's inevitable, he's a bit of an ostrich too, he doesn't sort of want to think about it yet. . . . I said to Beckie [her oldest daughter] "Further down the road you've got to see to this, see to that," and she seems to be accepting of it all, she's not quite, buries her head like her dad. . . .

Here, a spouse was characterized as avoiding thinking about or discussing "it," that is, the patient's imminent death. The behavior of each spouse can be readily understood as emotionally derived, and failing to meet the standards required for rational decision making. This potentially justified excusing them from the responsibility of the decision, rendering them inappropriate surrogate decision makers.⁵⁹ Certainly, insisting that such individuals actively deal with and make such decisions can be deemed to violate their autonomy, and thus would be of questionable ethical status.⁶⁰

If family members and patients can justifiably avoid these discussions as liable to have a negative effect on their (emotional) well-being, the extent to which family members can know and represent the patient's wishes will be compromised. Indeed, discussions of death by family members and patients are often limited.⁶¹ What is of critical importance here is that family members' participation in good familial relationships (and this includes the participation of the patient) may compromise the extent to which they can know and represent the patient's wishes. Similarly, Una specifically rejected her family members as appropriate surrogate decision makers, on the grounds that they would be too emotional and involved, implying that the "head medical person" was a preferable surrogate precisely because she or he would not be so involved.

Una: If the patient is not of mental capacity to make that decision, I think it's up to a medical doctor. Not the family because they get, there's too much emotional and other involvement.

Emotional involvement or closeness is typically used to justify naming a family member as a surrogate (see "Family Members Who Support the Patient," above), and such emotional involvement is part of normative notions of family.⁶² However, as the display of emotion in decision making can be deemed to interfere with the desired rational process, the very conditions that constitute family members as appropriate decision makers can function to identify them as inappropriate surrogate decision makers.

WHEN FAMILY MEMBERS AND PATIENTS ARE IN CONFLICT

Precisely because the concepts of family and autonomy can be differentially invoked to justify prioritizing the wishes of either the patient or the family, conflict is possible, as demonstrated in an interchange between Sean and his wife Vicky. The conflict followed Sean's justification of his deference to his family and his positioning of Vicky as integral to his decision making.

Sean: [I've] never even thought about anything like [making a decision about DNR]. But I think, yeah, I think my answer would have to be, well, . . . I'd be happy that the family, whoever were around at the time, would do just what they wanted to do. . . . I want to be so independent. And I don't want [Vicky] cracking herself up because of me. . . . Especially because we've [Sean and Vicky] worked so much together, that I don't like to work independently.

Here, Sean asserted his willingness to defer to his family members, notwithstanding a desire to be independent and ensure Vicky's well-being. The importance of "independence" is often associated with the patient assuming responsibility for the decision in order to relieve others.⁶³ Thus independence is valued because of the effects manifested within an interpersonal relationship: independence does not imply separation from others, but attachment to them. Sean presented interdependence as the habitual practice between

he and his wife, providing further support for his deference to her (as a specific member of his family). Drawing upon a relational version of autonomy and identification of the decisions about DNR as social, Sean justified his position of not accepting responsibility for it.

His wife Vicky, however, invoked the primacy of a patient-based decision to justify her insistence that Sean decide and she function merely to carry out his expressed wishes.

Vicky: I don't want to get involved. I want to get his opinion, not mine. I just want him to say what he wants. . . . Well, I think my decision really, should rest with the patient, so that his wishes are strictly carried out, and that is my opinion. That is strictly my opinion. Whether it is his opinion is totally different. . . . I won't say too much, because I don't want to sway him, but I really want him to have his say in what he feels, and what he wants.

Sean: Well, I feel I want you to say. I have said what I wanted to say. And I haven't asked you many questions. I haven't asked you for many questions.

Vicky: No, but I came in here to listen

Sean: Yeah, I know. . . .

Vicky: You can see that different people do have different views which is why I've kept quiet, I just wanted to get his.

Although Vicky was ostensibly prioritizing Sean's "wants," his wants were repeatedly framed in the context of what she wanted, thus asserting the weight of her wants. In doing this, Vicky (1) effectively invalidated Sean's position of wanting not to actively articulate (or make) a decision, and of wanting to know her position; (2) countered Sean's wants with her wants; and (3) placed some moral obligation upon Sean to respond positively to her desire to know his wants. Indeed, the conversation emerged as the clash of "wants." Both Sean and Vicky, however, could justify their own silence on the matter (and their deferral to the other) by invoking a particular aspect of autonomy, with associated representations of DNR decisions. Sean did this through an appeal to relational autonomy, and by construing DNR decisions as social decisions. Vicky did this through an appeal to individual autonomy, and by construing decisions about DNR as essentially personal decisions.

Nonetheless (perhaps unfortunately for Sean), his account and Vicky's account identified a patient's avoidance of making decisions as problematic; that is, if Sean continues to maintain his silence, he risks disappointing Vicky and demonstrating that he has dismissed her views, which he earlier identified as important to him. Conversely, Vicky's repeatedly stated preference — that Sean decide — undermines the validity of what might arguably represent an autonomous decision on Sean's part: to not make a decision regarding DNR. Finally, to the extent that Sean's equivocation can be seen as failing to meet his obligations to Vicky, or as failing to make an autonomous, adult decision about his own healthcare, Sean could be subject to moral censure. Thus, in contrast to normative assumptions regarding autonomy, individuals might be constrained to disregard their own preferences in situations such as these.

CONCLUSION

We acknowledge that only dying patients with cancer were interviewed, and patients dying from other illnesses may draw upon different discourses when making decisions at the end of life. However, as participants re-presented prevalent discourses surrounding autonomy, decision making, the patient, and the family, our analysis may be relevant to patients with other diagnoses. Participants were exclusively White and predominantly Christian, limiting the extent to which these findings may apply elsewhere; a future research program is planned to interview similar patients with a different language, religion, and culture. Even within a homogenous group, however, the positions of patients and family members regarding DNR decision making and surrogacy can be contested, indicating the complexity of these issues, and need for sensitivity and flexibility on the part of clinicians interacting with patients in and with their families.

We found that participants drew upon normative characteristics constituting family — namely, emotional closeness between a patient and his or her family members — to sanction and veto familial involvement in decision making. Practically, families who were emotionally close (perhaps providing the support valued by participants) are more likely to find objective decision making difficult. When objective decision making is sought, family may be seen as less than ideal surrogate decision makers, and professional detachment is seen as an endorsement of a physician as the surrogate. Alternatively in such situation, an independent entity (for example, a Guardianship Board) may be appropriately enjoined.

We found that family members' preferences were deemed to be central, but not equivalent to, those of the patient, indicating how family members' and patients' sets of preferences can invoke different construals of autonomy (individualistic versus relational), decision making (personal versus social), and the patient with and in the family, to justify avoidance or rejection of responsibilities for making DNR decisions — despite the force of arguments that would otherwise assign said responsibilities to family members. Practically, this may prove problematic for clinicians and policy makers when they address DNR decisions (individually or through policy), intending to ensure that patients' autonomy is appropriately incorporated and that patients and family are included equitably and compassionately in these decisions.

Most patients (especially those who face important decisions) will identify themselves as individuals and as part of a social structure, the family. Each patient, each family, will have its own history and habitual mode of addressing decisions that, though dealing with one family member, will affect all. When important decisions loom large, it would be advisable for clinicians to ascertain the habitual mode of decision making within a family. Family members will sometimes, but not always, be identified, or identify themselves (officially or otherwise), as appropriate surrogate decision makers. Familial involvement in decision making can be tailored to best meet the expectations of patients and their family members. Regardless, the opinions and needs of patients and their family members, although interconnected, will likely differ somewhat, and this may render family members as inappropriate surrogate decision makers, although they may continue to have a role to play in the decision-making process. Additionally, because normative familial behavior dictates that patients elicit and attend to the opinions of their family members (even opposing opinions), patients' and family members' decisions are unlikely to be made based upon biological or medical parameters. When differences exist, patients and family members may experience increased distress, particularly when differences center on a patient's desire to assign responsibility for making decisions to another person. Although this may be interpreted negatively as a patient's denial, we argue that respect for the autonomy of the patient dictates that the patient not be coerced to voice a direct preference, but rather that a patient's autonomous choice not to make a decision should be heard and accommodated. This may require increased familial discussion with clinical staff and assurance that appropriate decisions will be made in the best interest of the patient.

Medical policies that routinely assume that patients will make decisions about DNR, or that assign or deny surrogate roles to family members, or that assume that all patients will do likewise, will not meet the expectations of all patients and families, increasing the potential for distress and conflict. Such distress and conflict will be exacerbated if patients and families are confronted with making decisions at a time when they are not prepared to face them — at a time that is instead dictated by medical practice or protocol. A patient's or family's avoidance of decision making, or denial that a decision is required, is problematic only if patients' autonomy is deemed to be mandatory, or if the only acceptable model of decision making excludes a decision to remain silent or to defer decision making to another time or another person. When medical facts are known, denial need not be deemed as negative, but can instead be seen as a positive and often temporary psychological coping mechanism by patients and their families. Attempts to break down this response at a particular time to meet particular policy demands regarding DNR orders may be harmful to patients and their families. As such, the ethics of "one-size-fits-all" policies, which leave little room for sensitivity to patients' and families' circumstances, might be called into question. Conversely, policies that permit — but do not require — the participation of patients and families in determining the provision (or not) of CPR to a patient are more likely to adequately account for, and respect, the range of patients' and families' preferences and behaviors at the end of life.

NOTES

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7. D.W. Brock, "What is the Moral Basis of the Authority of Family Members to Act as Surrogates for Incompetent Patients?" *The Journal of Clinical Ethics* 3, no. 2 (Fall 1992): 121-3; Rhoden, see note 5 above.
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