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Features

Complex Discharges and Undocumented Patients: Growing Ethical Concerns

Kayhan Parsi and Nina Hossa

ABSTRACT

A growing number of discharges at acute-care hospitals involve patients who are undocumented and lack legal status. Because such patients are ineligible for public assistance, long-term care facilities will routinely deny them admission. These discharges become complex discharges because of such financial barriers. If local family support is unavailable, discharging such patients to a safe and suitable location becomes increasingly difficult. These complex discharges implicate a number of ethical principles. We describe such complex discharge cases, apply various ethical frameworks, and call for potential policy solutions to address this growing ethical concern.

INTRODUCTION

Case Study

A 22-year-old man was working in the construction industry as a roofer. He fell one day and was admitted to a nearby hospital. He experienced a neck injury that resulted in quadriplegia. He is now dependent upon a ventilator. His acute medical needs have been met at the hospital and he is ready for discharge. Unfortunately, he has no insurance and is an undocumented worker. He has no nearby family and is not eligible for any long-term care facilities because of his insurance status. How should his discharge be handled?[1]

Discharge planning, once relegated solely to the domain of the social worker, has begun to engage the interest of ethicists. Although most hospital discharges are relatively straightforward, an increasing number of them are becoming more complex. These complex discharges require a multi-disciplinary stakeholder approach. In this article, we plan to examine this increasingly prevalent phenomenon in the acute-hospital setting. We first define discharge planning, describe a complex or difficult discharge, identify relevant ethical principles and stakeholders, and examine the heightened burden such discharges place on hospitals, long-term care facilities, and communities. We focus specifically on the challenge of undocumented patients who are involved in difficult/complex discharge cases and the growing ethical concerns these kinds of discharges raise.

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Discharge planning is one of the main responsibilities of hospital social workers.[2] In planning for a discharge, social workers have to perform a number of tasks and ask a number of questions. First, they have to assess where the patient came from originally (home, nursing facility?). Second, they have to assess functionality and ask what are the patient's current care needs. Then, social workers have to determine whether the patient can go back to her or his previous setting. Still other questions need to be asked: Is it safe for the patient to go home alone? Does the patient have family/friends available to help with care upon discharge (transportation to medical appointments, physical assistance during recovery)? Does the patient have adequate insurance or private funding for recommended medical services upon discharge (prescriptions, further treatment)? Once a patient is deemed medically stable, the discharge plan needs to be arranged prior to the patient being able to leave the hospital. This can become a challenge when patients lack funding and family support, and are not able to receive necessary follow-up medical care for a variety of reasons.

A routine discharge becomes a difficult or complex one when there are barriers present to completing a safe discharge. These barriers may be financial—the patient lacks insurance coverage to provide care at a long-term care facility. The barrier may be familial—the patient lacks any kind of family support. The barrier may be one of safety—the team believes that discharging the patient may pose an unreasonable risk to the patient. An example of a simple discharge would be a patient returning home after hospitalization without further medical needs, other than outpatient follow-up appointments. An example of a complex discharge would be that of patients who are medically stable but who have limited options due to the barriers described above. The patients would not be able to return home due to an inability to care for themselves and would not be able to transfer to a lower level of care (for example, a skilled nursing facility) due to a lack of medical insurance or their undocumented status. For the purposes of this article, we will focus on complex discharges that entail substantial financial barriers.

The primary factor that categorizes an undocumented patient with long-term medical needs as a complex discharge is a lack of insurance. Such patients do not qualify for any public insurance, such as Medicare or Medicaid (although California and New York City do offer some moderate public benefits).[3] A non-U.S. citizen who is in the U.S. legally must remain in the country with legal documentation (green card, active visa, et cetera) for a minimum of five years prior to being able to apply for public insurance. The Emergency Medical Treatment and Active Labor Act (EMTALA) requires hospitals to accept and treat emergently ill patients regardless of their legal status or ability to pay.[4] This provision declares the necessity for hospitals to provide care, but it does not reimburse hospitals for emergent care, nor does it assist with patients' post-acute care needs. In these situations, while the law requires a hospital to stabilize an undocumented patient, it does not mandate that anyone care for a patient who requires continued non-acute care. The government does not assist hospitals or long-term care facilities to care for these patients. Moreover, once patients are deemed medically stable, there is no law or policy that intervenes or provides guidance on how a hospital is to proceed in discharging undocumented patients who have been left physically incapable of independently caring for themselves due to their medical condition.

APPLYING PRINCIPLE-BASED BIOETHICS

Traditional bioethics principles have been invoked when dealing with such complex discharge cases. Swidler, Seastrom, and Shelton applied principle-based bioethics when they examined this issue in a 2006 article in the *American Journal of Bioethics*.[5] The four principles of beneficence, nonmalificence, autonomy, and justice are all implicated in these kinds of cases. For instance, we want to honor beneficence and nonmalificence, but also ensure that principles of justice are upheld. Au-

tonomy plays a role when a patient is discharged without his or her consent. This occurred in the case featured at the beginning of this article. The hospital that was treating the patient decided to repatriate him to his country of origin. The patient, however, did not provide consent to be transferred to a facility in Mexico. This case generated a great deal of outcry in the local Mexican community in Chicago. Other cases of repatriation without consent have resulted in legal action, most notably the case of *Montejo Gaspar Montejo v. Martin Memorial Medical Center,* 874 So.2d 654 (Fla. Dist. Ct. App. 2004). Others have begun to explore the ethics of repatriation in the face of such difficult cases.[6] We will focus our discussion on some salient cases and argue that a more robust ethical framework is necessary to analyze and resolve such cases. In the absence of any uniform policy that provides for some kind of public assistance for the undocumented population in the U.S., such thorny cases will continue to emerge.

Utilizing traditional bioethics frameworks offers only limited solutions in such cases. The principle of beneficence suggests that the healthcare team is obligated to do only what is of benefit to the patient. Everyone involved in the direct care of a patient is striving to meet this obligation during a patient's stay at an acute-care hospital. Once, however, a patient no longer has acute-care needs, what does the principle of beneficence mean? For the social worker, this would suggest finding a safe place for discharge, along with ensuring that the patient's post-discharge medical care needs are met. This also meets the obligation of nonmalificence. In terms of the case discussed above, a discharge plan that would be in unity with the principles of beneficence and nonmalificence would include either a long-term care facility that continues to provide ventilator care, or sending the patient home with a home ventilator after adequate training is provided to family/caretakers on how to properly manage a ventilator. Yet, these cases pose serious challenges when there are no family members who are either willing or able to house patients with significant long-term care needs. Without the support of some kind of public assistance (for example, Medicaid), long-term care facilities will routinely decline to accept such patients.

With regard to honoring a patient's autonomy, we traditionally think of such an obligation as respecting a patient's wishes and values regarding his or her care. In classic cases, autonomy is honored when the healthcare team respects a patient's (or his or her surrogate's) refusal of some kind of medical treatment. What does autonomy mean when a patient (or surrogate) demands certain care beyond the walls of the hospital? Autonomy rights seem limited in such situations. As Swidler and colleagues stated: "put simply, autonomy supports a capable patient's right to leave the hospital despite his or her need for care—but it does not support a capable patient's right to remain in the hospital beyond that need."[7] Respecting autonomy does not necessarily include a patient's choosing placement that is inappropriate due to medical necessity or financial constraints.

This occurred in a case when an undocumented patient was admitted with lower extremity weakness. The patient was eventually stabilized and started to receive dialysis for kidney failure. The medical team recommended that the patient receive dialysis indefinitely on an out-patient basis as treatment for chronic kidney disease. Without regular dialysis, the patient was not expected to live much longer than weeks to months. The patient continued to be physically weak once he was stabilized and not able to ambulate out of bed and into a wheelchair without assistance. The patient lacked any family support nearby, was without health insurance, and also lacked legal status in the U.S. Without insurance or funding, the patient would not be able to receive the needed dialysis once out of the hospital. The patient's acute-care needs were long met, and the patient eventually stayed on the general medicine floor for several months. Such a stay incurred hundreds of thousands of dollars in expenses. Social work staff attempted to work with family members living abroad as well as the local consulate, but to no avail. This case resulted in an extended

set of discussions in the complex discharge committee meeting.

The principle that is most often invoked in such cases is the principle of justice. What is a just way to discharge such patients? Do these patients possess any basic rights to healthcare? Is the hospital obligated to keep a patient if they do not have the means to obtain necessary medical care post-discharge? Is it the hospital's responsibility to attempt repatriation of a patient to her or his country of origin, or should this be handled by the U.S. Immigration and Naturalization Service? At what point does this stop being a medical matter, but instead an immigration case? Hospitals typically do not have a set protocol to handle such cases, but rather are reactive on a case-by-case basis. This is primarily due to the lack of available resources that can be used for assistance in resolving such cases. A hospital's mission is to medically treat patients coming in for emergent care, regardless of where the patient came from or his or her ability to pay for treatment. However, with such complex cases, the hospital also becomes a residence for patients who, once stable, are now not able to safely return home and who are not accepted to lower level care facilities. The hospital is also transformed from a place for acute medical care to one that houses a medically stable patient for weeks and even months, while contemplating financial, political, and social decisions that can literally change the course of the patient's life.

REPATRIATION AND THE MORAL STATUS OF THE UNDOCUMENTED

Much attention has been placed on hospitals that repatriate patients to their country of origin. Repatriation is a process in which hospitals work with transportation firms to transport undocumented patients to their country of origin.[8] If a patient is deemed medically stable for discharge to home, the hospital staff (typically the social worker) takes on the role of finding family members in the country of origin who agree to take the patient into their home for further care. If the patient still requires substantial medical attention, the U.S. hospital will transport the patient directly to an accepting hospital in the country of origin. Both forms of repatriation require permission from the government of the country of origin to allow the patient back into the country. These repatriations ideally occur with the patient's consent, although not always. Some critics state that whether or not patients give consent is not the primary issue; rather, a hospital should simply not have such power over a person's life. The process raises ethical concerns, as it is assumed that patients returning back to their country of origin will not receive the healthcare needed to treat their illness. Arguments in favor of repatriating patients to their country of origin note that the U.S. struggles to provide healthcare to all documented citizens and therefore does not have an obligation to care for undocumented individuals, nor should U.S. hospitals be held ethically responsible to keep patients because there is a lack of medical care available in other countries. If a hospital does decide to repatriate a patient to his or her country of origin, the hospital typically takes on the financial responsibility for the transportation of a medically fragile patient, typically via air ambulance. Kuczewski has argued that repatriation can be done ethically, so long that the patient gives full and informed consent.[9] This is a serious challenge, in that many patients may refuse to give consent if they believe they will be repatriated to their country of origin, which may have very limited resources available for long-term care, which may result in the provision of suboptimal care.

During President Obama's address to Congress in September 2009, he adamantly stated that those who are in the U.S. illegally would not be eligible for any healthcare coverage under his proposed legislation. To this assertion, Congressman Joe Wilson uttered his famous "you lie" retort to the president. The exchange highlighted how hot the tension is regarding the rights of the undocumented to healthcare. Who "counts" in our moral community will influence who "counts" in our law and policy decisions. If undocumented patients are viewed as simply "illegal aliens" who usurp jobs and resources, then our moral sentiments (and le-

gal policies) will be shaped in a harsh and punitive way. On the other hand, as Kuczewski has argued, if the undocumented are considered a part of our community who work, produce, and contribute, then such participation in the community merits an appropriate moral status.[10] The National Association of Social Workers Code of Ethics speaks directly to the moral status of the undocumented in two provisions; for instance, section 4.02 proscribes social workers from condoning or facilitating any form of discrimination on the basis of immigration status. Moreover, section 6.04 encourages social workers to "promote policies that safeguard the rights of and confirm equity and social justice for all people."[11] Unfortunately, these aspirational professional obligations of social workers are routinely thwarted when there are policies that undermine the moral status of the undocumented.

APPLYING OTHER CLINICAL ETHICS APPROACHES

There are other venerable clinical ethics frameworks at our disposal in trying to resolve such cases. The Jonsen, Siegler, Winslade model would have us look at the facts of the case, the patient's preferences, quality of life issues, and then other contextual features.[12] Recall our opening case. Here, we have a young man who is working in this country as an undocumented worker. He suffers a catastrophic injury and is treated at a hospital. Once his critical injuries have been treated and he is ready to be discharged, how does this model help us? We have a good grasp of the facts. The patient is undocumented, has no family locally, and no local long-term care facility is willing or able to take him. The patient's preferences are to be cared for locally. It's not clear what his quality of life would be if he was repatriated to his country of origin. If the patient is someone who is culturally American but who lacks legal status, such a repatriation could be emotionally traumatic. The contextual features seem to garner the most attention. A patient who lacks insurance but does have legal status may benefit from public assistance. Such assistance simply does not exist for patients who are undocumented. This kind of clinical ethics approach helps us dissect the case in a careful way, but does not offer any clear solutions. Such complex discharge cases require other ethical frameworks to help us better achieve reasonable solutions.

AN ORGANIZATIONAL ETHICS APPROACH

Because of the inherent complexity of these cases, there are a number of parties who are involved. Patients, family members, healthcare professionals, administrators, long-term care facilities, government agencies, and local, state, and national governments are all involved. Each party has its own interests and each has its own set of obligations. The healthcare professionals who care for patients in acute-care settings have typically fulfilled their ethical obligations to patients once their acute-care needs have been met. When faced with a difficult discharge situation, social workers may find themselves working with a larger committee that is dedicated to placement of such patients. At our institution, a multi-disciplinary team will gather to discuss the facts of a given case and try to determine a reasonable solution. The social worker's obligation is primarily to the patient, in trying to achieve a safe and feasible discharge. The administrators also wish to see a safe discharge, but are also acutely aware of the expenses incurred by patients who are undocumented and uninsured. Long-term care facilities will typically deny admission to patients who lack any kind of private insurance or public assistance. The ethicist involved in such cases tries to mediate between the differing interests at the table. When a patient lacks insurance coverage for discharge placement, such problems seem intractable. This is especially the case with the undocumented, who are typically ineligible for any Medicaid coverage.

Can an organizational ethics approach help us address these kinds of cases? Organizational ethics utilizes a stakeholder theory approach: it attempts to balance the interests of these various stakeholders while remaining committed to issues such as stewardship, integrity, and

mission. Each institution has a mission statement. At our institution, we explicitly state the following:

> Loyola University Health System is committed to excellence in patient care and the education of health professionals. We believe that our Catholic heritage and Jesuit traditions of ethical behavior, academic distinction, and scientific research lead to new knowledge and advance our healing mission in the communities we serve. We believe that thoughtful stewardship, learning and constant reflection on experience improve all we do as we strive to provide the highest quality healthcare.
>
> We believe in God's presence in all our work. Through our care, concern, respect and cooperation, we demonstrate this belief to our patients and families, our students and each other. To fulfill our mission we foster an environment that encourages innovation, embraces diversity, respects life, and values human dignity.
>
> We are committed to going beyond the treatment of disease. We also treat the human spirit.

What can we glean from this statement? Values such as stewardship, care, concern, respect, and cooperation are all highlighted. Human dignity is valued. Moving beyond the disease process, the mission statement adds that we also treat the human spirit. How does this statement shape how we go about making the difficult decisions in cases involving undocumented patients? It appears that we need to balance being good stewards of scarce resources while also ensuring that individuals' dignity is respected and preserved. Yet, the onus is mainly upon the hospital that treats patients acutely, and not upon the myriad of long-term care facilities that are being sought for placement for such patients. This creates a stark discrepancy between the legal and ethical obligations of hospitals and long-term care facilities. The former are obligated to treat emergently ill patients. They may even have a mission that creates an ethical obligation toward the poor and underserved. Unfortunately, long-term care facilities have no legal mandate to accept patients, and unless they have some special mission (faith-based or otherwise), they lack any ethical obligation to accommodate the needs of the undocumented.

While many hospitals provide charity care to uninsured and undocumented patients, these hospitals must balance this free medical care with financially sound decisions that will allow them to remain open and serve the greater community. The question, "how much medical care does the hospital owe a patient?" is difficult to answer in these cases. The cases previously discussed involved individuals who were essentially bed bound and not able to physically care for themselves. Nevertheless, cases can also be complex for undocumented individuals who are physically independent upon returning home. For example, a hospital performed a surgery, via charity, that ended in a complication that left the patient needing expensive intravenous medication for the remainder of the patient's life. The patient was known to be a charity case prior to the surgery. However, the patient's undocumented status was not known to the hospital until after the surgery. (Which prompts us to ask, Should this be asked or discussed?) The complication was unexpected and irreversible. The cost of the medication needed was too high for the patient to afford. While the surgery was openly done through charity care, the cost of the medication needed afterwards was not considered, and increased the cost of the charity surgery. This opened up discussion as to whether the hospital was morally obligated to pay for the costly medication, as it was a complication of the surgery. The case highlighted the question of whether an extensive amount of charity resources should be provided to one patient or should be preserved to treat as many patients as possible. Moreover, the question as to whether such charitable offers should be time limited was also raised.

POTENTIAL POLICY SOLUTIONS

The current U.S. policy stance that excludes undocumented patients for healthcare coverage

does little to help hospitals across the U.S. when providing millions of dollars in unreimbursed treatment to such patients. It is estimated that approximately 30 million non-U.S. citizens are living in the U.S., and 11.6 million of these individuals are undocumented.[13] The topic of undocumented patients who are difficult to discharge from hospitals has drawn much attention in the last few years, as a struggling economy has placed increased political and media focus on the growing cost of healthcare, along with the lack of affordable healthcare for many American citizens. Despite the passage of the Affordable Care Act, nothing in the act provides for coverage of undocumented patients. Without a national strategy on how to discharge medically complex undocumented patients from a hospital, each hospital with such a case is left to deal with each patient on a case-by-case basis.

Recent cases examined by the media have prompted attention to the court-created designation "Permanent Resident under Color of Law (PRUCOL)." This court-created category is not considered an immigration status, but rather a public benefits eligibility category.[14] In order to be in this category, the U.S. Citizenship and Immigration Services (USCIS) must be aware that such a person is in the U.S. illegally, and must formally acknowledge the individual with a letter stating there are no current plans to deport said person. Being deemed a PRUCOL allows an individual to be eligible for public assistance benefits without being allowed to apply for U.S. citizenship. This category is without national guidelines for application or for approval; instead, the process of application and award has been left to individual cities and states.

Some hospitals in the U.S. have begun the process of attempting to have undocumented patients qualify for this category as a means to receive reimbursement and to place patients in post-acute-care facilities. This process may bring about another set of ethical concerns for the autonomy of patients. Individuals must declare themselves as being undocumented and residing in the U.S. Many undocumented individuals may not declare themselves, for fear of being deported. The issue then becomes, can a hospital force patients to apply for PRUCOL status, knowing that it will prevent them from being able to apply for citizenship? Most likely not, as a hospital does not have the authority to command patients to report their undocumented status to the government. On the other hand, even if patients do comply with applying for PRUCOL, attention may shift onto the financial benefits provided to individuals who are not paying taxes to the government. Should undocumented patients be allowed to qualify for public welfare? Should the financial benefits of this category be time limited? Should the USCIS limit what forms of healthcare are covered by such a provision?

Such questions inevitably raise ethical questions regarding the moral status of undocumented workers in this country. Some communitarian thinkers have argued that these individuals are part of our moral community, and therefore deserve the same level of rights and privileges as individuals who possess legal status.[15] Others have a more punitive approach—such individuals do not deserve the same moral status because they have circumvented the rules in establishing residence in the U.S. The law may like bright lines, but ethics is more nuanced. One could argue that individuals who have been in the U.S. since childhood and lack legal status are nevertheless American, both linguistically and culturally.

Without a national policy involving funding and adequate resources to aid such patients and complex discharges, there is not a clear solution for hospitals facing difficult discharges. For this reason, there is a need for increased open conversation regarding the topic on the micro and the macro level. Communities may need to examine what outpatient care and housing resources can be made available for undocumented patients. Hospitals may benefit from examining their policies for charity cases and developing a proactive plan that identifies undocumented patients prior to or immediately upon admission. This may include creating a permanent committee that meets to plan for such complex discharges. Some hospitals may have *ad hoc* committees that emerge once a

complex discharge is identified. Having a permanent group may benefit these cases, as the identified staff members would have worked on previous similar cases, giving them experience with options, resources, and possible outcomes. Lastly, some hospitals may consider helping to pay for patients' long-term care needs, at least for a certain period of time, as these costs are still considerably less than housing patients in acute-care settings.

Even with hospitals becoming more aware of such patients and cases early on in the admission process, it is clear that without adequate financial resources or government aid and involvement, such complex discharges will continue to heavily burden hospitals all over the U.S. The government may soon not be able to avoid becoming involved in such cases, due to the increased media coverage on the financial strain of the cases on the healthcare system. Hospitals may consider convening, on a macro level, with other healthcare institutions to bring further attention to the growing problem and to attempt to petition for government assistance to create a national policy.

With EMTALA ensuring that hospitals will continue to provide care regardless of legal status or ability to pay, policy changes to assist difficult discharges would be most effective when focused on reimbursement and availability of healthcare resources outside of hospitals. Some have called for EMTALA to become a funded mandate.[16] Many hospitals have charity care programs that allow them to receive some reimbursement for the emergent care they provide. How this is filed and reimbursed differs between states. Expanding policies and programs that mimic charity care into the community to healthcare clinics and to skilled nursing facilities would not only relieve hospitals of the burden to care for such patients, but the overall cost of undocumented patients' healthcare would be less expensive for that particular state. Rather than a state reimbursing a hospital several hundred thousands (or in many cases, millions) of dollars in charity care for a prolonged in-patient stay, the state would reimburse a great deal less to lower levels of care that are much less expensive.

Public hospitals do provide care to all patients, regardless of their legal status and ability to pay. However, often these hospitals are few and far between. Patients are unlikely to travel long distances for regular medical appointments and maintenance healthcare. Having more outpatient healthcare clinics providing care to undocumented individuals can assist in providing proactive care, and, in turn, reducing the emergent hospital visits that often lead to admission followed by complex discharge. While increasing the number of public healthcare hospitals and clinics could be effective, it would come at a large cost that many states simply cannot cover. Many public hospitals and clinics are currently reducing services and have long wait lists for clinic visits, due to lack of funding and continuing increases in healthcare costs.

Because the Affordable Care Act excludes undocumented immigrants, some commentators have called upon the states to create coverage programs for this population. In examining vulnerable populations in the U.S., we have historically provided charity to those we deem vulnerable (for example, the "deserving poor"). Orphans and widows were the traditional beneficiaries of such charitable care. With the creation of Medicaid in the mid-1960s, our commitment to the poor was formalized through legislation. Nonetheless, we have limited our obligations to certain individuals who meet very rigid definitions of poverty. Unlike Medicare, which is an entitlement largely determined by acquiring work credits throughout one's life, Medicaid utilizes means-testing (both financial and medical need) to determine who is eligible. Because Medicaid is a program that is administered through the states, commentators have called for the states to be creative in addressing the needs of the undocumented. Unfortunately, in the current economic crisis facing the states, there is little political appetite to argue for greater coverage of this population. Ultimately, we call for undocumented individuals to be able to participate in insurance exchanges that will provide some modicum of insurance coverage, and hopefully avert at least some of the worst-case scenarios we have discussed. Roman

Catholic healthcare argues that we have an obligation to care for all individuals, regardless of legal status.[17] Such a view should inform our public policy. As Martin Luther King, Jr., said, "Of all the forms of inequality, injustice in health care is the most shocking and inhumane."[18]

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MASKING OF THE CASES

The case at the beginning of this article was published in the *Chicago Tribune* on 6 February 2011, and so is part of the public record. Details regarding the persons in the second and third case examples in this article have been masked to protect the patients' privacy.

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