Abstract

As the population ages and medical therapies advance, more individuals are living in the community with complex health conditions. These individuals, as well as their clinicians, often uncritically assume their family members and friends will be capable of, and willing to, provide the caregiving work necessary to continue living at home and outside of institutions. There is an ethical problem in this assumption that unpaid community care will be provided by family or friends. Using Hunt and Ells's Patient-Centred Care Ethics Analysis Model for Rehabilitation (2013), this paper explores the ethical considerations involved in the hospital discharge planning of a fictional case involving a middle-aged, male stroke patient who is in a strained marriage. We discuss the ethical merits and concerns of the various discharge options. We conclude with recommendations to avoid uncritical assumptions that family or friends will provide unpaid care after a hospital discharge, while still meeting the patient's and institution's various needs. We share advocacy suggestions for improving community supports for caregivers and those with long-term care needs.

Beware of Discharge: A Case Exploring the Ethics of Caregiving Expectations Placed on Family at Hospital Discharge

As the population ages and medical therapies advance, more individuals are living in the community with complex health conditions. This situation is exacerbated by slashed healthcare budgets leading to hospitals discharging patients earlier and earlier (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). Discharged patients, as well as their clinicians, often uncritically assume that their family members or friends will be capable of and willing to provide the caregiving work necessary to continue living outside of institutions (Levine et al., 2006). These relations are expected to become informal caregivers, who are typically untrained and unpaid for their caregiving work. As the care recipient's health situation becomes more complex, the work component of care can become very intense for the caregiver. This work includes the emotional, physical, and mental labour of supporting a care recipient; coordinating healthcare appointments; assisting in activities of daily living such as toileting and administering medical treatments; and performing many other tasks (Gillick, 2013). In the United States, the opportunity cost of informal caregivers providing elder care alone is over $500 billion (Chari, Engberg, Ray, & Mehrota, 2015).

Informal caregivers are part of the family unit, and caring for the family unit is part of our nursing role (Gottlieb, 2012). Yet, while we care about the caregivers, as members of healthcare teams, we are all too aware of competing healthcare budgetary concerns exacerbated by lengthy patient stays. Nurses often become complicit in the passing on of expectations of unpaid care to informal caregivers, as discharges of our patients are rushed at the behest of both patients and institutions (Levine et al., 2006; White & Tronto, 2004).

Objectives

The purpose of this paper is to explore the ethics of societal expectations of unpaid community caregiving assumed by family members. We hope to render visible some of the key concepts that are too often ignored when providers and patients automatically *assume* the family of a patient will be capable of, and willing to, provide community caregiving work. This ethical analysis will consider a fictional case study which exemplifies our professional anecdotal reports and experiences, and which is becoming an increasingly common scenario: when an emotionally or physically estranged relation feels pressured to suddenly become an unpaid informal caregiver (Hubbard, 2014; Milan, 2015; Richtel, 2005).

This paper based its case on newspaper reports (Hubbard, 2014; Richtel, 2005) and one of the author's personal experiences of caring for an estranged relation. There is limited research on the experiences of informal caregivers during the hospital discharge (Aggar, Pryor, & Fisher, 2017) and even less on the experiences of caregivers providing care to persons they feel estranged from. Our goal is to offer a fictional case study that explores the elements of an ethical decision-making framework and reveals elements that may be disregarded when clinicians expect family or friends to become informal caregivers for patients in the community.

The Case

Mario is a 47-year-old man who two weeks ago experienced a stroke after returning home from his work as a car salesperson. After one week on a neurological unit, he was transferred to a stroke rehabilitation hospital. His wife, Wendy, works full-time as a pharmaceutical sales representative. Wendy has visited Mario a few times for short visits in the hospital. The healthcare team has had difficulties contacting her to discuss discharge plans, so those decisions were made instead with Mario who said he would regularly inform Wendy of the plans over the telephone.

The stroke has physically, but not cognitively, impaired Mario. Both Mario and the team believe that under these circumstances, Mario will not be able to continue working as a salesperson. While Mario still needs assistance with many activities of daily living, like using the toilet safely, cooking, and getting dressed, the team feels that he no longer needs round-the-clock rehabilitation services. Mario agrees with the team's plan to discharge him, saying that he is sick of the hospital, and that although they have "had some problems in the past," his wife can provide better care for him at home. On the day of discharge, Mario's nurse finds Wendy crying outside of Mario's room. Wendy says, "I don't know if I can do this. I only found out from Mario yesterday that I am supposed to take him home now! His parents and mine are both insisting that spouses don't abandon each other. I loved him once, and I still do in a way, but we were on the verge of separating, possibly divorcing! I work 60-hour weeks, and I like my work. I can't take care of Mario, too! But I'm not sure if I'd feel okay with myself if I leave him now…"

The only thing left to do is sign the discharge papers. The bed has been assigned to another incoming patient, and there are no other beds available at this hospital. How should the nurse proceed?

Ethical Analysis

Theoretical Model for Ethical Analysis of the Case

Hunt and Ells's (2013) model, a "Patient-Centred Care Ethics Analysis Model for Rehabilitation" (PCEAM-R), is a particularly useful six-step model for analyzing rehabilitation-related cases involving family concerns because it specifically includes prompts to discuss power and relational dynamics in families. Guided by the main steps of the PCEAM-R, we will analyze the discharge planning processes that have occurred so far for Mario, paying particular attention to the prompts and sub-concepts of the model that, if considered seriously earlier on, could have potentially helped everyone avoid this distressing situation at the point of discharge.

Step 1: Identify the ethical issue(s) to address: *What is at stake and for whom?*

Hearing Wendy's outburst, the nurse likely feels a lot of moral distress: she recognizes there is an ethical dilemma where the goals, values, and needs of the actors involved are incongruent. The healthcare system has a lot of money at stake and needs Mario's hospital bed to care for more acutely ill patients. Mario's bed has already been allocated to someone else, and Mario no longer needs the hospital's expensive level of care. Under increasing financial pressures, hospitals are discharging patients earlier and earlier to a patchwork of community care services, with the expectation that if patients have family or friends available, they will provide care (Bauer et al., 2009; Hokenstad, Hart, Gould, Halper, & Levine, 2005). The hospital's interests favour the common good of all of their patients; this common good includes the responsible allocation of public healthcare dollars more than it favours the interests of one patient's family or their potential caregivers. However, while the institution saves money in discharging the patient earlier, the costs of care may be spilled over to home healthcare services, instead, which are an important component of post-stroke care (Capriotti & Murphy, 2016).

Mario's goal of living at home and relatively autonomously are at stake. If Wendy refuses to provide care, he will be unable to care for himself at home and will not have his preferred person to provide care for him. If he can afford to and chooses so, he may have to sacrifice some of his own money to pay for in-home care services or to enter a long-term care facility. In contrast, Wendy's autonomy and livelihood are at stake. Mario and the healthcare team assumed she would suddenly disregard her own interests to provide free, complex custodial care for

Mario. Her social life is potentially at stake, as well, with her relatives pressuring her to care for Mario. These social pressures conflict with the ethical value of individual autonomy: the institution, Mario, and the couple's families are expecting Wendy to act and provide care against her own stated interests.

The nurse's values and ethical identity are being tested. She may feel that her first duty is to care for Mario (Nortvedt et al., 2011) and help him attain his goal of going home. Yet, considering Wendy's voiced concerns, the nurse may now be concerned Mario will not actually receive optimal care at home. With Wendy feeling pressured and on the verge of separating from Mario, Wendy may not be able to foster a healing environment for Mario (Hokenstad et al., 2005). Even if Wendy does decide she wants to provide care, in this stressful situation, she is more likely to experience caregiver burnout, which may also harm Mario (Lachman, 2012). The nurse realizes that it is unethical to be pressuring Wendy into sacrificing her goals and needs to provide care for Mario. The nurse likely feels torn between meeting the healthcare system's needs for fiscal responsibility, meeting their incoming patient's needs, meeting Mario's community care needs, and advocating for Wendy's right to autonomy.

Step 2: Collect more information.

More information is needed to determine the most ethical plan of action in this situation.

Are there relevant social and economic factors?

This situation has some relevant social and economic factors to consider. Wendy works as a pharmaceutical sales representative, and Mario worked as a car salesperson. These careers suggest that paying for home care support may be an economically feasible option for them. If Wendy chooses to reduce her work hours and care for Mario at home, will they still be able to maintain their previous standard of living on only one reduced income? The team must discover if paid community supports are a feasible option for Mario and/or Wendy. Additionally, the team needs to learn more about and share any community services or employment benefits that are available to support Mario once he is discharged. A lack of preparation and community supports are common experiences of caregivers, leading to unnecessarily increased burdens of care (Levine et al., 2006; Miller, 2010). With Mario still needing assistance with many activities of daily living, many weekly hours of caregiving work provided either by Wendy or home care services will be needed.

Finally, the team should learn more about Mario's and Wendy's personal values. Caregivers may feel pressured to become caregivers as a result of their religious values, societal expectations, and internal morals (Zhang & Lee, 2017). The team should explore Wendy's values and any potential cultural expectations to discover how these may affect any of the discharge options.

What are the preferences of* the *parties involved?

The team needs to know more about the preferences of Wendy and Mario. Wendy and Mario have to discuss whether a divorce is still what they want. It appears that Mario has changed his mind since the stroke, but Wendy seems less certain. Furthermore, it appears that Wendy will face some social stigmatization and emotional coercion, at least from their extended family, if she divorces Mario now. She may experience feelings of duty or guilt, leading her to accept a caregiving responsibility she would not have otherwise chosen (Hubbard, 2014). Will Wendy be able to cope with stigmatization and/or feelings of guilt if she refuses to become a caregiver to the husband she was on the verge of separating from? If she chooses to stay with Mario, will she be able to cope with the additional emotional and physical challenges that living together after his stroke will likely produce (Hokenstad et al., 2005)? The team should be sure to include a social worker in its discharge plans, and perhaps refer Mario and Wendy to a counsellor, to help them sort out their short and long-term relationship goals, as well as to organize community social supports for them (Levine et al., 2006).

Ultimately, the "unspoken demand from their loved ones who had suffered a stroke" often contributes to caregivers feeling pressured into providing caregiving labour (Zhang & Lee, 2017, p. 53). Mario's preference for Wendy to care for him at home conflicts with Wendy's plans to continue with her career and possibly divorce Mario. The team needs to learn what Mario's preferred options are if his emotionally estranged wife is no longer a caregiver option.

Are there any relationship and power dynamics that will impact our analysis?

Considering that Wendy was not included in any of the discharge planning thus far, and those plans included the assumption she would become Mario's informal caregiver, it is this prompt that has been most disregarded in this situation. It therefore deserves the most attention in the team's further discharge plans. The team does not actually know much about Mario and Wendy's strained relationship. Team members should explore Mario and Wendy's relationship further, to reveal anything that could be relevant to the implementation of an ethical discharge, such as past abuse, infidelity, or tangled financial concerns (Ho, 2008).

Are there any conflicts of interest?

Mario likely has a conflict of interest: he says their marriage problems are over, implying his wife will be comfortable providing care at home, but this statement contradicts Wendy's. He wants to go home and to receive care from a non-stranger. Wendy provides a way to achieve these goals. It benefits his interests to ignore Wendy's feelings, believe their marriage is fine now, and indicate to the team that she will be amenable to becoming his caregiver.

The healthcare institution has a conflict of interest in sending Mario home. While appearing to be providing patient-centred care by accommodating Mario's goal of going home with Wendy, the institution itself benefits from sending Mario home with her. Mario will no longer be taking up an expensive bed in the hospital, and the institution is saving the healthcare system money by conscripting unpaid care rather than discharging Mario to long-term care services.

Are there any concerns of justice or fairness?

There are concerns of justice and fairness to both, the patient expecting to take Mario's current bed, as well as to Wendy. A patient has undergone the complex process to be transferred to this hospital, expecting Mario's bed. It is unfair to this incoming patient to have no bed available. Meanwhile, Wendy is experiencing pressure by the healthcare institution, Mario, and her family to perform unexpected, unpaid caregiving work; this is work she appears to not want to perform, and it is work that would be required for the foreseeable future. Pressuring or coercing others into performing undesired work is unethical as it harms their autonomy (White & Tronto, 2004). It is an ethical harm against the principle of justice when the work others expect of them is undervalued and under- or un-paid (White & Tronto, 2004). In spite of this pressuring being unethical, Wendy's experience of being conscripted into providing more unpaid care than she expected or agreed to is not uncommon among caregivers, particularly women caregivers (Miller, 2010). Friends and family of patients who experience a stroke often feel pressured and unprepared by healthcare providers to become the informal caregivers of the patient once they are discharged (Zhang & Lee, 2017).

Finally, it is unjust to take advantage of a person in a vulnerable situation and impose uncompensated caregiving work onto them simply because they are available. Wendy appears to be somewhat vulnerable in this situation, as she acknowledges feeling pressured by her and her husband's family to become Mario's caregiver. If clinicians were unaware of potentially available informal caregivers, then clinicians would not assume that anyone would be available to provide care. In such cases, clinicians would advocate, lobby, and arrange for more community services; or they would discharge the patient into long-term care, if higher levels of care were needed (Aghazadeh et al., 2011).

Step 3: Review and analyze: *What legal and institutional policies are relevant?*

The third step reminds clinicians to consider any legal, professional, and institutional policies that may affect their ethical analysis of the situation. They should consider any other parties who should be consulted or included in the decision-making process, such as community organizations or other healthcare experts (Hunt & Ells, 2013). The team should discuss government community care and long-term care policies that may affect Mario and Wendy once Mario is discharged. The team must explore what community or government services Mario would be eligible for, what these services would cost Mario, and whether long-term care is a more feasible option for him.

Step 4: Identify and weigh the options.

Based on the above analyses, Mario, Wendy, and the healthcare team have several options to consider. The first option is what was already planned by the team, and what is an unfortunately common discharge practice: Wendy agrees under some social pressure to take Mario home with her, at least temporarily. Mario is discharged to the community with some referrals but little continuity of care to community services that Wendy is mostly expected to coordinate on her own (Gruneir et al., 2011; Levine et al., 2006). This situation supports the interests of the institution, since an expensive hospital bed is made available; and it supports the interests of Mario, who wants to go home to familiar care. However, it does not support the interests of Wendy, who is being expected to provide unsupported and unpaid labour. Additionally, it may not fully support the interests of the nurse because the nurse may no longer be convinced that her patient will be cared for well at home.

The second option is that Wendy agrees to take care of Mario at home, at least temporarily, with guaranteed outpatient, social work, and home care services to support her and Mario (Villapando, 2015). If later on Wendy decides she still wants a separation and/or chooses to provide less care, these community health services must assist in finding and moving Mario into his own home or to a long-term care facility (Gridley, Brooks, & Glendinning, 2014). This option supports the interests of the hospital best. Mario is achieving his stated goal only temporarily, and Wendy is still expected to provide some uncompensated care. However, if given time to think about her options, she freely decides that she will provide care for him, then this option, with the team's commitment to ensuring coordinated community services, is supporting her needs as best as the healthcare system can.

If Wendy refuses to provide care as is her right (White & Tronto, 2004), then the third option is to allow Mario to stay at the hospital or another institution until he can be moved into a different house from Wendy where he will receive home healthcare services or until he can be moved into a long-term care facility (Capriotti & Murphy, 2016). This option provides the best outcome for Wendy, but an ethical harm may be occurring if expensive, publicly funded healthcare services are being given to Mario when he does not need them. If Mario remains in his current bed, then this option harms the patient whose transfer process has begun. Ideally, another institutional bed will be found, allowing Mario to remain in institutional care temporarily. This option does meet some of the nurse's interests, though, by ensuring that her patient will receive adequate care until the team can coordinate a better discharge plan for him.

A secondary strategy to consider for all of the above scenarios is that the team advocates for policy changes so that informal caregivers receive paid compensation for their caregiving work, helping to limit the injustice of undervalued informal caregiving work. Such caregiver stipends are available in a few states for informal caregivers who meet specific qualifications and who have access to Medicaid ("AARP," n.d.). While a compensated informal caregiving situation still infringes on Wendy's autonomy since the team cannot realistically remove all of the relational pressures she will experience in this situation, a regular caregiving stipend or salary would at least alleviate some of the injustice of unpaid caregiving work expectations. Clinicians should advocate for better community and long-term care supports, in general (Levine et al., 2006).

Step 5: Make decision(s): ***What is the most ethical option and how should it be implemented?***

Caregiving relationships and the intertwined needs, goals, and rights of the involved parties are always particular to the relationship (White & Tronto, 2004). So, the team cannot truly act without investigating the many questions raised in the previous analyses further, such as exploring Wendy's preferences more, and asking Mario what his preferences are if Wendy refuses to care for him at home. There are no hard-and-fast rules for relational work or ethics. Mario, Wendy, and the healthcare team need to explore this situation further together using ethical models like the PCEAM-R to guide their collaborative decision-making processes (Hunt & Ells, 2013).

If in the end, Wendy refuses to provide care, then the team must implement the third option, where Mario is allowed to stay at the hospital, or preferably, at another institution with an open bed, until further discharge plans can be safely implemented. The team should never have assumed that Wendy would be willing to provide care without directly asking her. Therefore, the team should rectify its mistakes by creating time and space with Mario and Wendy to come to a plan that better includes Wendy's interests, too. If instead Wendy decides she wants to care for and live with Mario, then the team should try to coordinate as many outpatient services as possible to support her. The team should implement the second option, where Mario is discharged home with Wendy, but with guaranteed and extensive community supports in place to ensure adequate care is provided for Mario without over-burdening Wendy.

Regardless of the discharge options for Mario, as clinicians, the team should recognize and work to minimize the ethical harms revealed in this situation. In particular, healthcare providers should advocate for better support services for informal caregivers, including the provision of a paid caregiving stipend. They should advocate for better publicly funded, long-term home care services to provide relief to caregivers, prevent caregiver burnout, and ensure those without caregivers remain cared for.

Step 6: Evaluate the case and the outcomes of the decision. *What have we learned?*

In complex care situations like this one, discharge planning must begin shortly after the patient's admission and must actively include all relevant members of the family unit (Bauer et al., 2009; Miller, 2010). The assumption that someone will be willing to provide informal caregiving services, even if it is to a non-estranged relation, must stop. This assumption is an unjust expectation that infringes on someone else's autonomy. If relatives or friends want to provide care, they will freely offer it. Finally, this situation where an emotionally estranged relation is being called upon to provide unpaid care reveals the limitations of our current healthcare system and its dependency on billions of dollars' worth of unpaid labour (Chari et al., 2015). Clinicians must advocate for policies to better support caregivers who freely choose to provide care. Policies need to be enacted to ensure better access to home care and long-term care services so patients without willing informal caregivers are not left dependent on unwilling caregivers.

Conclusion

As clinicians, we are expected to care for our patients as well as for their family units (Gottlieb, 2012). We know the value of caregiving work, whether it is trained caregiving work, such as the work of nursing; or untrained but complex work, such as informal caregiving. There are harms that arise when care is chronically undervalued (White & Tronto, 2004). Clinicians are in excellent positions, as part of the discharge planning team, to note any plans that disregard any people, and to critique plans that undervalue the caregiving work required after discharge. By ensuring that a safe discharge for our patient does not depend on a potentially unwilling caregiver, we are advocating for our patient as well as for the potential caregiver.

More research on the ethics of care, and more advocacy for the value of care, are needed to properly address the broad social issue of the undervaluing of caregiving work (White & Tronto, 2004). Future research should establish actual incidences of caregiving between individuals in physically or emotionally estranged relationships, as there appears to be limited academic research on this specific topic.

In this paper, some of the ethical dilemmas that may occur in the discharge planning process when an estranged relation is called upon to provide care were identified and discussed. Guided by an ethical decision-making model, this paper offers specific insights on how to ethically discharge a patient in a complex family situation when the patient will need chronic caregiving supports. Considering that the frequency of such situations is likely to increase as the population ages alongside rapidly changing family dynamics (Milan, 2015), this paper offers clinicians some guidance on how to ethically navigate these situations.

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