Conclusion

> The responsibility toward other people's stories is real and inescapable, but that doesn't mean appropriation is the way to satisfy that responsibility. In fact, the opposite is true: Telling the stories in which we are complicit outsiders has to be done with imagination and skepticism.
>
> —Teju Cole

We have indeed presented the cases here as "complicit outsiders," and have endeavored to do justice to the situations we were privileged to witness and in some cases, participate in attempting to resolve. We have brought both our imaginative musings and a degree of skepticism that the difficult dilemmas in this book can be successfully resolved. It is our hope that by enlisting the efforts of others who would also feel complicit in how hospitalized patients die in the U.S., we can work toward solutions that are more inclusive, compassionate, and dignified for all.

The cases included in this volume presented many situations in which competing ideas about the "right thing to do" arose when the stakes were high. We live in an historical moment characterized by differing ideas of the good in almost all facets of life: education, politics, family life, and health care to name but a few. Gone are the days of tolerance of paternalistic physicians, or even agreement on where one should look for guidance in making end-of-life decisions. We have no shared "common sense" anymore about how life is to be lived, or how death can best be achieved (Arnett et al. 2009, 64). In such a time, the most important ethical commitment is to learn about competing ideas of the good. Most of us are far better at explaining our positions and trying to persuade others than we are at really listening and attempting to find at least a minimal set of ideas on which we might agree despite our differences (Arnett et al. 2009; Benhabib and Dallmayr 1990). We live in a time when learning and listening are more important than persuading and judging. Our hope is that this casebook has provided its readers with opportunities to learn more about different perspectives on challenging situations. Commitment to an ongoing "moral conversation" is more important than the desire to achieve consensus by persuading others to agree with what we think is the right course of action (Benhabib and Dallmayr 1990, 346).

As we present our own view of the themes that best characterize the compelling ethical dilemmas presented in this book, five major issues have surfaced

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prominently: poor access to health care; the intersection of cultures/religions; the "validity" of informed consent; problems with family members; and problems with hierarchy and teamwork.[1]

PoorAccess to Health Care

There have been a variety of legislative efforts over the past twenty years to improve access to health care in the United States. All of these contained significant flaws and were ethically controversial. For example, legislation in 2010 moved the country closer to achieving universal health care, but costs have continued to rise and nearly 26 million Americans are still uninsured according to the Congressional Budget Office. As this volume goes to press, further efforts are underway to revise or eliminate the gains made by this previous legislation. Case 1 (about CS, a pregnant prostitute dying of head and neck cancer) and Case 15 (about DJ, an unfunded patient who needed repeated heart valve replacements because of continued drug use) both highlight this issue. CS's unfunded status and social situation, undoubtedly complicated by her image as "the pregnant prostitute," reveal what can happen to someone without regular access to health care despite the fact that she was fortunate enough to receive excellent surgical and maternity care prior to death by virtue of a public safety net. The situation surrounding DJ was even more complicated for he was not only unfunded but burdened with a complicated medical history and a serious drug addiction, which he was unable to control and which led to a series of infections, while he attempted to bargain with his cardiothoracic surgeon for a repeat heart valve replacement. In his case the *scarce resource problem* became coupled with that of *access to care* as well as the question of a *right to care.*

It appears to us that there is more interest in investing in cutting edge medical technologies that might benefit a select few patients than there is in achieving broad access topreventive care such as prenatal care and childhood vaccinations, and similar services for adults designed to reduce the incidence of diabetes and heart disease. A recent report from the Commonwealth Fund[2] found that the U.S. trailed other developed countries in making medical care affordable and ranked poorly in providing timely access to medical care. Yet Americans spend $9523 per person per year on medical expenses—by far the most among developed countries—and still life expectancy in the U.S. is much lower. Many of us tend to credit the enormous gains in life expectancy over the past century to the rise in medical technology. Surely technology and pharmacology play a role, but the improvements in the

[1]We do not attempt to place each of the 16 cases in this book within one of the five major groups we have identified; any attempt to do so would be to force the issue. Similarly, readers should understand that a particular case might well be included in more than one group.

[2]David. Squires and C. Anderson, *U.S. Health Care from a Global Perspective: Spending, Use of Services, Prices, and Health in 13 Countries,* The Commonwealth Fund, October 2015.

health of our population due to cleaner water and air, better workplace safety efforts, and preventing maternal and infant deaths should not be overlooked. Similarly, increasing access to even basic health care would likely do much to improve the overall health of our population.

Intersection of Cultures/Religions

Several situations were featured where non-western cultures contrasted sharply, or conflicted, with generally accepted cultural norms, health care practices, laws and/or traditional values of the west; or, where a patient, firmly committed to a particular western religious practice, came into seemingly irreconcilable conflict with the usual norms and practices of American health care. Physicians, nurses and other American health care professionals can face enormous challenges in dealing with persons native to China or other Asian cultures. Case 2 described the dilemma of a young Chinese couple grappling with the needs of their Down syndrome baby. While this case raised a number of ethical issues, the fact that it had to do with a Down syndrome baby born to Chinese graduate students studying in the U.S., that is, to parents who did not desire treatment for an infant they viewed as "defective," underscored stark cultural differences between the Chinese and American people, not only in terms of traditional values but also religious beliefs and socio-cultural attitudes towards certain groups of persons. Cultural differences between east and west can be even more challenging as witnessed in the tragic events surrounding the death of LF in Case 11, whose Chinese husband beat her nearly to death yet continued to serve as her health care proxy. It may seem impossible at times to gain anything close to a full understanding of the mindsets of persons from cultures with which one has little or no first-hand knowledge and experience (including such things as linguistic, social, religious, political and historical factors). However, the case of VH (Case 8) did reveal how an open, empathic and compassionate health care team made every effort to understand and accommodate a Hindu patient and her extended family.

Two other cases should be singled out for inclusion in this category: first, the difficult case of MT in Case 12, born with Turner Syndrome, who required aortic valve replacement at age twenty-five, had nothing to do with a foreign culture, but rather with a Christian denomination. We highlight this case because of the conflict arising from the specific instructions MT had written into her operative informed consent for surgery reflecting religious prohibitions of Jehovah's Witnesses, as well as the intense pressure brought to bear on the surgeon and his team by MT's future mother-in-law and an Elder from the local Jehovah's Witness Kingdom Hall. The second one deals with another western culture, which happens not to be all that "foreign" to many health care settings in the United States, specifically, an American neighbor to the south. Case 13 documents the situation of thirty-nine year-old JG, an undocumented Mexican who had lived and worked in the U.S. for fifteen years and had two children (ages eight and ten) with his significant other. Neither JG nor his partner had insurance coverage or were eligible for government

aid, and neither had an advance directive or had identified one another as their health care surrogates. JG ended up in a persistent vegetative state after a motor vehicle accident, and he became the unfortunate, unwitting ward of the hospital.

The "Validity" of Informed Consent

Adults who are competent have the right to make their own health care decisions, which is protected by the right to privacy guaranteed by the Constitution of the United States. This right is grounded in the philosophical principle of autonomy, and the practical application of this principle is the practice of informed consent (Gracia 2012). There are two issues related to informed consent in this volume: The *interpretation* of informed consent, and what may actually constitute*full disclosure* in the consenting of a patient. Situations in which the interpretation of informed consent is involved may include how a patient's consent, written, stated or implied, may be loosely followed or even directly contradicted for some ostensibly good reason (particularly when the once-competent patient may no longer have capacity or may no longer be living); a patient's "self-contradiction" of what he clearly would like for himself; or someone acting as surrogate for an incapacitated relative but where this acting surrogate has, in fact, no real authority to exercise this formal, legal role.

The fascinating situation in Case 5 where MB offers her late husband's cryopreserved sperm to her sister, LC, is perhaps the most dramatic instance of an*interpretation* of informed consent that we have examined. Alongside the ethical issues of this case discussed earlier may now be added the fact that although MB provided a valid, legal consent for post-mortem sperm retrieval, she did so at the time with every intention that it one day be used for her own pregnancy. Without reviewing again the ethical questions raised in her ultimate donation of this sperm, to whom and for what purpose, her decision regarding the donation can only be viewed as one based upon an*interpretation*, or a "reformulation," of the consent she had given earlier; while her ultimate disposition of her late husband's sperm is very different from what had been her original intentions, her later actions do not appear to contravene the honest intentions of her consent to sperm retrieval in view of the circumstances of this case.

We witnessed an even broader*interpretation* of informed consent in Case 16, where JA's niece assumed the role of health care proxy for her uncle when his last remaining family member and legal guardian, a brother in California, told her he trusted her to make whatever medical decisions necessary for JA's care. She consulted with this brother in California only when necessary, and gradually took on full decision-making responsibility for JA despite having no real authority to do so. This ultimately included refusing consent to feeding tube placement and antibiotics for pneumonia, all as proxy on behalf of JA, at the end of his life. We saw earlier how all this managed to occur without challenge, yet it remains a rather striking example of how broad an*interpretation* of consent can be.

Advance directives were developed to extend a patient's decision making authority beyond a time when he or she might be competent to voice such preferences; done well, advance directives effectively provide "consent" from an incompetent patient near death for certain kinds of medical care. In Case 9, where an adult patient's mother contests the validity of her adult daughter's advance directive, provides an excellent example of how fragile such a document can be in the face of a parent or other family member who has decided to insist on what he or she feels is best for their loved one, in spite of evidence to the contrary.

Informed consent also raises questions related to *full disclosure*, which was underscored in Case 14. As mentioned in the case narrative, there was no consensus among those who attended tumor board conference the day CB's case was discussed; some members of the team felt CB should have the pros and cons of three treatment options fully laid out for him, after which he and the attending physician could make an informed choice; others felt that because of serious, complicating factors it would be inappropriate to offer him all options and that palliative care should be the only option offered. We also recall that the surgeon decided after private reflection to "play it by the book" and offer CB the three options, even though she did not feel all were advisable. His decision for palliative care not only surprised his surgeon but stands as a further lesson of the value of full and thorough disclosure in the process of informed consent.

Full disclosure requires not only that patients understand the risks and benefits of the proposed or recommended treatment, but also the benefits and potential burdens of all available options, including the option to cease aggressive treatment in favor of palliative care or comfort measures only. In our experience, too often patients are given only the information they need to make the *next* decision, which deprives patients of the ability to determine the route they may have wanted to take from the point of diagnosis until death (Roscoe et al. 2013, 190). Each decision a patient makes sets them along a particular trajectory, and as many of the cases in this book illustrate, it can be difficult for all involved to move away from increasingly aggressive and futile treatment until all options are exhausted, even those with extremely small odds of success.

Problems with Family Members

Almost every case included in this book includes examples of the ways in which family members, often with the best of intentions (but not always) are able to subvert the wishes of the patient, question the knowledge of the physicians, and try the patience and compassion of every nurse, social worker, or administrator involved in the patient's care. There are many reasons and explanations for why family members act and react in the ways they do when confronted with the serious medical condition of a loved one. Most families are unprepared for such difficult situations, and most have not had conversations that would allow them to help their family member make the decisions necessary to insure good care. Many people,

even those with advanced educations or prestigious careers, lack health literacy, i.e., the ability to navigate in complicated health care institutions, and to cope with medical information and decisions that have serious consequences. It is likely that most families are dysfunctional in some way, and lack the interpersonal skills, relationships, and conflict management abilities that would make such difficult situations more manageable. Families are tested by the realities of conflicting information about their loved one's condition, the challenge of managing a relative's serious illness while also managing other responsibilities, and the sadness and despair that can often accompany the realization that we are all, after all, mortal.

In Case 3, where young parents have to make decisions for their seriously ill and disfigured child, and in Case 4, where parents have to make decisions for their previously healthy child who has now been diagnosed with a terminal illness, we see many of these factors at work. In these cases a lack of credible information exacerbated problems in decision making. In Case 6, where the mother of a child deemed to be brain dead cannot accept this fact (or her own culpability in her child's death), and in Case 7, where the patient's mother blocks the palliative care team from mentioning how close to death her son is, we see the depths of denial and the extremes to which some family members will resort in order to hear only the information that conforms to their expectations and desired outcomes. Case 10, where the patient's wife pits her husband's oncologists against the intensive care team, is an even more extreme example of someone hearing only what she wishes to hear or to be true.

As a rule, health care professionals cannot simultaneously care for patients and serve as counselors to help families overcome the patterns, habits and beliefs that accompany them to their loved one's bedside. It is likely that there will always be situations such as those that we describe here. Our definition of autonomy and how it is best to be respected do not offer much help, since in theory we talk about one patient and his or her physician engaged in information exchange and decision making, but in practice family members are nearly always involved. The models that teach physicians how to discuss "bad news" with patients make similar assumptions: They encourage physicians to involve family members in decision making but do not provide guidance as to how to manage these difficult interactions. Utilizing the expertise of social workers and palliative care team members with this specialized knowledge could go a long way toward helping, and these professionals should not be blocked from their important role in patient care, even if their presence highlights certain realities such as the patient's impending death. If the question is asked, "should we consult palliative care?" the answer should always be "yes," and anyone involved in the patient's care should be able to request such assistance.

Problems ofHierarchy andTeamwork

When viewed as a whole, the cases in this volume may be seen not only to offer suggestions about what perhaps*should,* or*should not*, have happened in the situations presented, but also as sources of practical advice that could be offered to various "branches" of health care comprising the end-of-life tree. Among those

separate branches, otherwise identified as particular groups of persons functioning as component parts of the health care process, we would include the following: physicians, nurses, pharmacists, aides, technicians, hospital administrators, hospital ethics committees, social workers, hospice workers, spouses or partners of patients, other family members and friends of patients, and any others necessary for providing the best health care possible for the sick and suffering. The cases in this collection have demonstrated what many persons who have sat with dying loved ones in hospitals know only too well, the tension that exists between physicians and nurses, physicians and families, or physicians and virtually anyone else who might be part of the health care team. Physicians are traditionally respected, deferred to and treated as the pinnacle of responsibility and expertise and with good reason. Nonetheless, the respect accorded to physicians has not infrequently evolved into an unjustified feeling ofintimidation on the part of others. We believe there is simply no reason for the nursing staff in either Case 4 (where a child was denied appropriate pain medication) or Case 10 (where the patient dramatically changed his treatment preferences when his wife was present) to have acquiesced as they did instead of challenging, albeit professionally, decisions or orders they knew had not been made according to their patients' wishes or best interests.

We furthermore believe it imperative that nurses engage responsibly and professionally with physicians in this regard in order to further the well-being of their patients, and we believe this responsibility should be viewed as a moral obligation. If there is to be an ethic of health care designed around the patient's good, it cannot be subject to rank or privilege. Furthermore, if the team concept in health care means anything beyond a nice catchphrase, and we believe it does, it can only be effective where it functions unfettered in an environment consisting of multiple voices that are free, and encouraged, to speak as part of a process, albeit with the understanding there will always be some one person or entity charged with the ultimate responsibility of having to make important decisions, whether this be the patient, the surrogate, the physician, or whoever may be ethically and/or legally appropriate.

Cases 4 and 10 are particularly good examples of situations where nurses became frustrated by the suffering endured by their patients, yet did not feel empowered to speak up to attending physicians, believing that to do so would be insubordinate. Our experience in health care has led us to believe that this widely held attitude must change for the patient's good, and we believe that it is changing, slowly, where there is open communication and especially where physicians are not threatened by respectful input offered by other professionals on the team.

Another type of intimidation that we feel warrants serious attention today is evident in cases where physicians, nurses, entire health care teams, and even hospitals themselves appear to be held hostage by patients and/or families of patients. Case 3 (where young parents must make decisions for their seriously ill newborn), Case 6 (where the patient's mother refuses to acknowledge that her daughter is brain dead), and Case 7 (where the patient's mother refuses to let the palliative care team discuss options for the care of her dying son) are excellent examples of this sort of intimidation. We certainly understand the reluctance of physicians to challenge, argue or "lock horns" with patients and families over

treatment decisions, particularly when they have been their patients' primary care providers for some time, perhaps their entire lives. And, we most certainly appreciate the litigious nature of American society today. Nevertheless, we also believe that health care cannot afford to be held hostage to unreasonable demands. Medically appropriate care, humanely and ethically administered, is what is called for, and we trust those qualified to deliver this care will find ways to do so assertively and with the confidence that they are doing so for the ultimate good of patient and family. On the other hand, no one involved in health care should ever attempt to intimidate a patient, even if only because it is thought feasible, such as playing upon the fears of a foreign national unfamiliar with our laws, as evidenced in Case 2, where a Chinese couple needed to make decisions for their Down syndrome infant.

We also believe that there are institutional and organizational opportunities for changes in policy. In our view, whatever good hospital policies may have existed in the cases treated in this book, there was either a lack of appropriate policies designed to alleviate or avoid some of the problems discussed, or little to no effort by hospital administrators to help enforce such policies. We feel strongly that as hospitals undertake periodic review and revision of their policy manuals every effort should be made to ensure that reasonable policies are designed to be flexible, protective of the rights of patients and families, and at the same time protective of hospitals so that the latter do not become victims of bullying at the hands of the former. Case 6 (where the patient's mother refused to acknowledge that her administration of expired insulin had caused her daughter's illness) showed how an overbearing parent could manipulate hospital policies and administrators to her advantage by utilizing local media and legal threats. We believe that hospital administrators and members of hospital ethics committees can play significant roles in this regard; we come to this conclusion based not only upon the evidence found here, but also upon the observations we have each made over years of service on ethics committees.

Last Thoughts

This casebook has introduced numerous situations where things went about as poorly as possible at the end of a person's life. While we hope that these cases are thought provoking, instructive, and a bit unsettling, it is also important to keep in mind that things often go quite "right" at the end of life, where there are many instances of cooperation, dignity,closure, and compassionate care. The ways in which medical schools are educating new physicians, combined with the millennial generation's exposure to vast amounts of information and technology, their experience working in teams from a young age, and passionate idealism might indeed be the perfect combination of skills for a new generation of medical talent.

A palliative care fellow we recently met raised the following situation for discussion at the monthly meeting of an end-of-life research group of which we are long-time members. We were discussing patients' overall reluctance to complete

advance directives, and this young doctor added that in her experience even more resistance comes in the form of older physicians more accustomed to dealing with patients in paternalistic ways. The fellow had been picking up additional shifts "moonlighting" at a Veterans Affairs hospital. It was close to midnight, and a 97-year-old man was brought to the facility by ambulance from a nursing home. The man was quite short of breath and likely had pneumonia. He managed to gasp out "please call my daughters in Oklahoma and Wisconsin!" and he produced a piece of paper with their telephone numbers. The fellow conferred with the attending physician, who said, "just intubate him so we can all catch some sleep! You can make your phone calls in the morning." The fellow gave her patient oxygen to ease his breathing and called first one, then the other, of the man's daughters. Both women seemed as though they expected the news they received, as both had been in close touch with their father in recent days. Both women told the fellow that their dad had an advance directive that specified that he did not want to be intubated, and that he wanted comfort measures only. One of the daughters agreed to fax the document to the VA and did so as soon as she finished talking with the fellow. Both daughters agreed that their father's wishes should be respected and he should be allowed to die peacefully. They acknowledged that he had been dealing with numerous health issues in the past year which is what had prompted him to document his treatment preferences and discuss them with his daughters.

Once the document was received, the fellow talked with her patient about his stated treatment preferences and told him that without intubation he would surely die. The man said he knew that was the case and that he was at peace with his decision. He whispered that he had had a very good, long life and was grateful that the fellow took the time to speak with him and his family. The fellow ordered a morphine drip for her patient, who fell asleep and then drifted in and out of consciousness for several hours. The fellow sat by his bedside until he died and she could declare time of death. She then called both daughters to tell them that their dad had died peacefully, and that he was not alone.

The next morning at rounds the fellow came under severe sanctions from the attending physician for the way in which she had handled this patient's situation. He felt she had "wasted everyone's time" and that no harm would have been done had she "followed orders." The fellow went on to tell us that internal medicine residents, and even palliative care fellows, are evaluated based upon their efficiency, ability to adapt to the medical hierarchy (attending physicians first, fellows and others last), and detachment. It is more important to appear business-like than it is to show compassion or to take the time necessary to listen to patient and family concerns. Thefellow also told us that one situation like this, or at most two, would be enough for most of her peers to abandon any commitments to patient-centeredness, empathy and ethically right actions that they might have had prior to medical school and, moreover, that a de-emphasis of these commitments was reinforced through the didactic sessions of medical school.

Now, not all established physicians act in the callous way seen here, but those of us with some experience in end-of-life situations know only too well that putting

this patient on a ventilator would serve no medical purpose, and in fact, would have been expressly against the written wishes of this patient. His daughters would then have been faced with the difficult decision of determining if and when their father should be taken off life support, which would have involved coordinating a multi-state trip. And meanwhile, their father would have been in intensive care, tethered to a machine that he had expressly stated he did not want.

It may seem in some cases included in this volume that we are "doctor bashing," but nothing could be further from our intentions. What we are trying to say, among other things, is that it often comes down to one person's willingness to speak the truth as they see it in these complicated cases, accompanied by the courage to act accordingly. The way in which medical care is structured, particularly in hospital settings, is that the doctor is the one with the authority and responsibility to be such a truth-teller. Another message we hope to emphasize is that we feel everyone involved in a dying patient's care should be able to speak their truth and encourage right action on behalf of the patient.

Readers who are drawn to this casebook are the "complicit outsiders" we believe can continue the crucial moral conversation about how best to reform healthcare, promote health literacy around the end of life, and work to make death an accepted and expected part of life. We hope in some measure to have succeeded in providing readers a means of sharpening their own skills in ethical analysis and problem solving through the lessons and perspectives offered here, and that discussing these cases in classrooms, ethics committee meetings, and other places contributes to other on-going efforts to improve the ways people die in America. While most people say they want to die at home, nearly 40% of people die as hospital in-patients (Xu 2016). The hospital setting presents unique challenges for improving end-of-life care—a norm for aggressive rather than palliative care; fragmentation and specialization of care; a hierarchical and institutional setting; conflicts between families, patients, and health care professionals—all of which have been well-documented in the cases presented here. There is no reason, however, why hospitalized patients cannot experience deaths that are more comfortable and peaceful; indeed that happens for the majority of hospitalized patients who die. The cautionary tales and wicked problems discussed here indicate, however, that there is still more work to be done by those of us committed to improving the quality of dying in America.

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