CONFLICT OF INTEREST IN GLOBAL, PUBLIC AND CORPORATE GOVERNANCE

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CAMBRIDGE
UNIVERSITY PRESS

CAMBRIDGE UNIVERSITY PRESS
Cambridge, New York, Melbourne, Madrid, Cape Town,
Singapore, São Paulo, Delhi, Mexico City

Cambridge University Press
The Edinburgh Building, Cambridge CB2 8RU, UK

Published in the United States of America by Cambridge University Press, New York

www.cambridge.org
Information on this title: www.cambridge.org/9781107029323

First published 2012

Printed in the United Kingdom by MPG Books Group

A catalogue record for this publication is available from the British Library

Library of Congress Cataloging-in-Publication Data

Conflict of interest in global, public and corporate governance / edited by Anne Peters and
Lukas Handschin; assistant editor, Daniel Högger.
pages cm
ISBN 978-1-107-02932-3 (Hardback)
1. Corporate governance–Law and legislation 2. Conflict of interests. I. Peters,
Anne, 1964– editor of compilation. II. Handschin, Lukas, editor of compilation.
K1327.C655 2012
346′.0664–dc23
2012015925

ISBN 978-1-107-02932-3 Hardback

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Conflict of interest at the bedside: surrogate decision-making at the end of life

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1. Introduction

A significant tension besetting fiduciary or trust relationships is that the most able and desirable trustees – who offer familiarity and intimacy, caring and commitment, esoteric knowledge, inside information, expertise, hands-on experience, and political, financial, and social capital – are also least likely to be disinterested. Paradoxically, then, conflict of interest[1] is often embraced by principals even as it is renounced.[2] In this chapter, I explore the implications of this paradox in the most asymmetric and vulnerable of fiduciary relationships, in which surrogates make medical, often end-of-life, decisions on behalf of incompetent patients unable to speak for themselves.

This most asymmetric of fiduciary relationships was born of the core principle in Western bioethics of autonomy and self-determination: that we have the right to control our bodies, to make informed decisions regarding our own medical treatment, including the right to refuse life-sustaining interventions. Indeed, this right of autonomy is so fundamental, that it extends beyond our ability to exercise it. Federal and state

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* This material is based upon work supported by the American Bar Foundation, M.D. Anderson Foundation, and the National Science Foundation under Grant No. SES 0752159. Any opinions, findings, conclusions, or recommendations expressed in this material are those of the author and do not necessarily reflect the views of the National Science Foundation or the other foundations.

[1] The conception of conflict of interest employed in this chapter is that developed by Peters, 'Conflict of interest as a cross-cutting problem of governance', Chapter 1 in this volume. See also Davis, 'Empirical research on conflict of interest: a critical look', Chapter 3 in this volume.

[2] Shapiro, *Tangled Loyalties*, p. 8. For a somewhat similar insight, see Friedberg, 'Conflict of interest from the perspective of the sociology of organised action', Chapter 2 in this volume.

laws throughout the United States empower so-called surrogate or proxy decision-makers to act on behalf of patients who lack decisional capacity. These laws dictate that surrogates follow our stated wishes and, where they are not available or appropriate, use 'substituted judgments' choosing as we would now choose if we were competent and aware of all the relevant facts and circumstances, including the fact that we are incompetent.[3] In exercising substituted judgment, fiduciaries stand in our shoes – taking account of our prior statements, actions, instructions, personal value system, character, goals, beliefs, attitudes, and lifestyle – to try to replicate what we would have wanted.[4] Where our substituted judgments cannot be determined, legal doctrine instructs surrogates to adopt a 'best interest' standard, to advance our interests, promote our well-being, and choose, after weighing the benefits and burdens, a course of action with the greatest net benefit.

It is this delegation of the exercise of autonomy to a surrogate decision-maker that gives rise to a profound fiduciary relationship. Incompetent or comatose patients often do not select their fiduciaries, specify their obligations, direct or control their actions, instruct them of their preferences, have an opportunity to change those preferences, monitor trustee behaviour, or fire or replace their trustees. Fiduciaries, often making irreversible life-and-death decisions, typically have no training, no experience, no instruction in fiduciary responsibility or the laws that regulate their role. Their obligations often come suddenly on the heels of a medical crisis, out of the blue, with no opportunity to prepare for or to acclimate to their role and face decisions that must be made immediately, with no time for consultation or deliberation.

State laws provide an opportunity for us to minimise the asymmetries in this fiduciary relationship with our would-be surrogate decision-maker. We are encouraged to execute advance directives while we are still competent that name our future surrogates ('powers of attorney') and/or that specify our preferences regarding end-of-life care in instructional directives (sometimes called 'living wills'). But a large body of empirical research[5] indicates that Americans rarely do so. And even on

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[3] Buchanan and Brock, *Deciding for Others*, pp. 94–95.

[4] Emanuel and Emanuel, 'Decisions at the End of Life'.

[5] Kass-Bartelmes and Hughes, 'Advance Care Planning'; Pew Research Center for the People & the Press, *Strong Public Support for Right to Die: More Americans Discussing – and Planning – End-of-Life Treatment* (2006), available at http://people-press.org/report/266/strong-public-support-for-right-to-die (last accessed 15 December 2011); American Bar Association, *ABA-Commissioned Poll Finds More than Twice as Many Americans Talk About*

the rare occasions that patients do specify their treatment preferences in advance, instructions are often too vague or do not apply to the particular decision at hand and, therefore, provide little guidance to surrogates. Surrogacy laws specify who our default proxy decision-makers will be for those of us who decline to name them[6] as well as the kinds of medical decisions they are entitled to make.[7]

Surrogates, whether named by patients in advance or by legal default rules, tend to be their family members. The compelling case for entrusting them with this profound responsibility, especially with making substituted judgments, reverberates from Presidential Commissions to court opinions to empirical data. Rhoden summarises the argument:

> Not only are family members most likely to be privy to any relevant statements that patients have made on the topics of treatment or its termination, but they also have longstanding knowledge of the patient's character traits. Although evidence of character traits may seem inconclusive to third parties, closely related persons may, quite legitimately, 'just know' what the patient would want in a way that transcends purely logical evidence. Longstanding knowledge, love, and intimacy make family members the best candidates for implementing the patient's probable wishes and upholding her values.
>
> . . . The family is the context within which a person first develops her powers of autonomous choice, and the values she brings to these choices spring from, and are intertwined with, the family's values. A parent may understand a child's values because she helped to form them, a child may grasp a parent's values because the parent imparted them to her, and a couple may have developed and refined their views in tandem . . . [I]t makes sense, when trying to identify the choice the patient would make if she could, to defer to the family as one of the groups from which the patient's former power to make rational choices arose.[8]

But family members or other intimates have the most to gain or lose by discretionary decisions they make on the patient's behalf. This is not to say that surrogates intentionally put their interests first or are even mindful of divergences or tensions between their interests and those of the patient. It is simply to say that, as in all fiduciary relationships, conflict of interest is inherent in surrogacy and perhaps even more acute because of the overwhelming attraction of intimates as surrogate decision-makers.

The conflicts of interest investigated in most of the contributions to this volume are embedded in complex organisations, professional services, and state and multi-national political institutions, and inflamed by the increasing complexity and interdependence of social life, as Friedberg has observed.[9] This chapter reminds us that conflict of interest threatens even the most simple, primordial relationships that form the bedrock of our social structure.

2. Research methods

In this chapter, I explore how conflicts of interest arise at the bedside and how they are resolved with data from a multi-year (2007–2009) ethnographic study of more than 2,000 patients who passed through either the neurological or the medical intensive care unit (ICU) of a large urban Illinois teaching hospital in the United States serving a demographically diverse population. The neurological ICU houses patients experiencing brain trauma, tumours, haemorrhages, strokes, seizures and spinal chord injuries. Patients in the medical ICU suffer from organ failures, sepsis, respiratory distress, cancers, bleeding and so on. Two hundred and five patients (with at least a three-day ICU stay) lacked the ability to make medical decisions; the study focused on more than 600 surrogate decision-makers and others who spoke on their behalf. They faced a host of medical decisions, ranging from whether to undertake surgery or other medical procedures to whether to withhold or withdraw life support or donate the patient's organs.

Planning for Healthcare Emergencies than Take Action (2008), available at www.abanet.org/abanet/media/release/news_release.cfm?releaseid=345 (last accessed 15 December 2011); US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy, *Advance Directives and Advance Care Planning: Report to Congress* (Washington DC, 2008), available at http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf (last accessed 15 December 2011).

[6] A sequential order usually beginning with guardians of the person followed by spouses, adult children, parents, siblings, adult grandchildren, and close friends. Interestingly, despite the legal priority of spouses as surrogates for married patients, several studies find that a substantial number of married patients (a fifth to a half) indicate that they would not choose their spouse as their surrogate decision-maker. See Lipkin, 'Identifying a Proxy for Health Care as Part of Routine Medical Inquiry'.

[7] Not surprisingly, surrogates selected by state default rules have more limited rights to remove life support than powers of attorney who were chosen by the patients themselves.

[8] Rhoden, 'Litigating Life and Death', pp. 438–439.

[9] Friedberg, 'Sociology of organised action', Chapter 2 in this volume.

From daily rounds with the critical care team, observations of more than 1,000 interactions and meetings between almost 300 different health care providers and patient families and friends throughout the day, and both paper and electronic medical records, data were gathered on the medical issues patients faced, the interventions made, the disposition of their hospital stay, their advance directives (if any), what transpired in meetings with their representatives regarding their medical care, and their demographic characteristics and those of meeting participants. After each observation, detailed accounts of the interaction and what was said by each participant were prepared. They note the questions representatives ask; the concerns and values they articulate; their statements about the patient; references to advance directives; the memories, reasons, and justifications they share; references to their own needs or concerns or those of others; comments about financial matters, the things they do not say or ask; the disagreements among one another they negotiate; as well as the decisions that they make and remake over days and weeks. Observations also record how health care providers interact with patient families and friends, the conditions under which they confer with them, and how they frame the issues and advise them.

Despite the extraordinary opportunity to observe different configurations of surrogates and other family members on many occasions interacting with different medical staff, often in lengthy conversations, one faces significant methodological challenges assessing their conflicts of interest. First, actors engage in self-censorship, maintaining silence about their self-interests or pressures from others and how they may conflict with those of the patient (at least while talking with hospital staff). Secondly, it is rare that patient interests are independently known. Because most patients are unable to speak for themselves and few put their preferences in writing, information about their interests are typically reported by family members. Although the latter may not intentionally lie about the patient's preferences so that they appear consistent with their own, informants may not be aware of the divergences. As Rhoden observed, our preferences are first formed in the cauldron of family values; members may therefore erroneously assume that what they want for themselves replicates what patients also want.[10] Finally, surrogates and others face psychological blinders to the recognition of their own conflicts of interest.[11]

Surmounting these methodological limitations requires various indirect strategies, especially given that researchers were not authorised to address or question family members directly. One listens for questions asked as well as statements made, for inconsistencies in rationales or justifications, slips of the tongue, perseveration on a particular theme, inordinate numbers of references to the self ('I want') and infrequent references to the patient, and so on – none of which, of course, is dispositive that the speaker has succumbed to conflict of interest. One waits until conflicting interests or priorities within the family and among other members of the patient's entourage detonate and members begin questioning the motives of one another. Or one waits for physicians to explicitly ask surrogates to differentiate between patient interests and their own or those of others or to question their disinterestedness. No strategy is perfect, but one may get a better sense of conflict of interest by observing a population that is exhausted, frightened, under stress, battered repeatedly by questions from medical providers, and preoccupied by more serious matters, than a group of professionals, politicians, CEOs, and other fiduciaries better able to control the conversation and conceal their motives and interests.

3. Sources of conflict of interest at the bedside

> *NEUROSURGEON: One of the things I need to talk about is all of the delays that have occurred when your family refused or questioned various interventions that our medical team felt was necessary to provide appropriate care.*
>
> *DAUGHTER: What are you referring to? The delay in the EVD* [a drain to remove fluid from the brain]? . . . *We asked the resident if it could wait until the morning and he said that it could. . . . The next morning, when you said it was necessary, we agreed to it right away.*
>
> *NEUROSURGEON: With your delay on the decision regarding the EVD, we thought that maybe you were trying to decide whether to pursue the most aggressive care or whether to let him pass. But there have been many other delays or the refusal by your family to allow the doctors to perform what was in your father's best interest. I have had no problem with you. I have been able to work smoothly with you. But I have heard complaints among the staff that there was some motivation for your delay, that maybe you didn't*

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[10] Social psychologists label this phenomenon a *false consensus* effect, in which individuals – even strangers – tend to overestimate how much others agree with their judgements, values, positions, choices, or behaviours. See Marks and Miller 'Ten Years of Research on the False-Consensus Effect'.

[11] Chugh, Bazerman and Banaji, 'Bounded Ethicality'. See also Davis, 'Empirical research', Chapter 3 in this volume.

> *have your father's best interests in mind. I am the physician of record in this case. . . . If anyone makes an allegation, I am responsible. I need to air it and get it out on the record. If there is an appearance of impropriety, I need to consider it. Some day if there is a dispute about an inheritance, for example, I don't want to be responsible.*
>
> *DAUGHTER: Who has made these allegations? What exactly did they say?*
>
> *NEUROSURGEON: I don't think it would be appropriate for me to say more. I don't want to do anything that might undermine his care.* [Neurosurgeon continues repeating how much interference there has been.]
>
> [Daughter tries to find examples that he may be alluding to and providing explanations for the cause of the delay.]
>
> *NEUROSURGEON: I am not making any accusations.*
>
> *DAUGHTER: You said 'appearance of impropriety'; that's a quote . . . I could be a little offended by what you are saying. Actually, I could be extremely offended.*
>
> *NEUROSURGEON: I'm sorry, but you are not my client. The patient is my client.*
>
> *SON-IN-LAW: . . . I would like to be able to talk with the people who have reservations about us and address their concerns directly. Is there a way to expunge that accusation?*
>
> *NEUROSURGEON: I have no problem with you.*
>
> *SON-IN-LAW: If you hear this again, please address it to us in a timely fashion so that we are able to respond to it.*
>
> *SON: I am a simple man. All last week, we were told that there is a fork in the road and we need to decide which fork to take. If we wanted to do my father harm, we could have easily taken the other fork. We wouldn't have needed to delay procedures to do this.*

This dialogue that unexpectedly exploded in a family meeting meant to provide an update on the patient's condition and set goals for his care represents the most explicit accusation of conflict of interest in the study. The family was rather affluent and the uncharacteristically abrasive, distrustful, interfering, micromanaging children (who maintained a twenty-hour hour vigil by the patient's bedside for several months) were the subject of gossip, derision, and suspicion by many of the nurses and doctors entrusted with the patient's care. Unable to make sense of the family's extremely unusual behaviour in any other way, some medical staff apparently attributed it to a conflict of interest. The neurosurgeon's off-handed example of a future lawsuit regarding an inheritance suggests suspicion that family members were putting their interest in access to the patient's business and considerable wealth ahead of his best interest.

Having spent more time observing this family than any member of the medical team, I am convinced that these suspicions were ill-founded. But they represent an omnipresent source of conflict of interest in surrogate medical decision-making. Surrogates and other family members face substantial financial costs and potential benefits related to the admission of a loved one to an intensive care unit. On the one hand, ICU care is extraordinarily expensive – as much as $10,000 per day.[12] Authorising aggressive or experimental treatments increase both the cost of care and the length of hospitalisation. Few ICU patients return home immediately without continuing health care expenses. Some end up in rehabilitation facilities, nursing homes, or long-term acute care hospitals; even those who go home may incur expenses for visiting nurses, out-patient therapies, medical equipment, pharmaceutical or hospice costs. Roughly 84 per cent of the patients in the study had some form of health insurance or public aid; but even these more fortunate patients face coverage exclusions, deductibles and co-payments, yearly or lifetime maximum coverage ceilings or limited numbers of days of hospitalisation, rehabilitation, or long-term care. These uncovered expenditures diminish or deplete the patient's estate (if any), of which some surrogates are heirs. Many other surrogates must cover these costs with their own financial resources or those of their parents, children, or others for whom they also have fiduciary responsibility. For some surrogates, the timely death of the patient will stop the haemorrhaging of family financial assets; others may even enjoy a resulting life-insurance windfall. In short, the death of the patient might serve the financial interests of fiduciaries or of others who they also serve.

Less often, the death of the patient will threaten financial interests of the surrogate or others. Perhaps the patient is a principal in a lucrative business that will not survive his or her death or perhaps retirement benefits on which the surrogate relied may end upon the patient's death. Or an anticipated inheritance may be diverted to a surviving spouse who had been expected to predecease the patient. Chillingly, in a famous US bioethics case, the mother of a severely burned patient was advised by their lawyer that the patient (who was pleading to be allowed to die) was worth much more alive than dead in an upcoming law suit against the company whose pipeline had exploded.[13] On occasion, then, surrogates face financial incentives to undertake aggressive medical interventions to keep patients alive,

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[12] To get a different perspective, a week in the ICU costs more than the median income for an American family for a year. US Census Bureau, *State and County QuickFacts* (2010), available at http://quickfacts.census.gov/qfd/states/00000.html (last accessed 15 December 2011).

[13] King, 'Dax's Case'. The patient was also worth more alive to the lawyer (who was compensated based on the size of the award) – a double conflict of interest. The mother ultimately ignored her son's pleas and ordered that the excruciating treatment be continued.

sometimes against their will. As these examples suggest, the financial consequences of a particular medical decision may affect the interests of various friends or family members differently, another reason significant others may disagree about goals of medical care.

There is surprisingly little talk of money in an intensive care unit – by patients, families, or even physicians, who rarely have any idea of the cost of the medical interventions they recommend or undertake without a second thought. Comments that suggest that financial concerns may play a role in surrogate decision-making are even more rare. Table 18.1 summarises comments made by surrogate decision-makers pertaining to conflicts of interest that may have affected their deliberative process. For only 2 per cent of the patients were financial concerns mentioned by the surrogate. Two surrogates in the study were unusually blunt. One, a hospice nurse and wife of a patient with a life-threatening genetic condition that had already required scores of surgeries, was finally approaching the lifetime maximum on the patient's medical insurance policy. She expressed her doubts about the point of continuing aggressive care in the face of the patient's impending suffering and death and commented that:

Table 18.1: *References to conflict of interest by surrogates in family-physician interactions*[14]

	Per cent of cases:
Financial concerns	2%
Responsibilities	2%
Loss	7%
Guilt	2%
Emotional burden of decision-making	3%
Conflicting personal values	1%
Concern for the needs of others	5%
Pressures from others	2%
Personal desire[15]	6%
Some reference to conflict of interest	23%
1 type of conflict of interest	16%
2 types of conflict of interest	5%
3+ types of conflict of interest	2%
NUMBER OF CASES	(205)

> *the technicians thought I was nuts when I wouldn't let them do their tests because we couldn't afford them. They can practice medicine the old-fashioned way. They can start with a small amount of medicine and gradually increase it. They don't need to run tests to determine the dosage.*

(After the insurance company increased the lifetime maximum, the spouse authorised another surgery. The patient died about a month later.) A spouse in the other ICU also expressed financial concerns (among others) in deciding whether to reintubate (reinsert a breathing tube into) his wife:

> *RESIDENT: So one option is to take the tube out and if she needs it back in, we could do everything possible to treat her, including putting the tube back in.*
> *SPOUSE: So she'd need to be in a nursing home, right?*
> *RESIDENT: If we were to continue treating her and doing everything, then yes, she would ultimately need to be in a facility.*
> *SPOUSE: I can't afford a nursing home. With the ventilator and the feeding tube and everything, that'd put me in the poor house. I just can't afford that. Neither of us can really. I don't want that tube back in, I'm set on that.*

Undoubtedly other surrogates kept their financial concerns, opportunities, or incentives to themselves. Yet it is striking how few even ask circuitous questions or make indirect comments that would suggest that money or insurance coverage is on their minds, certainly a legitimate factor in decision-making, even if it also sometimes triggers a conflict of interest. A number of patients and families, especially those authorising the most aggressive and expensive of interventions, were clearly destitute (and, ironically, therefore more disinterested); perhaps they didn't talk about money because they had none and knew that someone else would have to foot the medical bill. Perhaps families in countries with universal health care would behave similarly.

A related source of conflict of interest comes from the caretaking responsibilities demanded of family members. The trajectory of a decision to undertake more aggressive treatment usually requires more long-term familial involvement. Whether it is to quit one's job or take family leave to care for the patient, to provide a host of therapies to the patient

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[14] The table includes comments that seem to be weighing heavily on decision-makers as they deliberate. Comments about guilt, loss, the emotional burden of deciding, concern for others, questions about cost, and so forth that trouble the surrogate but do not seem to affect decision-making are not included in the table. Nor are comments made by non-surrogates. More than one type of conflict of interest may be affecting a single surrogate.

[15] The speaker simply indicated that is what I want or this is my choice, without any further elaboration. Many of these surrogates elsewhere expressed fear of loss.

at home, to move in with the patient or renovate the home to accommodate patient disabilities or medical equipment, or to commit time to visit the patient institutionalised in a treatment facility, the long-term responsibilities typically exceed those of a decision to withhold or withdraw life-supporting therapies. It was far more common to hear family members express willingness or even insistence to take on these responsibilities (many of them too busy to visit patients during their brief stint in the ICU), than to eschew them. Though, on occasion (2 per cent of the cases), a surrogate would refuse a recommended intervention because it would require unwanted familial assistance after the patient was released from the hospital.

The most common source of conflict of interest expressed in the ICU reflected emotional issues (11 per cent of cases) in general, and fear of loss (7 per cent) in particular.

> *PALLIATIVE CARE ATTENDING PHYSICIAN: I think the question at this point is how long are we going to allow her to suffer?*
>
> *GRANDDAUGHTER-IN-LAW: That don't matter to us, we just want her alive.*

> *CRITICAL CARE FELLOW: But before we get into all the details of the tracheostomy, I think it's important to look at where things are at with him. He's very critically ill. I don't know him as well as you folks do, and that's why it's important to look to you guys to ask what he would have wanted in this situation, and what his wishes were.*
>
> [Partner starts to cry.]
>
> *CRITICAL CARE FELLOW: I'm sorry to upset you, it's just really important to stop and think about what it is that he would want in this situation, since he's so sick.*
>
> [Partner totally breaks down.]
>
> *PARTNER: I want EVERYTHING done for him. So the trachea whatever, let's do it.*
>
> *CRITICAL CARE FELLOW: Okay, and this is what [the patient] would have wanted?*
>
> *PARTNER:* [Nods] *Please do everything you can do for him. Be aggressive.*

7 Days Later

> *CRITICAL CARE ATTENDING PHYSICIAN: So the update for today is basically that he's doing worse now . . . You know, the risk – I mean, the chances of him recovering at this point are in the miracle range.*
>
> *PARTNER: I just, I'm having a really hard time giving up.* [Starts to cry] *I'm sorry.*
>
> *CRITICAL CARE ATTENDING PHYSICIAN: I would like to point out that you're really not giving up . . . We've really done everything possible to support him and despite all those measures, his body is not able to fight all this. Have you two ever talked about what his wishes would be in this situation?*
>
> *PARTNER: Oh yes.* [LAUGHS] *He would not be here. I know that for sure. I don't care though* [LAUGHING], *I just don't care. I know it's selfish, but I don't want to let go. I know I'm not being rational right now. I just can't imagine not having him.* [Starts to cry more]
>
> *CRITICAL CARE ATTENDING PHYSICIAN: I just think it's important to think about what he would want.*

Few surrogates were so open as these two about their fear of loss or their unwillingness to put their selfish interests aside to honour patient wishes, even if it meant misrepresenting those wishes. But fear of loss, of letting go of a life partner they cannot bear to live without, of being alone, comes up relatively frequently in discussions about goals of care. And several surrogates admitted regretfully after the patient's death or after months of tortuous futile treatment that they had been selfish and should have decided to stop aggressive care much earlier. As the mother of a 42-year-old who had suffered multiple surgeries and interventions for a devastating brain tumour confessed many months into her child's hospitalisation, 'we have been flouting her living will' (which indicated that the patient didn't want to continue to live the way she had been previously living) 'and perhaps it is time to honor it'.

Other emotional needs of the surrogate sometimes got in the way of advocating for the patient as well. They included guilt or fear of being responsible for the patient's death (which was typically manifested in demands for continued, usually futile, treatment and interventions long beyond what was in the patient's best interest), anger (e.g. at the doctors, which was expressed in refusal to accede to their recommendations, thereby causing needless suffering for the patient), the emotional stress of decision-making (which resulted in avoidance or delay, again increasing patient suffering and sometimes undermining care), or suffering from watching the patient suffer (which might be alleviated by the patient's death).

Rarely (1 per cent), the values or religious beliefs of the surrogate and patient conflicted. One of the most ethically mindful of surrogates in the study acknowledged as much and asked to meet with the hospital ethics committee and a priest. The spouse explained that, although the patient was an agnostic and had expressed in a lifetime of conversations that he would not want to be kept alive under existing circumstances, she was a practising Catholic and concerned about the moral claims of the church. Whether she ultimately put her beliefs aside or was counselled how to reconcile the conflict, the spouse forcefully and lovingly reprised and advocated for her husband's interests. Other surrogates expressed religious values or doctrine, concern about playing God, the belief that life must be prolonged at all cost, and so forth as they worked through their fiduciary obligations. It was unclear whether the patient shared their religious views or whether surrogates were speaking only for themselves. In many of these conversations, the patient's interests, beliefs, or preferences – religious or other – were entirely absent from the conversation; it is likely that the religious values that guided surrogate decision-making were those only of the surrogate or that their personal religious convictions trumped their advocacy of incompatible patient interests.

As noted earlier, few patients bother to name their own surrogate decision-makers; they are chosen according to legal default rules, which do not always identify the most appropriate decision-maker for a given patient. It was not uncommon for the prior relationship between patients and family members to be fractious or dysfunctional. Some patients were estranged from the default decision-maker, sometimes even in the process of divorcing them. A few surrogates learned at the bedside that the patient had been cheating on them. In other cases, ex-spouses were at the bedside allegedly to support their children faced with decision-making responsibility; though other family members questioned their influence on the children and tried to exclude them from deliberations. In a few instances, health care staff or family members suspected that the default surrogate was responsible for the injuries (physical or substance abuse) that landed the patient in the hospital. Needless to say, compromised surrogates may experience greater difficulty silencing their own interests or championing those of the patient.[16] Some of these would-be surrogates sensibly delegated their fiduciary responsibility to another. Others perhaps achieved disinterestedness despite the obvious challenges. And others probably did not. In one troubling case, the patient's extended family believed that her husband was responsible for a fall that caused life-threatening brain injuries. The husband believed that his wife would want to donate her organs. But the family threatened that if he made such a decision, they would file criminal charges against him. So, tearfully, he decided against donation.

Like this last spouse, some surrogates were pressured by others (2 per cent) or by fiduciary obligations toward others (5 per cent) – typically their children – that conflicted with their obligations to the patient. They were torn about the impact of financial pressures occasioned by the extended treatment of the patient on their obligations to provide for their children, about caretaking responsibilities to the patient that would steal time away from their children or other vulnerable family members, or about the emotional consequences of the patient's death or disability on the children or others. Some surrogates were pressured by family members to make a different medical decision; this was especially common when the surrogate was a recent spouse, significant other or friend. And other surrogates delayed decisions so that family members could travel to the hospital to say goodbye, sometimes at the cost of extended pain and suffering for the patient. One extremely distraught and tearful sister insisted that her brother remain on life support until his financial estate was legally processed because she felt an obligation to her brother's employees to whom he had left his business and might not receive it if the patient died first.

4. Complications

Of course, the sister's sense of obligation to the employees was inflamed by the patient himself who, on his deathbed, had prepared his financial will only to insure that his employees would inherit the business. So surrogate conflict of interest becomes far more complicated and less transparent when patient autonomous choices give priority to the needs or interests of others (including the surrogate) over their own – something far more common when intimates rather than strangers act as their fiduciaries. Hardwig argues that they should and quarrels with the assumption of Western bioethics:

> . . . our present individualistic medical ethics is isolating and destructive. For by implicitly suggesting that patients make 'their own' treatment decisions on a self-regarding basis and supporting those who do so, such an ethics encourages each of us to see our lives as simply our own . . . To be part of a family is be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself.[17]

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[16] Although they may be less conflicted by fear of loss than those still connected with the patient.

[17] Hardwig, 'What about the Family?', pp. 7, 6.

Other scholars point to cultural differences in conceptions of autonomy and norms about family authority and decision-making dynamics, even about putting one's wishes in writing (which indicates lack of trust in some cultures), that also diverge from the prevailing individualistic ethics that allows for clear demarcations of conflict of interest.[18]

Some patients really do not want to be an emotional burden to others, do not want health care expenses to bankrupt the family, do not want their loved ones to become their nursemaids, saddling them with caretaking responsibilities. Empirical research has consistently demonstrated that a majority of patients indicate that the wishes of their surrogates ought to override their own, even if they are the opposite of the patient's expressed wishes.[19] It is one thing to prefer conflicted agents over strangers; it is quite another to want agents to act on this conflict of interest. For such patients, substituted judgements must also incorporate these other-regarding interests. Are we acting on a conflict of interest if our principals want us to put our interests ahead of theirs or at least to consider them? If not, where do we draw the line? How do we operationalise a vague, perhaps disingenuous expression (tainted by social-desirability bias) that the patient does not want to be a burden? Is a month of family leave from work too much burden? $10,000 in medical bills? Moreover, since few patients express these sentiments in writing or to a disinterested other, there is no way to know whether a seemingly conflicted surrogate is honouring the patient's altruistic wishes or betraying the patient's trust and giving way to the interests of self or others. Perhaps many seeming cases of conflict of interest at the bedside are not conflicts at all. But because much of what we know about patient preferences comes from those with the apparent conflict of interest, it is impossible to distinguish.

Finally, the analysis has implicitly assumed that patient interests and preferences are clear and knowable and are being disregarded (even 'flouted' as one guilty mother in the study confessed) by surrogates in favour of other interests. Yet the literature suggests that the assumption of knowable preferences is far from true, even for the minority of patients who bother to talk about or document them.[20] First, research finds substantial instability in patient preferences over time, even over short periods of time.[21] Secondly, work on affective forecasting suggests that we are very bad at predicting how we will feel about medical problems in the future, generally overestimating the intensity and duration of our emotional reactions to bad events.[22] Thirdly, abstract preferences expressed when we are healthy and unaware of the particularities of various treatment choices, side effects, risks, and uncertain prognoses do not provide clear or appropriate guidance about how to choose among specific interventions to unforeseen medical crises. And then there's the confounding factor that some patients want family interests to be considered as well. In short, surrogates rarely have a clear script to follow or to disregard in favour of other interests. It is not that the patient said 'blue' and the conflicted surrogate picks red. Rather, the patient said 'bluish, if I experience X'; the patient experiences Y, and the surrogate picks 'bluish-purple'. This ambiguity or lack of clarity surrounding patient preferences may allow for other interests to creep in unrecognised. For example: I know the patient does not want to be on life support forever, but would want to have a chance to get better. (I can't bear to lose him.) So let's just continue the aggressive treatment.

5. The prevalence of conflict of interest at the bedside

Table 18.1 shows that for not even a quarter of the patients did conflict of interest besetting surrogates arise in the sometimes dozens of meetings regarding their care. Although many of the examples I described showed fiduciaries who were unable to resist their conflicts and admitted as much, most of the cases in this group involve real threats to disinterestedness to which surrogates probably did not succumb. And perhaps a few apparent breaches actually represent fidelity to patient instructions that surrogates accommodate self and other interests. Because surrogate decision-makers must exercise discretion, there are few right or wrong decisions and therefore no way to determine whether end-of-life treatment choices reflect fidelity to patient interests or were coloured by interests of the surrogates and others. But just as the 23 per cent figure appears too large an estimate of actual conflict of interest compromising surrogate decision-making, other methodological challenges suggest that it could, indeed, be larger. How many surrogates never let on that their

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[18] Berger, DeRenzo and Schwartz, 'Surrogate Decision Making'; Chan, 'Sharing Death and Dying'.

[19] Hawkins et al., 'Micromanaging Death'; Puchalski et al., 'Patients Who Want Their Family and Physician to Make Resuscitation Decisions for Them: Observations from SUPPORT and HELP'.

[20] Shapiro, 'When Life Imitates Art'.

[21] Kirschner, 'When Written Advance Directives Are not Enough'.

[22] Wilson and Gilbert, 'Affective Forecasting'.

decisions were influenced by conflict of interest? Some self-censor, some misrepresent or confuse their interests with those of the patient, some lie (especially in the face of physicians who insist that the patient's wishes and not the surrogate's guide decision-making), some fail to give any rationale or justification for their decision, and others may be psychologically blinded to their conflicts of interest.[23] Is the glass half empty or half full? Given that every surrogate comes weighted with multiple and significant sources of conflict of interest, the fact that conflicts usually play quietly in the background is probably a hopeful sign. On the other hand, given that these are literally life-and-death decisions, even a half-empty glass of conflicted choices is a glass too full.

Who seems to be most troubled by conflict of interest? Because potential conflicts are so rare in this study, few differences between types of surrogates are significant. Two patterns are notable. First, most surrogate decision-makers are close family members – especially spouses and children, but also parents and siblings. When surrogates are not, for example, significant others, friends, or more distant relatives (less than 10 per cent of the cases), they are much more likely to talk about pressures from others affecting their decision-making. This is true of 15 per cent of these surrogates, compared with 2 per cent of the close-family surrogates. Family members are suspicious of the motives of or even resentful of the non-family surrogates' connection with the patient and seemingly feel entitled to pressure them to take into account what they consider their more legitimate preferences in end-of-life decisions.

Secondly, of all surrogate categories, conflict of interest overall is most likely to arise in discussions with parents; this is true of 35 per cent of parents compared with 22 per cent of other surrogates. Parents serve as surrogates for patients who are half the age (thirty-four vs. sixty-seven, on average) of those represented by other types of surrogates.[24] Although the ramifications of medical decisions (long-term caretaking responsibilities, implications for other family members, lack of medical insurance, etc.) for patients so much younger are likely to be quite different and perhaps give rise to different considerations and conflicts, I think a different explanation is compelling. Parents sometimes do not think of their children as autonomous actors to whom they owe fiduciary responsibilities, but rather extensions of themselves. This is likely exacerbated by the fact that patients so young are less likely to express their end-of-life preferences, and when they do, have more difficulty standing up to their parents who may have different priorities. It seems reasonable that parents do not see their self-regarding decisions as conflict of interest in quite the same way that a child making decisions on behalf of a parent would.

6. Silencing conflict of interest[25]

So what to do about conflict of interest at the bedside? As noted earlier, physicians sometimes help surrogates recognise their obligations. Several physicians would repeat the litany, even to surrogates behaving disinterestedly: 'It's not what we want, but what the patient wants.' And there was the example presented earlier of the neurosurgeon who would not be quieted about rumours circulated by others that the family did not have the patient's best interest at heart. Health care professionals could certainly play a greater role assisting surrogates maintain disinterestedness and ferreting out the breaches. But that presumes that physicians themselves understand what conflict of interest is, that they have the time to listen and sometimes interrogate or argue when emergency decisions must be made quickly, and that they have continuing relationships with surrogates (something rare in rotating shifts in a teaching hospital and the 24–7 nature of intensive care) so that they can mentor surrogates and recognise subtle behaviours that may reflect self-delusion or the tug of other interests. Although this certainly happens on rare occasions, especially if families are in conflict or if the surrogate stubbornly disagrees with the physician's recommendations for no good reason, and where time permits, a large-scale change is unrealistic. Hospital ethics committees are available to help, but they need physicians to refer them the potential problems. If a conflict-of-interest expert observing families day in and day out (i.e. the author) could not always recognise their conflicts, it is unlikely that physicians with more pressing responsibilities, few incentives, and less concern about or sensitivity to conflict of interest would do so effectively.

Some of the typical responses to conflict of interest in other contexts do not translate easily to those at the bedside either. For example, agents

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[23] Chugh, Bazerman and Banaji, 'Bounded Ethicality', pp. 74–95.

[24] With very few exceptions, the ICU patients are over 18 years of age.

[25] For a more theoretical perspective on the difficulties of controlling conflict of interest, see Friedberg, 'Sociology of organised action', Chapter 2 in this volume.

disclose their conflicts to their principals.[26] But, of course, most patients are aware of their surrogates' lack of disinterestedness and embrace it as a reasonable price to secure a trustworthy surrogate who knows them well. Besides, most patients never picked their surrogates, so disclosure comes too late, when patients are incapable of responding to the disclosure by hiring a different more disinterested fiduciary. Recusal is equally ineffective. Surely when disinterestedness or the appearance of it is particularly problematic, some surrogates do recuse themselves or are encouraged to do so. Soon-to-be ex-spouses, for example, often cede responsibility to another, as do those paralysed by the emotional burden of the surrogate role. But most of the alternative candidates have their own conflict of interest. And turning over responsibility to one with fewer conflicts also threatens to enlist a surrogate less able to know or champion the patient's interests.

Pursuing the recusal route, some bioethicists and others have proposed wresting end-of-life decision-making from conflicted families or devising an alternative set of default rules when patients have neither named their surrogate decision-maker nor specified their wishes concerning end-of-life treatment. These proposals generally look to strangers as a source of default preferences, determining community[27] standards using survey research, public opinion polling data, or content analysis of the advance directives of those who bothered to execute them to serve as instructional directives for those without them.[28] In other words, we treat the patient as other patients would want to be treated under similar circumstances. There is insufficient space here to critique adequately the many difficulties with such a proposal. But it is hard to imagine a better incentive to get patients to put their directives in writing than facing the loss of autonomy and the likelihood that the preferences of strangers (even experienced ones) will be imposed when they are no longer able to speak for themselves. Nonetheless, this proposal takes us full circle to the tension between conflicted intimates who know us well and disinterested strangers who do not and our abiding preferences for the former, even with the baggage they bring to the role.

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[26] See also Davis, 'Empirical research', Chapter 3 in this volume.

[27] Defined variously as members of one's health care plan, by residence, demographic characteristics, etc.

[28] Emanuel and Emanuel, 'Decisions at the End of Life'; Lindgren, 'Death by Default'.

7. Conclusion

A handful of times over the course of the study, a comatose patient would be admitted to the hospital with no identification. After taking fingerprints, following up on everything in his pockets,[29] and making other inquiries, no one would be found to serve as a surrogate decision-maker and a state guardian would be assigned to the patient. The public guardian would come to the hospital, talk 'at' the comatose patient, leave some legal documents on the patient's rigid body hooked up to various machines, and 'inform' him that he has the legal right to make a court appearance and object to this arrangement. The encounter was a bit surreal. With no information about the patient or his preferences, and in an abundance of caution, the guardian would then consent to every procedure requested by the physicians and pursue aggressive care until the patient woke up, died, or a family member or acquaintance eventually showed up at the hospital. Public guardianship represents yet another fiduciary arrangement for those of us unable to speak on our own behalf. Again, it is no wonder intimates encumbered by conflict of interest seem a more compelling alternative.

Conflict of interest is typically used to refer to the problems of disinterestedness between principals and fiduciaries with distinct interests. Is the concept appropriate for intimates whose interests are often interdependent and for whom there is rarely objective information or self-awareness about where the interests diverge? I think the answer has to be yes, but with the caveat that for both the intimates themselves and for outsiders, disinterestedness will be more of a work in progress. Just as some surrogates at the hospital seemed to delude themselves that their interests replicated those of the patients or simply ignored the patient's preferences, others undoubtedly championed the patient's interest at their own expense or that of others in ways that would have probably mortified the patient.[30] With perhaps the exception of the public guardian, all surrogate decisions are made by conflicted fiduciaries and some are tainted by these conflicts. For some patients, conflicts result in futile care or delay and therefore needless pain and suffering. But for others, the conflicts bring unwanted death, a persistent vegetative state, or a lifetime of excruciating disability and loss. Though the conflicts cannot

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[29] They were often homeless men or men who had been the subject of street violence.

[30] Not unlike Davis' notion of 'bending over backward'. See Davis, 'Empirical research', Chapter 3 in this volume, p. 60.

be obliterated, they can be challenged and the divergence of interests can be identified and clarified when patients are still competent. That will require the commitment of all of us destined to make, receive, or preside over life-and-death decisions.

It is rare that ICU patients regain competence while still in the unit and comment on their surrogate's medical decisions. The words of one such patient, a seventy-six-year-old farmer's wife whose husband's fear of loss impelled him to seek aggressive care despite what he described as his wife's wishes, continue to haunt me. After she awoke, she bit through three breathing tubes in an effort to kill herself. Each day, she pleaded with the nurses:

> *Please kill me. Please help me die. Make it quick.*

They did not and the patient was transferred to a long-term acute care facility. The consequences of decisions tainted by conflict of interest are indeed very real.

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