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12 Grief and End-of-Life Surrogate Decision-Making

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Summary

Because an increasing number of patients have medical conditions that render them incompetent at making their own medical choices, more and more medical choices are now made by surrogates, often patient family members. However, many studies indicate that surrogates often do not discharge their responsibilities adequately, and in particular, do not choose in accordance with what those patients would have chosen for themselves, especially when it comes to end-of-life medical choices. This chapter argues that a significant part of the explanation of such surrogate failure is that family surrogates are likely to undergo anticipatory grief when making end-of-life decisions. After clarifying both the emotional structure and object of grief, I propose that the pending death of a loved one induces an emotional conflict in surrogates between the care demanded by their responsibilities as surrogates and the attachment surrogates feel toward their dying loved one, a conflict surrogates “resolve” in the direction of attachment rather than care. This hypothesis helps to explain both surrogates’ general inability to exercise “substituted judgment” on behalf of their loved ones and a wide swath of the particular data regarding this inability (e.g., that surrogates more often err by choosing overtreatment). I conclude by considering possible clinical and philosophical responses to this hypothesis.

Introduction

One unmistakable feature of modern medicine is its increasing reliance on surrogate decision-makers, individuals charged with making medical care decisions on behalf of individuals whose illnesses make them incapable of making such decisions. Because of increasing longevity and the greater prevalence of chronic illnesses associated with aging, more and more of the responsibility for medical decision-making falls on these surrogates.

The purpose of this chapter is to explore a novel set of practical concerns regarding surrogate decision-making at the end of life—namely, the role

played by the emotions in such decision-making. The clinical settings in which end-of-life care is typically provided are hothouses of emotion. For medical professionals, providing care to end-of-life patients is itself an intensive act of emotional labor, putting great strain on their capacities for empathy (Bagdasarov and Connelly 2013). For end-of-life patients, emotions such as fear, shock, anger, sadness, and regret can compound the physical toil of a body in its last throes (Kubler-Ross 1969). For family members of the critically ill, anxiety, anger, and emotional fatigue are common (Davidson et al. 2007). Add volatile interpersonal dynamics to these emotional stresses, and the result is an environment where what moral philosophers call the “moral emotions”—guilt, shame, resentment, and so forth on the “negative” side, pride, gratitude, hope, and so forth on the “positive” side—are never too far below the surface (Dillon 2010).

Unfortunately, ethicists have said little to illuminate how moral emotions shape end-of-life care and decision-making. A general account of this relationship is beyond the scope of this chapter. My purpose is narrower: to investigate the role that one particular moral emotion, grief, has in end-of-life medical decisions. I shall argue that that even if grief itself is often a rational response to one’s loss and the relationship transformed by that loss, we have good reason to think that grief nevertheless compromises the specific sort of rationality needed to act effectively as a loved one’s medical surrogate. More specifically, I propose that the anticipatory grief experienced by surrogate decision-makers helps to explain the well-corroborated finding that surrogates often fail to satisfy the “substituted judgment” standard widely thought to provide surrogate decision-making its ethical foundation. Irrespective of whether I am correct in these conclusions, I hope to inspire other ethicists to examine end-of-life decisions, and medical decision-making more generally, through the lens of the moral emotions.

The first section provides an overview of the current clinical environment surrounding surrogate decision-making and describes the currently accepted rationale and standards for such decision-making. In the second section, I adumbrate the evidence indicating that surrogates routinely fail to satisfy such standards. I defend a crucial philosophical claim regarding grief in the third section—namely, that grief’s object—what it is that individuals grieve for across the course of their bereavement—is the transformation or loss of the intimate relationship the grieving individual had with the deceased. In the fourth section, I apply this claim to surrogate decision-making to argue that such decision-making often occurs in the midst of anticipatory (i.e., pre-mortem) grief, and that decision-making in that context involves a powerful emotional conflict between the decision-maker’s attachment to the ill patient and the demand that the decision-maker exercise care on that patient’s behalf. The difficulties surrogates face in exercising the kind of “substituted

judgment” called for by their roles as surrogates can be partially explained by their resolving this conflict (understandably, mind you) in the direction of attachment rather than care. The fifth section considers some possible responses to this phenomenon.

The Rise and Rationale of Surrogate Medical Decision-Making

In modern industrialized societies, dying has changed rapidly in the space of just a few generations. Where our grandparents were more likely to die of accidents or communicable diseases, we are now much more likely to die of chronic or degenerative diseases. The leading causes of death at the turn of the twentieth century included flu, pneumonia, and tuberculosis, whereas the leading causes of death today include heart disease, cancer, and lung disease (Jones et al. 2012). As a result, far more individuals now reach old age than in the past (Arias 2014). That life spans have increased so dramatically has its downside, though. For one, the conditions that cause the majority of deaths these days tend to lengthen the process of dying and lead to sustained stretches wherein patients have depleted or intermittent consciousness. Moreover, far more individuals live long enough to become demented for some portion of their lives. A principal result of these changes in how we die is that individuals are now more likely to undergo periods in which their ability to make medical decisions for themselves is sufficiently compromised to render them incompetent. Their medical conditions make it impossible for them to understand their diagnoses, rationally engage with alternative treatment options, communicate their decisions, and so forth. About 40 percent of hospital patients are sufficiently cognitively impaired that they lack the capacity to make competent medical decision for themselves (Fritsch et al. 2013: 126). Prior to the 1960s, incompetent patients would likely have had their medical decisions made by their medical caregivers (Rothman 1992). However, as patient autonomy has become the cornerstone of contemporary clinical ethics, the right to make medical decisions is increasingly placed in the hands of a decision-making surrogate or proxy. Surrogates now make 75 percent of the medical decisions for patients hospitalized with serious illnesses (Hiltunen et al. 1999) and around half of the medical decisions for patients in nursing homes (Kim et al. 2002).

Who serves as a patient’s surrogate is determined by an established legal and professional protocol. In some cases, the patient will have designated a surrogate prior to becoming incompetent. Usually this surrogate is a family member or loved one. In cases where a patient has not assigned the power of surrogacy to anyone, the patient’s next of kin is designated as her surrogate (and if this is not possible, an administrative surrogate—a social worker, attorney, etc.—may be appointed).

The underlying rationale for using surrogates in such circumstances is that this is the best way for patients who are not competent to nevertheless exercise autonomy regarding their own medical care. Since they themselves are incompetent and so cannot exercise autonomy on their own behalf, a surrogate, ideally one knowledgeable about the patient's preferences and values, is designated to make medical choices regarding the patient. The patient's 'autonomy' is thus exercised at one remove: when a patient cannot choose which interventions will or will not be administered to her, she will nevertheless receive treatments that reflect *her* preferences and values. Note, then, that the surrogate is not supposed to be engaging in "hard paternalism," choosing for the patient what the surrogate believes to be best according to some supposedly objective or all-things-considered standard (Feinberg 1986: 12). Rather, surrogates are charged with choosing that course of care that answers to the *patient's* preferences and values (Buchanan and Brock 1990).

This autonomy-based rationale for surrogate decision-making thus implies a counterfactual standard for responsible surrogate decision-making: a responsible surrogate chooses those treatment options that the patient would have chosen for herself were she competent and able to do so. The surrogate is thus to exercise *substituted judgment* on the patient's behalf. Those who have long-standing relationships with a patient—the patient's spouse, children, parents, siblings, and so forth—appear best suited to exercise this sort of substituted judgment. After all, who is in a better position to know what someone wants than those who know her best and longest?

The Unreliability of Surrogate Decisions

But do surrogates in fact discharge the decision-making responsibilities assigned to them? How often and to what extent do patient-designated or next of kin surrogates exercise substituted judgment properly—that is, choose those courses of treatment that patients would have chosen for themselves?

Such questions are not easy to investigate, especially because establishing what patients would prefer in contexts where they would be incompetent is not straightforward. Nevertheless, empirical investigations of surrogate decision-making are discouraging. Surrogates are not particularly reliable with respect to the counterfactual standard of exercising substituted judgment. Shalowitz et al. (2006) is the most comprehensive metastudy of the relevant research. Among its key findings:

- Patient-designated and next of kin surrogates accurately predict patient preferences about two-thirds of the time, whereas attending physicians predict patient preferences just over half the time.
- Surrogates are slightly more accurate regarding choices about current patient health (e.g., whether to administer more pain medication) than

they are about projected future medical conditions, such as dementia or late-stage cancer.

- Surrogate accuracy does not significantly vary based on type of medical intervention proposed (e.g., surgery versus pharmaceuticals).
- Surrogates tend to err in the direction of overtreatment, advocating treatments that patients would refuse.
- Surrogates' specific relationship to patient (sibling vs. spouse vs. child, etc.) is not correlated with surrogate predictive accuracy.
- Patient-designated surrogates are not more accurate than legally assigned administrative surrogates.
- Surrogates having prior discussion of patient treatment preferences slightly *reduced* accuracy of subsequent surrogate predictions.

Needless to say, the hope that surrogates will “stand in” for the patient and thereby enable the patient to receive those treatments that reflect her preferences does not seem well founded. Shalowitz et al. dismally conclude that patient-designated or next of kin surrogates satisfy the counterfactual condition implied by the substituted judgment standard at a rate “only slightly better than chance” (2006: 495).

That surrogates are not as reliable in their decision-making as we might hope can be explained based on what surrogates report about their own methods of decision-making. Indeed, if surrogates' own reports of how they go about making medical decisions for incompetent or incapacitated patients can be trusted, they often make use of methods that probably do *not* correlate with patient preferences (Vig et al. 2006). Some of the methods surrogates report using at least purport to track patient preferences. For example, just over two-thirds of surrogates report relying on conversations with patients as a guide to the decisions they make as surrogates, and about half of surrogates infer patient preference from their background knowledge of the patient. But among methods that at least purport to track patient preferences, some warrant skepticism. For instance, about one in six surrogates reports that she used the values or life experiences she presumed to have in common with the patient to make decisions for the patient. These surrogates often report that they have an “inner sense” of what the patient would want or that they will “just know” what the patient would want when the time comes to exercise medical judgment on the patient's behalf. (Only about 10 percent of surrogates report having relied on written statements made by patients.) Whatever their reliability, at least these methods are facially focused on the patient and her preference. Worse still, many surrogates concede that they use methods of decision that bear no apparent relationship to patient preferences at all. About one-quarter of surrogates report simply using their own medical care preferences to make decisions for the patient. About 15 percent make these decisions based on their own interests and 12 percent make them based on their own religious convictions.

The methods surrogates draw upon to make their medical decisions are thus a hodgepodge of suspect reliability and clear irrelevance. That surrogate choice often fails to reflect patient preferences is unsurprising (Fritsch et al. 2013).

The Nature of Grief

Exactly why surrogates are so ineffective in exercising substituted judgment has not been investigated in much depth. Perhaps surrogates' unreliability has a cognitive origin: surrogates lack sufficient information regarding patient preferences or do not understand what the substituted judgment standard asks of them. Alternatively, their unreliability may have a moral explanation. Surrogates may simply be indifferent to the moral demands implied by the substituted judgment standard. While these considerations can no doubt play an explanatory role, I would like to explore a partially *affective* explanation—namely, that surrogates face an emotional conflict between their own grief and the emotional detachment needed to choose as others would choose for themselves.

Artists are fond of depicting grief as a flirtation with madness and unreason. Hamlet's paramour Ophelia jabbars in riddles after the death of her father, Polonius. In his memoir *A Grief Observed*, C. S. Lewis speaks of the "mad words, the bitter resentment, the fluttering in the stomach, the nightmare unreality" that sent him "round and round" after the death of his wife Joy (2009: 69). Anne Roiphe's grief leads her into an insomniac haze (2008). Indeed, that grief can seem antithetical to rational self-control is part of the reason why ancient philosophers typically saw grief as a threat to moral virtue and to a well-lived life (LeBarge 2012).

To contemporary eyes, such worries appear hyperbolic. Nevertheless, the powerful affective manifestations of grief raise questions about the rational capacities of the grieving. To get a handle on how grief influences end-of-life decisions, we must first get a handle on the emotional complexities of grief itself.

Categorizing grief as an emotion risks oversimplifying it. While philosophers disagree about whether emotions are best thought of as cognitive states such as beliefs, conative states such as desires, or states of bodily awareness, they standardly think of emotions as responses to particular facts that elicit them. Anger, for example, is generally analyzed as the emotion elicited by the sense that one has been wronged; fear is generally analyzed as the emotion elicited by the belief that one's well-being is under threat; and so on. The state that elicits the emotion is the emotion's *object*.

In the case of grief, one complication here is that grief does not seem to be a single response. Rather, grief unfolds as an emotional process. Since the work of Kubler-Ross (1969), the notion that grief fits into a five-stage

pattern (denial-anger-bargaining-depression-acceptance) has been ascendant. While this model is certainly incorrect at the level of detail—few bereaved persons undergo precisely those five stages in that order (Maciejewski et al. 2007; Konigsberg 2011)—that grieving involves multiple affective states is widely recognized. Grief is more than simply sadness or suffering at the death of another. Rather, grief often involves anxiety, joy, fear, and other affective states along the way. As Wittgenstein noted, grief differs from other emotions in that it is less a momentary sensation than a prolonged emotional engagement with a change in one's condition (Wittgenstein 1958: 174–175). In this respect, grief seems to resemble a kind of “narrative” response, a complex emotional arc with a beginning, a climax, a resolution, and so forth (Goldie 2011; Higgins 2013).

But the composite emotional nature of grief only seems to make its object more elusive: imagine an individual whose loved one dies and she undergoes an episode of grief that conforms to Kubler-Ross's denial-anger-bargaining-depression-acceptance pattern. In what sense are these particular emotional stages parts of the same grieving episode? If grief is a story, what is this story about? What object unites these stages as elements of a larger emotional episode?

That we “grieve for” a person might be taken to imply that the object of grief is the bereaved individual's belief that the deceased has been harmed by death, perhaps by being deprived of further opportunities to enjoy the goods of life. Admittedly, some of what we experience as bereavement is other-regarding in this way: we grieve for what the deceased have lost by dying. But this is implausible inasmuch as we do not grieve for everyone, despite the fact that many people “lose out” on the goods of life by dying. Thousands die each day, but we individually do not grieve for each of them, or for even a tiny fraction of them. If grief's object were what the deceased have lost by dying, we would grieve for far more deaths than we in fact do. Genuine grief instead requires some sense of familiarity or intimacy with the deceased, a fact that implies that grief's object is more self-regarding. In other words, the object of grief is not our awareness of what the deceased lose by dying but what we the bereaved lose by their dying.

But loss of what exactly? We might think that what is lost are the various goods that the deceased individual provided to the bereaved: companionship, comfort, and so on. However, this claim is at odds with the fact that we can grieve those who disappointed us by failing to provide these goods (as when an adult grieves the death of a parent who abandoned her at a young age). We instead grieve for those in whom we invest our hopes regarding our well-being, even if they ultimately do not live up to those hopes (Nussbaum 2001: 81–82). Furthermore, to think that the loss that is grief's object is the loss of the goods provided by the deceased overlooks the sense of *irreplaceability* that

the bereaved attach to the deceased. To suppose that the right response to having lost, say, one's spouse is to immediately find another spouse with the same desirable attributes is to overlook that the value of our relationships with one another, especially our loving relationships, cannot be reduced to the value of the goods that others provide us. We relate to others as persons first and foremost, not as baskets of goods.

The object of grief, I propose, resides in the fact that death necessitates a transformation in the relationship that a surviving individual has with the deceased. Our relationships with the deceased do not necessarily end with their deaths, but they cannot but be changed by death. Obviously, the relationship becomes much more one-sided, given the impossibility of the deceased communicating with the bereaved. Lacking agency, the deceased can no longer be directly addressed with our pleas. Certain characteristic attitudes a person may have had toward the deceased no longer make apparent sense. Certain ethically salient acts (e.g., forgiveness or the keeping of promises) can no longer be performed in a straightforward way. The activities that constitute the relationship—conversations, dining, enjoying nature, and so on—cannot continue. With the death of one of its members, a relationship crosses a critical Rubicon.

As social animals, human beings' sense of themselves and their orientation in the world is significantly constituted by their relationships with others. Many bereaved persons report feeling a loss of a part of themselves. This is not surprising, since the death of the partner in a crucial relationship can lead to a sense of identity crisis in the bereaved as they struggle to grasp their own situation in light of a reconfigured relationship with the deceased. Note that the relationship need not be lost in its entirety. It is instead transformed by the other's death. Grief, I suggest, is the emotionally fraught process by which we regroup our relationship with a deceased individual on new terms.

My concern here is with how grief in turn shapes end-of-life decision-making by patient-appointed or next of kin surrogates. Of course, the patients in question are not yet deceased. Hence, the surrogates are undergoing anticipatory grief, grief predicated on the awareness that the patient is dying (or is likely to die). Yet anticipatory grief has the same source as "ordinary" grief—namely, the awareness that one's relationship with a particular person is (or is about to be) transformed by that person's death. It may seem odd that we can undergo an emotion or emotional process prior to its object being present. But this is commonplace. We sometimes experience anticipatory anger in the expectation that we are about to be wronged. We sometimes experience *anticipatory* joy in the expectation we are about to have our sense of well-being augmented. As an emotion, fear thrives on the anticipation of a threat. In this respect, that grief can precede the object that, properly speaking, triggers it is to be expected.

Surrogate Competence and the Care-Attachment Conflict

Many surrogates, I claim, are asked to make end-of-life medical decisions in the midst of anticipatory grief. Anticipatory grief is the first stage in a process whose psychological object is the crisis that an intimate's decline and impending death bring about in the surrogate's relationship with that intimate. This crisis, I now argue, compromises the surrogate's capacity to exercise the substituted judgment that, according to the standard model of surrogate decision-making, a surrogate is obliged to exercise on the intimate's behalf. More specifically, surrogates undergoing anticipatory grief experience a conflict between two central emotional facets of this relationship—namely, attachment and care.

As we saw in the third section, we experience grief at the loss of relationships with those who matter to us. But others can matter to us in multiple ways.

On the one hand, we typically *care* for those we grieve. To care for another is to regard her as important in a specific way—to wit, to see her well-being or concerns as an especially powerful sources of reasons for acting. In caring about another, we render ourselves emotionally vulnerable to their states. To care about another is to feel

joy and satisfaction when the object of one's care is flourishing and frustration over its misfortunes; anger at agents who heedlessly cause such misfortunes; pride in the successes of the object of care and disappointment over its failures; the desire to help ensure those successes and to help avoid the failures; fear when the object of care is in danger and relief when it escapes unharmed.

(Jaworska 2007: 560–561)

The care stance is thus one in which the other is a source of *second*-personal concern—that is, their weal or woe is given greater weight in one's choices and actions than that of strangers or of those with whom one does not have a caring relationship.

On the other hand, we generally grieve for those with whom we stand in a relationship of *attachment*. To experience attachment to a person is for that individual to serve as a source of security. Monique Wonderley (2015) analyzes attachment as having four features:

1. The attached individual seeks to be proximate to, and to interact, with the person to whom she is attached.
2. The attached individual experiences distress upon separation from the person to whom she is attached (or at the prospect of such separation).
3. The attached person derives a sense of security from the presence of the person to whom she is attached.

4. The person to whom she is attached is a “non-substitutable particular” for the attached individual—that is, only that person instantiates features 1–3 in precisely the way she does.

To the extent that security is a human need, we thus come to need those to whom we are attached. Attachment thus has a decidedly *first*-personal quality. Our attachments to others give us reasons to act that are inextricably tied to our own sense of identity and well-being.

Not every important relationship involves both care and attachment: Adult siblings, for instance, may care for another but not have the sense of felt neediness or security that characterizes attachment. A person may be romantically obsessed with someone to whom he is attached but about whom he does not care. However, many relationships that matter to us will include both attachment and care. Long-term romantic partners, for example, generally are attached to one another, but also care for one another. And the balance between care and attachment in relationships may shift over time. A relationship with one’s parents may shift from one dominated by attachment to one dominated by care once one’s parents become aged, debilitated, or ill. Similarly, as one’s children mature, care may begin to recede in importance as attachment grows in importance.

Critically for our purposes, attachment and care generate two competing sets of emotional prerogatives. The desires rooted in attachment to another lead us to hold fast to her as a source of security, to fear (and hence avoid) the distress associated with loss of that individual, and to seek to sustain the relationship with that individual on familiar and welcoming terms. The prerogatives of care, in contrast, lead us to be concerned for another’s welfare for her own sake, occasionally even at cost to ourselves. My hypothesis is that in the midst of anticipatory grief and the relationship crisis wrought by it, surrogates undergo a clash between these two sets of prerogatives, a clash in which (unsurprisingly) attachment’s prerogatives often prove stronger than those of care. Grieving surrogates must in effect undertake two cognitively and emotionally taxing tasks simultaneously: reorienting or reconfiguring a relationship with a person who is rapidly withdrawing from that relationship while also exercising impartial judgment on that person’s behalf. Grief can thus cloud surrogate decision-making thanks to the difficulties of shifting between the first-personal attachment-based evaluative perspective characteristic of grief and the second-personal care-based evaluative perspective demanded of competent surrogates.

This hypothesis helps to explain, in both general and specific terms, the empirical findings laid out in the second section. Surrogates report significant stress surrounding the accuracy of the medical choices they make (Wendler and Rid 2011). This stress, I suggest, can partially be traced to the conflict between care and attachment that surrogate grief evokes. In a moment when attachment

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is threatened, surrogates are asked to undertake an unusually demanding care task: deciding what is best for an incompetent other by that other's lights.

This conflict can also account for specific findings about how surrogates tend to err. First, that surrogates undergoing a care-attachment conflict will often err in favor of overtreatment relative to patients' own wishes is readily explained by our hypothesis. Surrogates wish to maintain their attachment with the patient on familiar terms and so may opt for aggressive treatments in the hope that such treatments will enable that attachment to continue. Similar considerations indicate how my hypothesis explains why surrogates are particularly unreliable regarding end-of-life decision-making. With other medical decisions, the life of the intimate is not so directly at stake and so the surrogates' attachment is less threatened in those decision-making contexts. My hypothesis also helps to account for surrogates' common and almost magical belief in the congruence of their values and preferences with those of the patient (the putative "inner sense" of the patient's values and preferences). Surrogates in the midst of a relationship crisis will understandably want to maintain attachment with the dying patient. The belief in this congruence likely reflects a yearning for that attachment. After all, by identifying her preferences as the patient's preferences, the surrogate sustains a sense of unity or presence with the patient. Finally, prior communication between surrogates and patients regarding patient values and preferences often fails to improve subsequent surrogate decision-making. Here my hypothesis implies that this failure may be due to the fact that such communication will often occur near the onset of the surrogate's anticipatory grief that takes her rapidly changing relationship with the dying patient as its object. The stresses of anticipatory grief may make it difficult for surrogates to process or fully attend to statements made by the patient.

Obviously the hypothesis that surrogates undergo anticipatory grief and an ensuing attachment-care conflict that is often resolved in favor of the former does not explain every instance in which surrogates fail to exercise substituted judgment or every facet of those failures. However, given the absence of extant explanations of surrogate unreliability in either the philosophical or psychological literatures, and the hypothesis's fruitfulness in explaining the available evidence concerning surrogate unreliability, I contend that this hypothesis deserves serious consideration.

From a broader philosophical perspective, this hypothesis implies that in defending surrogacy and the standard of substituted judgment, many bioethicists have unwittingly adopted too harmonious or unified a picture of human rationality. Note that I have not said that anticipatory grief, or the attachment-care conflict it tends to invite, is an irrational reaction on the part of surrogates charged with end-of-life decision-making responsibilities. Quite the contrary. Such reactions will often be perfectly rational responses to the changes that

the impending death of a loved one brings about or anticipates (Cholbi 2016). However, human rationality is multifaceted and in some respects fragmented. One and the same action or reaction may be rational along one dimension but irrational along another dimension. Such is the case with respect to anticipatory grief and surrogate medical decision-making, I propose. A bereaved surrogate can be torn between a legal (and moral duty) to be a reliable decision-maker on a patient's behalf and a prudential imperative to grieve so as to sustain whatever attachment she may have with that patient. The former duty and the latter imperative can fail to coincide, despite the fact they owe their existence to a common source—namely, the surrogate's presumed intimacy with the patient. In such circumstances, it may prove effectively impossible to divorce the rational, attachment-based responses evinced by anticipatory grief from the irrationality surrogates often exhibit when they attempt to exercise substituted judgment on behalf of the very individual for whom they are grieving. At the very least, faulting surrogates for resolving this conflict by prioritizing their own attachment to the dying individual over their care-based duty to exercise substituted judgment for that dying individual seems unsympathetic, even hard-hearted.

Possible Responses

The claims I have defended regarding how anticipatory grief undermines the sort of rationality necessary for surrogates to exercise substituted judgment on behalf of patients undergoing end-of-life care are troubling. After all, a going assumption of the existing regime of medical ethics is that surrogates are well situated to make rationally grounded judgments regarding another's care precisely *because* most surrogates stand in an intimate relationship with the other individual (Lindemann and Nelson 2014: 163). If sound, my arguments demonstrate that exactly the opposite is the case: intimate surrogates undergo a conflict between their duties of care and the attachment threatened by the patient's death, a conflict that makes surrogates substantially less rational qua proxies—that is, far less able to make those choices that the patient herself would have made while competent. Of course, my hypothesis remains somewhat speculative. To be empirically vindicated, investigations would have to be made targeting two relevant populations, surrogates facing end-of-life decisions undergoing anticipatory grief and surrogates facing end-of-life decisions not undergoing anticipatory grief. My hypothesis would predict greater difficulties in exercising substituted judgment in the former population than in the latter. At the very least, my hypothesis suggests an agenda for research bridging clinical psychology and clinical ethics.

In the meantime, however, how ought the bioethics and clinical communities best respond to this conclusion? The most radical response would be to declare the regime of surrogacy a failure and jettison it altogether—that is, to

have medical decisions for incompetent patients not be made by designated or legally mandated familial surrogates but by institutional professionals. This option may seem attractive inasmuch as such professionals, because they lack the intimate ties to particular end-of-life patients, would not undergo the emotional conflict we have articulated and so would be better positioned to exercise substituted judgment on a patient's behalf. I am reluctant to embrace this option, however. While I have made clear that there are strong reasons to doubt that intimate surrogates can circumvent their anticipatory grief and exercise the proper form of surrogate rationality, the specter of such decision-making being *automatically* delegated to physicians, social workers, attorneys, and so forth is likely to be highly traumatic for families. To deny family members or other intimates the right to make medical decisions for incompetent patients may increase its epistemic reliability, but at the cost of alienating the former from the latter just when the desire for a sense of connection or intimacy is at its greatest. And the great majority of patients prefer family members or loved ones to make their medical decisions for them when they are incompetent, in large measure due to the belief that such surrogates will in fact make the medical decisions that the patient would (Kelly et al. 2012).

A second possibility would be to change the standard of judgment applied to surrogates. Under the substituted judgment standard, a surrogate's duty is to decide in accordance with what the patient would have wanted while competent. However, alternative standards are possible. One would be to require surrogates to decide only on the basis of a patient's past express statements of her wishes—that is, not on the basis of potentially iffy conjectures about the patient's preferences or values but solely based on relatively unambiguous patient declarations. Another possibility would be to hold surrogate choice to standards that are not indexed to patient preferences, whether explicit or inferred, at all. For instance, surrogates could be asked to decide solely on what is in the patient's best interests, objectively understood.

The difficulty with proposals to apply these other standards to surrogate decision-making is that it is not clear they evade the challenges presented by anticipatory grief. A surrogate asked to decide solely on the patient's past explicit statements can nevertheless, because of the care-attachment conflict I have identified, disregard or unwittingly misinterpret those statements. Indeed, the earlier evidence that communication between surrogates and patients does not contribute much to the reliability of surrogate decisions supports this contention. Similarly, surrogates asked to decide based on the patient's objective best interests can nevertheless have their decisions clouded by the very same mechanisms of anticipatory bereavement that I have argued cloud the decisions of surrogates asked to exercise substituted judgment. In all likelihood, surrogates in anticipatory bereavement will be prone to represent judgments of their own attachment-based interests as judgments of a patient's best interests.

But so long as surrogates are employed and the presumption is that these surrogates will typically be intimately familiar with the patient, what can be done about the apparent gap between surrogate choice and patient preferences, a gap that (I have argued) can be partially explained by surrogates undergoing anticipatory grief that impedes their capacity to exercise substituted judgment? One clinical response to the way in which anticipatory grief undermines the rationality needed for surrogates to exercise substituted judgment would be to attempt to counteract the effects of anticipatory grief on surrogate decision-making. Such a strategy could involve promoting awareness of anticipatory grief among clinicians, patients, and their families. At the very least, my conclusion implies that grief counseling, a common feature of the end-of-life care environment nowadays, should begin not when the patient dies but when it becomes evident that the patient's death is imminent. Such a policy would require more candor than is sometimes in evidence in end-of-life settings: traditionally, the medical profession has believed in the therapeutic value of hope and has thus been reluctant to tell families outright that their loved ones have a negligibly small chance of recovery and will almost certainly die (McMillan et al. 2014). Still, providing "pre-mortem" grief counseling may lead surrogates to be more aware of the effects of their own grief on their decision-making and thus enable them to compartmentalize that grief so as to focus on their duty to exercise substituted judgment for the patient.

Beyond this, my conclusion suggests that the ethical rationale for surrogacy may need to be reconfigured so as to displace surrogate reliability as the sole factor in judging surrogate performance. In other words, it may be possible to retain surrogacy but ground it, at least partially, on a different ethical basis. From the patient perspective, surrogacy is ostensibly valuable because it enables the medical decisions made for the patient to reflect the patient's values or preferences. However, attitudes toward surrogacy are complex. First, while patients do anticipate that their surrogates will make a decision reflecting their (the patients') values and preferences, patients recognize that surrogates have a difficult responsibility and are therefore reluctant to blame their surrogates for decisions that deviate from their preferences and values (Fins et al. 2005). Indeed, patients generally understand that surrogate decision-making is burdensome and that surrogates must live with the medical choices they make. These considerations suggest that while patients do in fact value their autonomy and so desire a surrogate to exercise it on their behalf, they are fairly forgiving about how surrogates exercise their autonomy so long as it is done conscientiously. Second, there may be reasons besides the value of autonomy, especially reasons rooted in patients' relationships with their surrogates, for valuing surrogacy arrangements. We might attempt to identify these reasons by considering whether, if we knew beforehand that whomever we designate as our medical surrogate would nevertheless make medical decisions at odds with those we

would make for ourselves, we would nevertheless proceed to designate our chosen individual as our surrogate. If the answer is “yes,” that implies that something besides the purported reliability of the surrogate may explain the desire to have surrogates make our medical choices for our incompetent selves. One possibility is that designating a surrogate may be seen as an act within a relationship. In selecting a surrogate, we may not be so much identifying the individual who we believe will best exercise the quasi-fiduciary responsibilities of a surrogate. Rather, we may be signaling to an individual our love or esteem for her by selecting her as our surrogate. If so, then the message sent by patients to their medical surrogates may be less egocentric and more other-regarding, less “you know what I want (or will want)” and more “you are the one that I want to choose for me.” In that case, surrogacy is more akin to an honor bestowed upon the surrogate than a moral responsibility transferred to him, for the patient’s concern is less with “what is decided” than with “who does the deciding” (Lindemann and Nelson 2014: 166). On this model, the surrogate’s authority is not simply a reflection of her presumed knowledge of the patient’s preferences. And although it may still be desirable for surrogates to exercise appropriate substituted judgment, it may be less crucial to the patient that the surrogate make the medical decisions her counterfactually competent self would have made.

Conclusion

In tandem, the two measures described in the previous section—greater emphasis on pre-mortem grief counseling and less concern that surrogates replicate the decisions patients themselves would have made while competent—narrow the gap between surrogate decisions and the moral expectations imposed on them, both by improving surrogate capacity to exercise substituted judgment and by de-emphasizing the centrality of reliability in evaluating surrogate performance.

All the same, grief is a ubiquitous part of the human condition, and it would be vain to think that its negative effects could be entirely mitigated or ethically cabined. Hence, the common gap between surrogate decisions and patient preferences or values may be one we must tolerate to some degree. Indeed, it may be effectively impossible to mitigate grief’s negative effects on medical decision-making without stanching grief altogether, an ethical price that may be too great to bear.

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Related Topics

Chapter 7, “Deciding for the Incompetent” by Eric Vogelstein

Chapter 13, “Solidarity near the End of Life: The Promise of Relational Decision-Making in the Care of the Dying” by Bruce Jennings

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