Caregiving and Role-Conflict Distress

Abstract

When our nearest and dearest experience medical crises, we may need to step into caregiving roles. But in doing so, some people find that their new caregiving relationship is actually in tension with the loving relationship that motivated us towards care. What we owe and are entitled to as friends, spouses and family members, can be different from what we owe and are entitled to as caregivers. For this reason, caregiving carries with it the risk of a type of moral distress that I call 'role conflict distress'. Rather than view role conflict distress as a sign that we are falling short, I suggest that it actually speaks to the commitment that we have to the loving relationship that grounds our duty of care.

Introduction

When my father was dying from pancreatic cancer, I could always tell what sort of day he was having by listening to how my mother spoke to him. My parents had enjoyed three decades of witty banter punctuated by lighthearted spats. On his bad days, there'd be no bickering—my mother just would accede to whatever requests he made. On his good days, however, they'd go back to their usual ways—she'd complain about him being difficult, he'd tell her to stop being such a busybody.

There was a sense in which my parents shared two relationships with each other simultaneously in the last weeks of my dad's life. In one relationship, my father was a patient, and my mother his caregiver. She took responsibility for both his daily needs and his emotional stability, and she consistently put her own needs on the backburner. The second relationship was the relationship that they had enjoyed throughout their marriage: in it, they were co-carers, capable of helping, hurting, and above all, annoying, each other. The relationships were not totally separable; after all, it was my mother's love for my dad that motivated her to provide care. And yet, my parents experienced a conflict between them: being a good spouse just wasn't always compatible with providing good end-of-life care.

The conflict that my parents felt may initially seem strange. After all, loving relationships carry with them serious obligations of care. How, then, can the very obligations that structure our loving relationships be in tension with those relationships? But as I'll argue in this paper, even though loving relationships feature stringent obligations of care, 'care' is nevertheless a big tent that picks out a wide range of activities. We conventionally associate different types of care with different types of relationships–medical care, for instance, is conventionally performed by medical professionals to patients. When we perform these forms of care to someone with whom we share an loving, egalitarian relationship, we may come to feel that we are standing in multiple relationship-types with them simultaneously: we are both spouse and nurse, family member and doctor. Crucially, even if our loving relationship motivated us to take on this additional relationship of caregiver, we may find the norms structuring both relationships to be in tension with each other. And so, we must make serious normative tradeoffs between our loving relationship and caregiving relationship. This makes caregiving a potential site for a type of moral distress that I am calling 'role conflict distress'.

My paper proceeds as follows. In Section 1, I outline what I mean by a 'loving relationship', and explain why some relationships generally carry with them both obligations and entitlements to care. In Section 2, I consider how the norms of quasi-medical caregiving can be in tension with some of the norms that commonly structure our loving relationships, thus making caregiving a potential site for role conflict distress. In Section 3, I explore several strategies for combatting role conflict distress: increasing resource distribution, reconceptualizing quasi-medical care, and drawing boundaries around specific forms of quasi-medical care. I suggest that while each strategy may help, no strategy is a panacea.

Before I begin, let me offer three comments about the scope and value of this project. First, while I think that the phenomenon that I am describing may accompany many caregiving experiences, I am particularly interested in caregiving at the end of life. This is in part for autobiographical reasons: I have first-hand experience with phenomenology of end-of-life care. But I think that caregiving at the end of life has two features that make it particularly vulnerable to role conflict distress: it is often done in the midst of a crisis, and is often time-limited. This limits our ability to bring the norms of our caregiving relationship into alignment with the norms of the relationship that preceded it.

Second, while I am focusing on the experiences of caregivers in this paper, I think that care-receivers may also experience role-related distress. What it takes to be a good *patient* may also conflict with what it takes to be a good friend or spouse. Nevertheless, I think it is important to attend closely to the experiences of caregivers, who continue to perform a massive amount of quasi-medical labor (Feinberg et al. 2019) while occupying only a marginal role within contemporary bioethics.

Now a comment on the value of this paper. Narrowly, this paper captures a piece of phenomenology that is, I think, quite familiar to those of us who have taken on caregiving roles towards our loved ones. More broadly, I hope that the paper offers can be used to help counteract what I like to call the 'myth of the saintly caregiver'. We sometimes assume that people owe it to their loved ones to become veritable 'moral saints' when they get ill.[1] Often, people attempt to counteract this myth by pointing out that caregivers can't do it all (see e.g. Wei 2018). But I think there's another way to push against it. Even if we *could* do it all, we shouldn't–because being a good friend, spouse, or family member is in tension with being a moral saint. The expectations that we place on caregivers must thus be sensitive to the realities of the relationships that ground obligations of care. When we demand perfection ourselves as caregivers, we risk damaging the underlying relationship that motivates us towards care.

Section 1: Loving Relationships, Moral Obligations, and Care

I think it would be impossible to capture the experience of caring for a loved one without understanding why it is that we so often feel that we have duties to care. Even if we take on our caregiving role willingly and out of love, after all, we also experience that role as one that we are obligated to take on. What sort of spouse, or friend, or child would we be if we *weren't* willing to provide care for our loved one in the wake of a terminal illness diagnosis?

Why think that we have a duty to step into caregiving roles when our nearest and dearest fall victim to a life-limiting illness? Here's one way to tell this story. Our relationships are structured by particular moral norms. And different relationships are structured by different moral norms; what you owe to a colleague is very different from what you owe to your spouse. Loving relationships – like friendships, familial relationships, and romantic relationships – typically feature stringent obligations of care. We ought to care for our loved ones, and they too ought generally care for us. These obligations are unsurprising given the sort of thing that loving relationships are. Part of being in a loving relationship with another person *just is* having a heightened non-instrumental concern for that person's interests and values (Kumar 1999; MacKenzie 2018). And so too does standing in a loving relationship typically entitle us to reciprocal concern.[2] Just as I owe it to my partner to care about his well-being in a way that goes far beyond the amount of care I am obligated to have for humanity at large, so too does he owe it to me to care about my wellbeing in this special way.

But what exactly does care involve? Speaking generally, caring for someone involves taking an interest in their good. But this very general definition isn't much help when it comes to figuring out what *types* of care we owe to our loved ones. Here, I think the norms governing what forms of care go with what types of relationship may be somewhat conventional. I owe it to my best friend to act as a sounding

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[1] Caregivers, for instance, repeatedly report feeling guilt (del-Pino-Casado et al. 2019; Gonyea et al. 2008, Martin et al. 2006), and have been found to neglect their own health in the service of caring for their loved one (Connell, C.M. 1994; Hoffman et al. 2012).

[2] Not all relationships involve reciprocity. Parents can expect no reciprocal concern for very young children, for instance. Nevertheless, even non-reciprocal relationships feature some degree of reciprocal entitlements; parents are entitled, for instance, to take breaks from caregiving in order to maintain their own mental health.

board when she has a personal problem, and to help her move. I don't, however, owe it to my best friend to make career sacrifices on her behalf, or to serve as her medical proxy if she is ever incapacitated. These are things that we might reasonably expect our aunt and spouse respectively to be willing to do for us, however.[3] Crucially, I think that some of our care-related norms could have been otherwise. But that they are the way they are can lead them to have normative pull. We have a sense of what we can expect from our friends, family and romantic partners – and that, coupled with the fact that we have broad obligations of care within our loving relationships, is sufficient to make it the case that our loved ones are doing something wrong when they fall short.[4]

Here's why this stuff about social convention matters: we associate different forms of care with different types of relationships. Caring for someone as a friend looks different than caring for them as a child, or nurse, or mentor, or romantic partner. Of course, we *could* have drawn different conventional associations – and we still might. But given that the forms of care that we perform during end-of-life caregiving are not, generally, forms of care that we perform within loving relationships generally, we may experience those forms of care as serious disruptions to the relationship. Indeed, I don't think it's metaphorical to say that, when we step into the caregiving role at the end of life, we actually take on another relationship towards our loved ones.

It might initially seem bizarre to talk about sharing multiple relationship-types with a single person, but I think it's actually quite normal. Friends can be mentors, parents can become friends, spouses can also be colleagues. Sometimes, indeed, we may be under moral pressure to take on additional relationships. If the only way to help your friend is to become their mentor, then you may owe it to them to step into a mentorship role.

We may sometimes experience normative conflict as a result of sharing multiple relationships with the same person. Consider the sort of conflict you might experience if your spouse is also your colleague. Spousal relationships are highly partial. We ought to privilege our spouse's interests over the interests of others. But such partiality is inappropriate in the workplace. This can create moral conflict: are you being a bad spouse if you don't take time out of your day to help them through a problem at work? Over time, couples who work together likely find ways to reduce normative conflict between their

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[3] We form care expectations in other ways as well. For instance, we might mutually agree to perform certain forms of care for each other, and we might explicitly negotiate what those forms of care will look like.. But I think that the conventional story often sets defaults that we then toggle.

[4] Of course, social expectations can run afoul of basic moral norms. If we as a society, for instance, determine that mothers ought to provide an amount of care to their children that is incompatible with their own self-respect, then we've set a social norm that can't be justified morally. In this way, morality places a negative constraint on what social norms of care are morally permissible.

competing relationships–but the process of bringing these two relationships into better normative alignment is rarely automatic.

I'm going to tell a similar story about normative conflict in quasi-medical caregiving relationships. The loving relationships that motivate us towards care, I will suggest, are often structured by very different moral and nonmoral norms than quasi-medical caregiving relationships. This creates a high potential for a type of moral distress that I will be calling 'role-conflict distress'.

Section 2: Quasi-Medical Care and Role-Conflict Distress

Let's start this story by taking a closer look at what sorts of care goes on in quasi-medical caregiving relationships. By 'quasi-medical caregiving relationships' (or 'caregiving relationships' for short), I have in mind loving relationships in which one or both parties perform forms of care that we would typically associate with the medical profession. This care includes, but is not limited to activities such as: intravenous therapy, including intravenous antibiotics and total parenteral nutrition, feeding, gastrostomy and/or nasogastric care, urinary catheter care, wound care, and ostomy care (Mong 2020, p. 19). In addition, quasi-medical caregivers may be called on to perform 'body work': toileting, assisting in feeding, wound care, rotating to avoid bed sores, and so forth.[5] Finally, quasi-medical caregivers often serve as medical advocates and managers: they may be responsible for arranging appointments, providing transport, negotiating with hospital staff, and even making demands on behalf of their loved ones. Taken together, the activities of quasi-medical caregiving establish it as a unique role. When we take on these activities, we come to occupy a different (and sometimes competing) relationship with our loved one: that of caregiver to care-receiver. And this, I think, creates a potential for a form of moral distress that I call 'role conflict distress'.

Occupying two different relationship-types may create moral distress for two reasons. The first reason is captured in Goode's scarcity hypothesis (1960): we may simply not have enough time, energy or resources to fulfill multiple sets of relationship-based obligations. The second reason has to do with the normative conflict between different relationship-types. Different relationships may be structured by different and sometimes incompatible moral obligations and entitlements. This means we may sometimes find ourselves in genuine moral dilemmas, wherein being a good caregiver requires us to be a bad spouse, or friend, or family member. Insofar as both relationship-types matter morally, we might struggle to figure out which one to privilege. And even if we know which one 'trumps' in a given situation, we may still feel like we're falling short. After all, the other relationship still matters to us, and we thus may experience violations of its norms as serious moral harms.

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[5] 'Body work' might initially not seem like quasi-medical care. But I think that it is: once we have grown past infancy, it is rare for us to receive body care from others outside medical contexts.

Role conflict distress, I think, is a form of moral distress. The term 'moral distress' picks out the feelings of distress that we often experience in situations where we are constrained from making the moral decisions that we believe to be right or most reflective of our values.[6] The reason that we sometimes can't make these sorts of moral decisions in caregiving contexts is because our relationship-based obligations and entitlements point in opposing directions; no matter what we do, we're undermining a relationship that we care about deeply.

Let's take a closer look at how the norms of loving relationships may come into conflict with the norms of quasi-medical caregiving relationships. Loving relations feature stringent obligations of care, but they are also conventionally associated with particular *types* of care. Outside of the context of serious illness or early childhood, we rarely perform 'body work' on our loved ones. This can radically change how we relate to our loved one's body. As Donna Thomson and Zachary White (2019), writing on the transformational power of caregiving, observe:

> Simply bathing a spouse you are caring for can change how you think about your relationship. This act of care can become charged with meaning that threatens relational identity. No longer is physical intimacy and touch designed to enhance your relationship. Rather, the caregiver role changes the meaning of physical intimacy, from enhancing closeness to fulfilling a need. Overtime, this can create confusion and resistance because it unsettles the way you once viewed your relationship as a spouse or partner.

Some loving relationships are not characterized by very much physical intimacy at all; body work may thus be experienced as a radical disruption within those relationships. Other loving relationships, such as romantic partnerships, *do* involve physical intimacy. And yet, this physical intimacy often looks very different from the physical intimacy involved in body work. Physical intimacy in romantic partnerships is often sexual, for instance, while body work is typically not.

Further, while physical intimacy is something that we can *expect* from romantic partners, it is not generally something that we are entitled to *demand*. Indeed, we want our loved ones to give it freely, and not out of a sense of duty. But physical intimacy becomes obligatory within informal caregiving: if I agree to take over some of your physical needs in the midst of a medical crisis, I come to owe it to you to ensure that those needs are met. This changes the expressive significance of physical touch, from

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[6] Campbell et. al. (2016). Traditionally, 'moral distress' has been construed more narrowly as the feeling of distress that accompanies situations in which one's ability to do what one knows is right is constrained by internal and/or external factors (2). Even on this narrower definition, however, I think role conflict distress still qualifies as moral distress. Specifically, people experiencing role conflict distress are unable to do what they think is right relative to one relationship that they stand in because they are internally and externally constrained by the demands of the other relationship.

something that was freely given but not demanded, into something required, from something personal to something clinical, from something sexual to something platonic. As one caregiver interviewed as part of a qualitative study on family caregiving put it,

> There's times when I do have to do some personal care. And I mean after doing that, one doesn't feel very romantic…if you probably did everything all the time you would move out of a wife role and become the nurse type role, the caring type thing. (Sawatzky and Fowler-Kerry 2003)

We may feel guilt at this transformation: how dare we feel uncomfortable with our loved one's body? And yet, the discomfort comes from an intelligible place, namely, the norms that had governed our loving relationship prior to illness, and that we continue to care about throughout illness.

Caregiving can transform the non-moral norms governing intimacy in ways that make us vulnerable to feelings of guilt. In addition, caregiving carries with it a potential for moral norm conflict. For instance, loving relationships are often structured by strong egalitarian norms. Absent a serious crisis, my partner and I can both generally legitimately expect high levels of care from each other. But these expectations become fraught in the context of informal caregiving. For starters, care-receivers may genuinely not be in a position to provide support themselves. This puts caregivers in a difficult position; they are generally entitled to care from their loved ones, but their entitlement must go unfilled. They may feel conflicted about seeking support from others: are they betraying their loved one if they look to others for support?

Caregivers may also feel *external* pressure not to seek care from care-receivers. As Kate Washington, a young woman who became a caregiver when her husband was diagnosed with cancer, described:

> I felt constant pressure to be sunny and upbeat. There's a strong culture of positivity around cancer in particular — "You've got to stay positive for him." I found that pressure hard to take. I wanted to retain control over my emotions and how I was feeling. It was tough to feel positive when he was as sick as he was. (Washington & Pawlowski 2021)

A 'culture of positivity' may make sense in professional contexts; we want our medical professionals to keep a certain emotional distance from us, and to not add to our burdens with their own fears and anxieties. But this culture is alien to the norms of loving relationships, which often carry with them strong presumptions in favor of emotional vulnerability. We want to share our emotional lives with our loved ones, and this involves being honest about the bad as well as the good. This makes caregiving a site for genuine moral conflict: being a good spouse (or friend, or family member) requires emotional vulnerability, but being a good caregiver may demand emotional fortitude.

Someone might point out here that the conflict between the moral norms of caregiving relationships and loving relationships have both been conflicts between entitlements and obligations. We're entitled to forms of care as loved ones that may conflict with the obligations we have as caregivers. Given this, perhaps there's an easy answer to the dilemmas I've flagged: prioritize your obligations. But I think that this answer ignores the tradeoff that we make when we perform such prioritization. Specifically, when we waive our relationship-based entitlements in order to meet our caregiving obligations, we may struggle to maintain our loving relationship. Being a good spouse, friend or family member, after all, is not tantamount to being a moral saint. Our loved ones love us for our flaws as well as our strengths, and for the unique complicated dynamics that we share with them. Erasing those dynamics can have the effect of erasing the relationships that have been built around them.

Section 3: Reconceptualization and Boundary-Setting

How might we mitigate the normative conflict between competing relationship-types? Let's first take a look at how we answer this question outside of caregiving contexts. Consider again the example of the spouses who work together. Initially, it might be quite hard to navigate these two competing relationship types: spouses may feel that their work life is trickling into their home life, and may be confronted with genuinely competing moral obligations. Over time, however, a consensus about how to deal with these competing obligations and entitlements may emerge. Spouses may, for instance, agree not to talk about work at home, or adopt a blanket policy of impartiality in the workplace.

These strategies, which we employ readily outside of caregiving contexts, may not be available to caregivers. Often, medical crises rob caregivers and care-receivers of opportunities for mutual negotiation: care-receivers may be incapacitated as a result of the crisis, or there might just not be time for deliberation. Further, caregivers don't have the luxury of separating 'church from state', as caregiving often happens in the home (Mong 2020). Instead, we often settle normative conflicts by prioritizing care. There's a good moral reason for this: often, our loved one's care needs are so pressing that we feel that we have no choice but to make trade-offs in our loving relationship in the service of those needs. And yet, even if we think that we've made the all-things-considered best moral decision, we may still feel that we're losing out on the very relationship that motivated us to provide care. Thus, navigating relational conflict by prioritizing care brings with it a high risk of role conflict distress.

What else might we do? For starters, we might appreciate the broader social context in which we perform care. Like many moral issues in practical ethics, this moral issue is partially the result of scarce resources. We wouldn't feel so much pressure to step into caregiving roles if we had better and more easily accessible palliative care, or a less gendered division of caregiving labor. But I think that the normative conflict that I am describing cannot be fully ameliorated by better resource distribution.

Even if we were able to outsource all of our loved one's medical care and body work, we might not want to do so. After all, they're our loved ones – and loving them makes us want to care for them in seriously robust ways. Indeed, family caregivers often underutilize what services are available to them, especially when they do not self-identify as caregivers (Eifert et al. 2015).

Even under ideal conditions, then, we might need other strategies for combating role conflict distress. One strategy might involve reconceptualization. As a society, we might strive to normalize body work, and reconceptualize caregiving as a normal component of loving relationships. Even absent societal change, individuals might strive to transform their own sense of what care involves within loving relationships. Sherrell, Buckwalter and Morhardt (2001), for instance, suggest that adult children caregivers can benefit from learning to view their caregiving role as natural development of the parent-child relationship. Our relationships are dynamic, after all: the norms governing them naturally grow and change. Likewise, we may be able to find ways to highlight similarities between caregiving relationships and loving relationships. As MacKenzie (2022) notes, the sorts of lies that we may tell loved ones with dementia in the service of providing quasi-medical care are actually quite similar to the lies that we tell our loved ones in other care-related contexts.

Caregivers may also be able to reconceptualize how they *receive* care from their loved ones. Consider how Terri Corcoran describes the care that her incapacitated husband continued to provide for her throughout their marriage:

> I just kept communicating with him even though he couldn't talk. I told him that this is how we are having a marriage: I would tell him what was on my mind and his "job" was to listen since I was putting everything I had into caring for him. He never seemed upset, so I felt free to express what I was feeling. (Corcoran & Cuffey 2017)

That Terri was able to conceptualize listening as a form of care allowed her to feel connected to her nonverbal husband in the last years of his life.[7]

Still, reconceptualization has its limits. For starters, caregivers may not *want* to have to reconceive their relationship-based duties and entitlements: most of us want a spouse who *talks with us*, rather than just listens. Further, while some caregiving happens over a long span of time, much of it occurs very suddenly and for a relatively short duration. We may just not have time to reconceptualize the norms governing our relationships in the wake of a medical crisis, or to wait for society's expectations surrounding care to change.

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[7] Feeling emotionally supported by one's care-receiving partner is consequentially valuable: caregiving wives and husbands who continue to receive emotional support from their care-receiving spouses report lower levels of caregiver burnout and higher levels of emotional satisfaction than caregivers who don't. See Wright & Aquilino 1998.

Instead, alleviating role conflict distress may require us to set boundaries (Montgomery 2013). In my own family, I recall my mother refusing to learn how to give my father heparin injections. At that point, he had very little body fat left, which made injections painfull. It was important to my mom that she not be the one who caused him additional pain at the end of life – that, to her, was inconsistent with performing the care she wanted to provide as a spouse. And yet, I recall her getting a lot of pushback from medical professionals for this decision: they repeatedly told her that *most* families take on this job themselves. Her boundary was important, however, as it allowed her to continue to feel like she was a spouse rather than a professional caregiver.

We might also set boundaries by calling on our broader social network for support. Often, care is treated as a private family matter; only our innermost circle, it is supposed, should be called on to attend to our most intimate needs. But there is empirical evidence that suggests that we experience more caregiving-related distress when caring for our nearest and dearest. Spouses, for instance, typically experience more distress than adult children. Likewise, adult children report more depression in caregiving than adult children-in-law.[8] There are doubtless a number of reasons for this disparity, but one may be that it is easier to step into caregiving roles when one doesn't already share a robust loving relationship with the care-receiver.

Setting boundaries and outsourcing care may be difficult for caregivers, who often face internal and external pressures to go at it alone (Mong 2020, pp. 86-88) . To combat these pressures, we sometimes tell caregivers that good care starts with self-care (Wei 2018). But this message may be a bitter pill to swallow. After all, it feels selfish to care about one's own mental and physical health in the wake of a loved one's medical crisis. I want to suggest that we can translate this message as follows: good care starts with the relationship that motivates you to care. Some of the boundaries we draw around forms of care are drawn not simply with the aim of self-preservation, but also with the aim of relationship-preservation.

Conclusion

I'll conclude by turning back to a pernicious social myth–the myth of the saintly caregiver. We often feel that we owe perfection to our loved ones when we step into caregiving relationships with them. This myth isn't simply psychologically damaging; it also lies on a false picture of our obligations of care. Our obligations of care often stem from a particular place: the loving relationships that we stand in with others. But these relationships are not ones that demand sainthood–indeed, sainthood is

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[8] Pinquart & Sörensen (2011). Still, adult children also report higher levels of gratification when caregiving goes well than adult children-in-law. This may be because they feel that they are reciprocating their parents' care.

anathema to them. We love our friends, spouses and family members for their imperfections as well as their perfections, and we are invested in their good as well as their own. Saintly caregiving is thus not only psychologically unattainable. It also risks undermining the very normative basis upon which our obligations of care rest.

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