COMPLICATAED MORALITIES: RELATIONAL ETHICS AND CAREGIVER BURDEN

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THESIS

Introduction

It is a well-recognized trend that medicine has transmogrified over the 20th century. It has taken up the challenge of wrangling the chronic diseases such as uncontrolled diabetes and hypertension. This has challenged the structure of the medical system (Rose 2007). Where hospitals once kept patients for weeks to allow time for an illness to heal, it does not have the capacity to care for a person this long: particularly when a person's functional capacity declines and it becomes unclear if they will ever be able to fully care for themselves again (Berg and Harterink 2004). This has ballooned the population of people living in long term care. We can expect that the number of people that will require assistance from formal and informal care networks will increase in the coming decades (Friedland 2004). However, living in a medical institution is not an ideal scenario for most people, and families try to find ways to care for their loved ones at home. Indeed, many states encourage this effort through the Home and Community Based Services (HCBS) Medicaid waiver. This program offers aid family members acting as informal caregivers. Not only does this align with patients' stated wishes, but it also is fiscally advantageous to the state to offload some of burden of caregiving onto willing family members (Holstein 2013). The cost of supporting informal caregivers is less than would be spent if those patients entered the formal care system. Yet, there are consequences to that transition for informal caregivers. Care ethicist Carol Gilligan was prescient when she talked about the complicated moralities that arise when care shifts to family relationships.

Informal caregivers pay a psychological and physical tax when they agree to care for their loved ones. They are at a higher risk of cardiovascular disease and there are higher

rates of depression, anxiety, and loneliness (del-Pino-Casado et al. 2021; Bom et al. 2018; Liu, Heffernan, and Tan 2020; Choi and Seo 2019). Aside from affecting health outcomes, acting as an informal caregiver has been shown to negatively affect social engagement and career development. Caregivers are more likely to deprioritize their job and not seek better compensated positions if it is perceived that it would come at the expense of their responsibility to the care recipient (*ibid*). This depression on upward mobility preferentially affects families that do not have the resources to pay for outside help. Since current stipends for caregivers are specifically designed to decrease costs to the healthcare system, they are insufficient, on their own, to cover the cost of hiring a dedicated aide. Thus, it is frequent practice for families to hire relatives to act as the caregiver, since they are willing to work without a benefits package (Blaser 1998). The context of the growth of informal family caregivers is important because it informs the degree to which the phenomenon preferentially affects socioeconomically disadvantaged people.

I will start this paper by introducing the theoretical frameworks under discussion. I will start with a relevant summary of traditional biomedical ethics. I will talk about ways in which it is ill suited for the case of the informal caregiver. This ethical system evolved to address for a starkly asymmetric relationship between relative strangers: the doctor and the patient. However, it is being used to inform the activities of people that are relatively equal and are typically intimately familiar. I will then introduce an alternative ethical framework that is better suited for this relationship. Relational Ethics, alternatively called Ethics of Care, is an ethical framework conceived by Carol Gilligan and further

developed by Joan Tronto (among others) that traces the ethics of an action to the ways in which each party attends to the needs of the other people in the relationship.

At its foundation, it is an ethical code in which the extensive personal knowledge that participants in a caring relationship have about each other's needs informs the acceptability of an action. It figures that the responsibilities that a person has towards others are based on their relationship. After exploring this ethical framework, I then compare relational ethics with traditional biomedical ethics, and discuss why the two ethical codes are better suited for different situations. I then discuss some of the mechanisms and effects of caregiver burden. I will then argue that some of the source of caregiver burden is from an application of traditional biomedical ethics in a situation for which it was not intended. I then discuss social capital, and the negative effects that it can have, and consider how this relational ethics can be used to inform how social capital theory can be applied to caregiving relationships. Finally I offer a clinical example, and discuss how traditional and relational ethical lens could affect how we understand the caregiver relationship and shift caregiver behavior and burden.

 Throughout this paper I argue that Care Ethics is a natural fit for the informal care relationship. Viewing the informal caregiver relationship with this ethical lens requires a more thorough exploration of the connection between care-giver and care-receiver. If healthcare providers focus on the application of an ethics of care on a clinical level, it would force care teams to better evaluate caregiving capacity and dynamics. This would focus attention on caregivers so that efforts can be taken to reduce caregiver burden

The Traditional Biomedical Ethic Framework for Formal Caregivers

It is useful to take a step back and look at the bioethical underpinnings that govern formal caregiving. The four pillars of traditional biomedical ethics are patient autonomy, beneficence, non-maleficence, and justice (Beauchamp and Childress 2013). The core components of American biomedical ethics arose from the Nuremburg Code and The Belmont Report (Shuster 1997; Adashi, Walters, and Menikoff 2018). These documents were written in reaction to monumental injustices that arose from stark power imbalances. Thus, the principles they contain are designed to protect a care receiver who is participating in a greatly imbalanced power relationship. This suits the doctor-patient relationship well: the doctor holds most of the medical information and the patient has to rely on the physician's professional ethic to enforce beneficent behavior. While modern practice encourages practitioners to allow the patient to participate in the decision-making process, the provider ultimately has unilateral control over decisions of prescription and referral.

There are two salient features that arises from this history, and the type of modern practice to which it led. The first is that a provider's responsibility arises from abstract principles. This allows providers to enter nearly every clinical situation with a relatively clear sense of what they ought to do. Recent research has suggested that providers ought to consider broad demographic information when they are deciding how to approach a patient encounter: accounting for things like implicit bias (Kanter et al. 2020). However, they do not require any knowledge about the patient's life history outside of the facts deemed pertinent to the case. Indeed, there is even concern that a too personal

relationship could represent a hazardous source of bias that would cloud professional decision-making.

The second salient feature, a corollary to the first, is that since the two parties do not have a personal relationship, the patient does not have a responsibility to the welfare of the physician. There is no facet of medical ethics that governs how the patient ought to act; indeed, a review of the literature at the time of submission did not reveal any scholarly writing on an ethical responsibility safeguarding the wellness of physicians. Indeed, this is in line with the history of the discipline: the focus is on respect for and protection of the patient.

There is a plethora of discussion around physician burnout, though it is only tangentially connection with biomedical ethics. There is research around the risk of burnout leading to unethical behavior (Bullock et al. 2017; Dyrbye et al. 2010; Jennings 2009). This is in fact illuminating in considering how the medical profession protects provider wellness. We can see that this is a longitudinal *professional* concern; educators introduce the concept of burnout, and the importance of guarding against it, at the beginning of training, prior to when a person becomes a clinician. Providers are supposed to spend their years of training cultivating a sustainable caregiving practice. Informal caregivers do not have this luxury of time. And we will see below that when resources are scarce, and personal relationships are featured prominently in formal practice, many providers are unable to prevent excessive burden and burnout.

We can look to an edge case within the formal care system to demonstrate what happens when the personal emotions feature heavily in a clinical relationship. Danielle T.

Raudenbush performed a sociological study of the underground healthcare system in a socio-economically disadvantaged urban center. The healthcare providers in this system utilized a combination of formal programs and personal assistance to help their patients. This personal assistance is often at their own psychological or financial expense. They are driven by a number of factors when deciding how much risk they will expose themselves to in order to help patients outside of formal professional boundaries, but one of the overriding factors was a personal sympathy for the patient and their life story (Raudenbush 137). If trained providers, who are socialized in the practice of medicine which instructs them to maintain a professional detachment when rendering care, are prone to place themselves at personal hazard when caring for a patient, then it is reasonable to conclude that informal caregivers are even more likely to prioritize the care-receiver's wellness over their own. Now that we have introduced the traditional biomedical framework, we will turn to a discussion of informal care relationships.

Family Relationships and Informal Care

Families are crucial to the functioning of informal care networks. Over 95 percent of caregivers are a relative of the care recipient (Wolff et al. 2016). The familial relationship is complex, it varies across cultural boundaries, and it has changed during the twentieth century. One can look at scholarship on the American family to understand the context in which the informal caregiver relationship arose. The normative-integrative approach to intergenerational family relationships was pre-eminent in the early 20th century. It focused on, "cohesion between family members based on bonds of solidarity and norms of filial obligation" (Silverstein, Conroy, and Gans 2012). This paradigm functioned in a pre-globalized society in which families were expected to remain relatively

geographically cohesive. This meant that there was a large reservoir of family contacts to draw from when support was needed. Moreover, it meant that there was tangible censure by other family members if an individual were derelict in their responsibilities.

However, the growing globalized economy incentivized workers to leave their hometown and find work at economic hubs (*ibid*). As this happened, a new paradigm for understanding the family arose. The functionalist-normative approach became more prominent which elevated the nuclear family as the indivisible unit. This expectation created tension as the needs of the extended family competed with the needs of the nuclear family for autonomy to maximize their economic prospects (Daatland and Herlofson 2003). For nuclear families that remained geographically close to their families of origin, it could only be expected that an idiosyncratic hybrid of the normative and functionalist approaches developed.

Since the social construction of each family is dependent on their individual dynamics and the microclimate of their personal histories, one can expect that each family will have different levels of normative and functionalist approaches. This makes us wonder: what dynamics motivate family members to act as informal caregivers? There are several theories that attempt to explain this motivation. One theory is that there is a moral capital that is developed in early childhood (Silverstein, Conroy, and Gans 2012). To maintain familial integration, parents inculcate a moral responsibility for helping other members of the family (specifically the parents) into their children. This concept is echoed in religion and media and overtime moral capital develops that, in essence, transmogrifies into a social capital for parents. This moral-social capital makes it difficult for children to not act as caregivers, even if it is not in their best interest.

Another possible factor contributing to the expectation that children act as informal caregivers is an element of reciprocity. This can be conceptualized as a either a direct reciprocity between parent and child: the child expresses their gratitude for the cost of childrearing decades prior (Pei and Cong 2020). However, there is also an element of reciprocity in some Care ethicists conception of informal care. This is a theory that was advanced by Care Ethicist Eva Feder Kittay who sees intergenerational care as a form of transitive responsiveness: one cares for the older generation with the assumption that the next generation will care for oneself (Kittay 1997). From this we can see that the moral foundation of the formal caregiver's responsibilities is different than that of the informal family caregiver. The concept of filial duty is ingrained from early childhood, while professional ethics are taught in adulthood. It would be illogical to expect a family member to execute a professional code of ethics in the same way that a non-family member would because they have a different moral responsibility to the person being cared for. Regardless of the exact motivation for informal care work, it is apparent that it is found *within* the relationship between the caregiver and the care receiver rather than arising from abstract principles. It would be more appropriate to look at alternative modes of bioethical reasoning to formulate the ethical practices of informal caregivers.

Relational Ethics

Relational ethics or Ethics of Care are a bioethical framework that is more responsive to the positionality of the members of the care relationship. Instead of considering all elements of the moral question as they relate to the patient, relational bioethics considers all members that are affected by the situation. Carol Gilligan developed the Ethics of Care in the 1970's and 1980's, and it has been expanded upon by numerous scholars

since its conception. At its core, "Care ethics seeks to explain the imperative to enter into and maintain caring relationships" (Collins 2015). Its morality is derived from the relationships between particular people, and that the deliberation of how to address a question should be based on an empathic understanding between those people rather than an appeal to general principles. It recognizes that, "morality demands not just one-off acts, but also certain ongoing patterns of interactions with others and certain general attitudes and dispositions" (Collins 2015).

To better clarify the specific nature of a care relationship within the context of relational ethics, it would be useful to review the principles discussed by Joan Tronto. She advanced five ethical qualities of care: <u>attentiveness</u> to the needs of others, a sense of <u>responsibility</u> for the wellness of others, <u>competently</u> responding to the needs of others, each member in the care relationship being <u>responsive</u> to the needs of the other members, and <u>solidarity</u> with other people in society (Cudd and Andreasen 2005). The demand for responsiveness is particularly important because it recognizes needs of all members in the discussion, including the caretaker.

Susan Collins performs a thorough evaluation of relational ethics in *The Core of Care Ethics*, and she demonstrates how the precepts espoused by relational ethicists can be seen to arise from the dependency principle (Collins 2015). This principle is accepted in the traditional philosophical tradition that form the backbone of Western Bioethics (Relational Ethics is—of course—not required to have such a pedigree to be considered *valid*). In short, the dependency principle suggests that a person has a moral responsibility to assist another person in accomplishing a valid interest if they are best placed person to assist in achieving that interest, and it would be at a reasonable cost to

the person being depended upon. Using this as a backbone, Collins shows how the responsibilities and practices endorsed by care ethicists naturally arise from the position of participants in caring relationships. This conception of care ethics is concordant with the clinical experiences of patients with serious illnesses. Informal caregiving relationships often form slowly and naturally because family members are best-placed to assist the care-receiver in managing their health.

It will be particularly important for our purposes to note which relationships generate a moral responsibility according to relational ethicists. The conceit for relational ethics is derived from familial relationships. Indeed, in Collins description, the strongest moral indications are generated by personal relationships (e.g. family, close friends, *etc.*). Thus, when looking at ongoing, interdependent relationships, like spousal relationships, it is logical that a moral responsibility arises when one of the partners becomes ill. Thus, it is natural to see how the relational ethics framework would be well suited to guide informal caregivers.

Finally, relational ethics is particularly well suited for the informal care relationship because it places the *relationship* itself as a moral core. Collins summarizes the work of Virginia Held, Nel Noddings, Grace Clement, and Anca Gheaus when she notes that, "some of the most morally important actions and attitudes aim to value, preserve, or promote personal relationships" (Collins 2015). This shift away from a sole focus on the patient forces a consideration of the caregiver. We can look back to the writings of Carrol Gilligan who writes that, "In a world that extends through an elaborate network of relationships, the fact that someone is hurt affects everyone who is involved, complicating the morality of any decision and removing the possibility of a clear or

simple solution" (Gilligan 1993). Consistent with this theoretical assertion, we have observational clinical data that suggests that well-functioning families experience less depression and caregiver burden (Ghasemi, Arab, and Mangolian Shahrbabaki 2020). Relational ethics is specifically social, and avoids an individualistic or dyadic frame. On other hand, traditional bioethics *centers the patient*; the frame is always from the point of view of a caregiver asking whether a particular action would advance the patient's interests. Instead of asking solely what is best for the patient, a relational ethical frame asks what is best for each person in the relationship, and what is best for the relationship itself.

With this broad explanation in mind, we can explore caregiver burden and then we can turn to a clinical scenario. We will see how caregiver burden arises from the expectations created by a bioethical model that was not intended for informal caregivers. We can also infer deeper issues related to role changes that arise from the misapplication of the traditional bioethical model, and how this might be ameliorated by using a care ethic model to conceptualize informal caregiver relations.

An Introduction to Caregiver Burden

Caregiving can take a tremendous toll on informal caregivers. Family caregivers of seriously ill individuals have higher rates of cardiovascular and psychological disease, delays in life milestones, and lower professional attainment. Liu et al. performed a concept analysis of caregiver burden, defining it as a perceived burden due to a multitude of interrelated strains arising from a conflict of competing responsibilities and a deprivation of personal social interactions (Liu, Heffernan, and Tan 2020). The result of

these demands manifests in a plethora of ways: physical symptoms, psychological distress, impaired social relationships, spiritual distress, financial crisis, role strain, disruption of daily living, and uncertainty (Choi and Seo 2019. This group suffers from increased anxiety and depression and poorer health (Bom et al. 2018). It is possible to attenuate these effects by supporting caregiver resiliency and perceived social support (Palacio G et al. 2020; del-Pino-Casado et al. 2021). Alam et al. explored whether early palliative care intervention could be used to influence caregiver burden, and it did have a modestly positive effect on some dimensions (Alam, Hannon, and Zimmermann 2020). They also must allocate financial resources for their sick family member, and they also report passing on career advancement if it would prevent them from adequately caring for their family member (Thomas Hebdon et al. 2022).

Caregiver burden is delineated into an objective component and a subjective component. Some elements of caregiving are easily quantifiable and plans for their amelioration can be proposed. For example, many states offer financial assistance from Medicaid funding for informal caregivers of qualifying patients through Home and Community Based Services (HCBS) Waivers. Though, notably, the amount of funding that is offered through the program is orders of magnitude less than the value of care that is rendered by informal caregivers ("State of the States in Family Caregiver Support" 2014). However, even if the healthcare system were able to adequately fund informal caregiver programs, some issues are not easily addressed through typical assistance programs. Social isolation and loneliness, in particular, are hard to address, and have a complex relationship with caregiving. Many programs have attempted to ameliorate caregiving related social isolation. A computer based program in 2018 showed improvements in depression scores,

but did had mixed results on other outcomes (Hopwood et al. 2018). Caregivers discuss a number of themes when describing their experience of loneliness (Vasileiou et al. 2017). They talk about having a reduced number of social interactions, often related to a feeling that we would be derelict in their caregiving responsibilities if they left their home. Even when they do have social engagements, they report feeling a sense of separateness because they did not feel like friends could understand their struggle. They also discussed how the experience of battling a progressive disease engendered feelings powerlessness which made caregivers feel lonely.

One final theme that Vasileiou *et al* discussed deserves special attention because it subtly conflicts with other emotional elements of the caregiving experience. At times caregivers report that the care relationship brings them closer with their loved one. However, caregivers also note that they feel lonely in the face of their changing relationship with the cared-for person. This dynamic is particularly notable in spousal caregivers of dementia patients. Many caregivers note having less interest in physical intimacy with their partner: a feeling that is at times reciprocated by the care receiver (Adams 2006). They note that their relationship had fundamentally changed with the cared for individual.

Another study in 2017 looked specifically at the anguish of caregivers of patients with heart failure. Issues around Role Definition were one of the four themes that fed into caregiver anguish. One caregiver spoke about the guilt that she felt when she had to balance her role as a mother with her role as a caregiver. She notes, "That's hard. Especially when you, and two children, 'Mum, can we do this?' 'No, sweetie, because I can't, not really, because your dad's not well enough' and…that and the guilt with the

children is hard" (Wingham, Frost, and Britten 2017). Other caregivers in the study noted that it was even difficult to maintain a sense of personal identity.

Social Isolation and Loneliness

Social Isolation and Loneliness, in themselves, are believed to have a significant role in heart failure and its management. It is believed to have direct effects and indirect effects on cardiovascular health. It is believed to directly impact the body through changes neuroendocrine and vascular effects. It leads to increased cortisol signaling which worsens blood pressure control as well as fluid retention (Hawkley and Cacioppo 2010). Vital exhaustion has been strongly linked to incidence of heart failure, and this marker is exacerbated by social isolation and loneliness (Shah et al. 2021; Coyte et al. 2022; Cené et al. 2012). To consider the effect that this has on a person's heart, a prospective study of adult men looked at the correlation between social isolation and incident heart failure. They found that socially isolated men had a 60 percent greater chance of developing heart failure. Similarly, men who reported low satisfaction with their social relationships, a proxy for loneliness, also had a 55 percent greater chance of developing heart failure (Coyte et al. 2022). These studies exemplify the deleterious effect that social isolation and loneliness end up having on a person's heart. However, when one looks at the experience of individuals with heart failure, it becomes apparent that one must delve into the manifestation of these effects to elaborate effective interventions

Aside from the direct effects that isolation and loneliness have on the body, they also impair individual's ability to make the necessary changes to cope with their diagnosis. Isolation and loneliness predispose individuals to depression which is a potent barrier to

things like fluid restriction and necessary dietary changes. These effects are restricted to the specific physiology and behavior of the patient. Moreover, they are agnostic of the specific aspects of heart failure. Looking further into how these patients experience their disease, it is possible that the ill effects of how social isolation and loneliness affect their relationship with their caregiver can lead to even poorer outcomes.

To understand this, one must examine how patients with heart failure experience their disease, and how social relationships play into their coping strategies. Several studies have analyzed the experience of patients as they adapt to a diagnosis of heart failure. Each of these reviews feature social relations as a key factor in living with this disease. Jeon et al. conceptualized the changes that this diagnosis triggered in three categories: impact of CHF on everyday life, coping, and factors influencing self-care (Jeon et al. 2010). Within the broad category of the impact of CHF of everyday life, they note that social isolation was a significant sub-theme. They note that one of the contributors of this social isolation was the changing role that they had within their social structure. This change was accompanied by guilt and anxiety about being a burden to others. Within the larger domain of 'factors influencing self-care' they note that changing personal relationships were impactful. They note that patients had various negative emotional responses: such as anxiety about being a burden to their relations and frustration with dependency.

It is worth noting that the experiences of social isolation and loneliness in patients and caregivers is particularly impacted by socioeconomic disparity. The first is by noting that poor individuals need to rely more on family members for medical support. Caregivers note the difficulty of juggling the demands of their loved one's medical ailments and

other life responsibilities. This challenge is exacerbated by pre-existing precarity. We can

look at a recent study on the effect that caregiving had the ability of millennials to reach

life milestones. In this study, caregivers related how caregiver responsibilities interfered

with their ability to commit to education or career advancement. Similarly, their

responsibilities interfered with their ability to extend their other interpersonal networks

(Thomas Hebdon et al. 2022). It is not surprising to note that caregiver burden is

associated with pre-existing poverty. Shrestha et al studied caregiver burden in patients

with cirrhosis and found a negative correlation between socioeconomic status and burden

(Shrestha et al. 2020). Further research ought to be done to better detail the mechanisms

by which families cope with this challenge, and how these coping mechanisms affect the

trajectory of the patient's illness, for both the patient and the caregiver. However, one can

look to research around social capital to theorize some of the processes at play.

Social Capital and Caregiver Burden

We can use the framework of social capital to understand the caregiver-patient

relationship. Nearly every study talks about the importance of a patient's social network

for physical and psychological support. The availability of these benefits is dependent on

their social capital: the amalgamation of resources that are at one's disposal due to their

social relationships. We can also look at understandings of social capital to understand

caregiver burden. Villalonga-Olives and Kawachi talk about a variety of diverse ways

that one's social network places demands and restrictions on an individual (Villalonga-

Olives and Kawachi 2017). In wording that feels like previous discussion on caregiver

burden, they talk about how strong bonding capital—the type of capital between similar

people (e.g., family)—places obligations on people to perform tasks against their best

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interest. Kim and Jung have importantly extended this work to talk about relational burden (Kim and Jung 2022). They have described how this dynamic is instantiated in caregiver relationships.

Other aspects of their discussion on the dark side of social capital could be important to understanding variation in the ways that individuals use their social network, which would have impact on both patient and caregiver wellbeing. Another example of how individuals in poor neighborhoods are preferentially affected by disease burden can be seen in looking at cross-level interactions. This concept refers to a dark side of social capital that arises when people who require a high degree of trust, like patients with heart failure and their caregivers, in their relationships live in a low trust neighborhood. It can disincentivize leveraging one's relationships to distribute caregiving needs and reduce the caregiver burnout (Adams 2006). Qualitative research has shown that there is a complicated relationship between trust and the exchange of healthcare related services (Raudenbush 2020). In this study, participants describe themselves as low-trust individuals, but their actions demonstrate that their social interactions are highly dependent on non-guaranteed reciprocity. It would be worthwhile to investigate whether caretakers do high trust activities to alleviate some of their burden (e.g., asking for social support). If families do activities requiring trust, it would be worthwhile to investigate the outcome of these attempts.

Now that we have examined some of the dynamics of caregiver burden, it is worth theorizing the degree to which caregiver expectations align with traditional biomedical ethics, and ways in which a relational ethic might offer a different solution. Much like Raudenbush's analysis of physicians in urban areas, there are many times in which it

appears that informal caregivers straddle the line between formal and informal care. I posit that this tension contributes to some of the subjective burden.

A Clinical Example: A Congestive Heart Failure patient and their caregiver

One can look at some of the themes that arose in qualitative interviews with caregivers of patients with heart failure to see how physical challenges manifested through issues with identity and relationships. This is a situation where care ethicists have written about, but which traditional medical ethics is ill-equipped to handle. One of the issues commonly discussed by patients with CHF is a concern that they are being a burden to their caregivers. Care recipients are aware of the cost of caregiving, and at times will exclude their caregivers from their medical affairs in an effort to relieve some of the burden (Wingham, Frost, and Britten 2017; Jeon et al 2010). Their behavior shows that they are reticent to utilize their social capital because they know that it is a form of dark social capital for their caregiver.

Contributing to this difficulty in utilizing family caregivers, previously independent individuals report that they are uncomfortable being dependent on loved ones because of how it changes their role. One of the common ways that individuals initially cope with their diagnosis is through denial. Patients describe themselves as strong-willed or independent to avoid accepting their need for support (Yu et al. 2008). After this avoidant stage patients adjust by going through periods of disruption, incoherence, and then reconciliation. During periods of disruption and incoherence new challenges are faced, and patients report feeling burdensome and having a loss of identity related to their disease (Mahoney 2001). Until these identity issues are reconciled patient are not able to

trial lifestyle modifications and come to a new equilibrium. This period is sub-optimal from a self-management perspective, strains caregiving/family relationships, and exacerbates caregiver burden, and increased frequency of hospitalization (Sevilla-Cazes et al. 2018).

Given this situation, we can look to our ethical frameworks for guidance. Using the traditional biomedical framework, a canny informal caregiver may see this as a delicate balance between autonomy and beneficence. On the one hand, the caregiver ought not force treatments (fluid restriction or medication administration) if the patient is not ready to accept their clinical need. However, beneficence would encourage the caregiver to promote an efficacious therapeutic option. Striking this balance is not particularly difficult for a healthcare provider because they have the professional distance to accept the patient's decision and move on, even if their decision is deleterious to their health. However, an informal caregiver is intimately involved with the long-term effects of every health decision. For example, Wingham *et al'*s mother who had to tell her children that their activities were limited because of their father's illness. Like Gilligan noted above, the fact that one person is sick affects everyone in their social circle.

An adherent of relational ethics would handle this situation differently. While medical ethics focuses on the patient, relational ethics looks at each individual's needs, and how well other people are able to competently respond to those needs. A health care provider could spend a visit reviewing how the patient and the care giver are experiencing the patient's health challenges. They could spend time looking at the ways care arrangements could be adjusted to maximize care and minimize burden. This attentiveness to the relationship between the caregiver and care recipient would likely reduce subjective

caregiver burden, even if it did not lead to any substantive changes, by optimizing the family dynamic.

Conclusion

Throughout this paper we have looked at the foundations of traditional bioethics and care ethics. We have also looked at the history of formal and informal care and seen how each bioethical model relates to the experience of caregivers. In particular we have looked at the phenomenon of caregiver burden and analyzed ways in which relational ethics might provide a better framework for conceptualizing the informal care relationship. We then looked at examples of how prior qualitative interviews with caregivers of patients with serious illness exemplify some of the theoretical dynamics introduced earlier. Further work should be done to clarify ways that a relational ethical approach might be used to screen for and optimize care relationships.

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