

## PAPER

## Where families and healthcare meet

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**ABSTRACT**

Recent developments in professional healthcare pose moral problems that standard bioethics cannot even identify as problems, but that are fully visible when redefined as problems in the ethics of families. Here, we add to the growing body of work that began in the 1990s by demonstrating the need for a distinctive ethics of families. First, we discuss what 'family' means and why families can matter so deeply to the lives of those within them. Then, we briefly sketch how, according to an ethics of families, responsibilities must be negotiated against the backdrop of family relationships, treatment decisions must be made in the light of these negotiated responsibilities and justice must be served, both between families and society more generally and within families themselves.

Annie has a problem. Her brother Stewart, who is in renal failure, has been on dialysis for years. She would like to give him one of her kidneys but cannot: she is not a suitable match. Now, however, thanks to a new state initiative, she could enter a donor pool. If the computer found a suitable cross match, she could donate her kidney to that unknown recipient while someone else in the pool donates a suitable kidney to Stewart. The end result, the transplant nurse assures Annie, is the same: Annie donates, Stewart receives. It looks the same, it sounds the same. But to Annie, it does not feel the same. **And she cannot articulate quite why she feels so disconcerted when the transplant team treat it as if it were.**

For transplant providers, the priority is to increase the number of organs available to people who need them, so a diversity of schemes for cadaver and living donation—including paired and pooled donation—have been devised to achieve this. From a professional point of view, the move to indirect donation via an organ pool is a logical one. Moreover, it is *structurally* the same as direct donation: Annie gives a kidney and Stewart receives one.

**But it is not the same in a relational sense.** For someone like Annie, what makes donation of her kidney even thinkable in the first place is that it is to someone in her family. Annie would never have contemplated donating to an unknown stranger.

The problem that Annie faces arises, in part, from the discordance between the sorts of ethical relationships and perspectives that exist within a family and those that govern the behaviour of the healthcare system dealing with those families, as empirical work on family consent to donation has revealed.<sup>1</sup> From a standard bioethics perspective, Annie's problem cannot even be seen to be a

problem. This is especially troubling since her problem is not an ethical oddity, the kind of thing bioethicists only run up against every once in a great while. Many other facets of medicine generate moral problems that could be better understood if they were viewed as problems in family ethics. The burden of this paper is to make out a convincing case for this claim.

Taking seriously the thought that **most people are situated in and primarily socially shaped by their families**, we aim to develop an ethical approach to professional caregiving that can draw family relations to the foreground without assuming that familial involvement renders any course of action or pattern of care either morally suspect or naturally good. We cannot hope to offer a full account here; we aim solely to set out some of the chief issues that need further attention and explain why they are of special importance.

**CHARACTERISING WHAT 'FAMILY' MEANS**

First, it might be helpful to clarify what we think 'family' means. Some understandings of family appear so self-evident that it is easy to miss the varied historical, cultural, political, and social structures and processes that inform what counts as family across different locations and contexts. However, across historical studies, sociology of family and cultural anthropology, there is a rich body of work that renders problematic the assumed naturalness of any family roles, structures and obligations.<sup>2-4</sup> Such work reveals that kinship is secured in social and cultural values and understandings, rather than being produced by nature and biology.<sup>5,6</sup> This view recognises that there can be different configurations of family and that the available templates for how to 'do' family change over time.

Familial configurations differ from other clusters of relationships in that not all of the moral ties understood as binding within families are based on explicit or implicit acts of consent. Annie, for example, may feel a kind of emotional and moral necessity to give a kidney to her brother, while she would never have contemplated giving it to an unknown stranger. Her response reflects something about what familial responsibilities in general are like. Those responsibilities present themselves as 'given' rather than chosen (desired, wished for, consented to). Moreover, **they owe their power to relational proximity, whether that is understood as stemming from shared genetic heritage and attendant physical signs of 'flesh and blood' links, from their shared history, from cultural assumptions about the emotional nearness of families,** or some

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Received 27 August 2013

Revised 21 March 2014

Accepted 21 August 2014

Published Online First

10 September 2014



CrossMark

**To cite:** Verkerk MA, Lindemann H, McLaughlin J, et al. *J Med Ethics* 2015;**41**:183-185.

## Theoretical ethics

combination of these. Annie's relationship with her brother, understood as their shared genetics and shared childhood, has provided the criteria for determining who is close and who is not. In other words, it is the fact that Stewart counts as a brother to Annie, and not the specific criteria that ground that relationship, that is salient here.

Part of her quandary is that she is now presented with the possibility of admitting a complete stranger who satisfies none of her qualifying criteria of genetic heritage, shared history and so on, to those she sees as family. Nor can other relational accounts of ethics really help here. Care ethics views situations of ethical difficulty through the lens of essentially asymmetric relationships of care; but while many familial relationships are asymmetric and caring, not all are. Care ethics by itself then does not explain why Annie might feel ready to donate her kidney to her brother. Nor can ethical accounts that prioritise relationships of choice account for the felt givenness of these moral requirements. She needs an ethics of families.

### WHY FAMILIES MATTER MORALLY

In the ideal, families are supposed to protect, nurture and socialise their children, see to their moral formation, and give them a sense of belonging. Adults in the family are supposed to look to each other for love and acceptance, as well as for help in times of need. It is true that many families fall short of this ideal and are damaging or oppressive; nevertheless, in the main, they are good enough. Their functions give families *instrumental* value, but many people also regard families as *intrinsically* valuable, as mattering independently of whatever goods and services they provide.<sup>7</sup>

An important element of the case for families' moral value is their significance, however structured or experienced, to constituting the self. Some of what makes Annie's donation seem possible or even required is the embodied connection to her brother that contributes to her sense of self. Her kidney, a part of herself, takes up residence in and becomes part of him. For as long as he survives, she will be able to look at him and know that the kidney that was once part of her organism, sluicing her blood and kept going by the pumping of her heart, is now doing the same for him. This seems okay to Annie because, as her brother, he is already genetically or biographically connected in a way that the putative unknown pooled donor is not (as far as she knows). The knowledge of this is not so much physical as an imaginative projection. Nevertheless, it provides a very real grounding for the sense of increased connectedness that living donors and recipients have sometimes reported.

### NEGOTIATING RESPONSIBILITIES WITHIN FAMILIES AND WITH HEALTHCARE PROFESSIONALS

The significance of family to the relational development of the self is situated within broader social and cultural norms, which frame the forms of moral self that seem achievable, valuable and allowable within families. The form and force of caring obligation assigned to family members results from many material and social contingencies,<sup>8–10</sup> including how gender roles are understood in different families and societies, and in general how social and personal forms of power are distributed.

A male and female adult sibling may express a different level of obligation to look after a sick family member; similarly, mothers more commonly give up work to look after a sick or disabled child than fathers.<sup>11 12</sup> These differences can be explained, at least in part, by recourse to established gendered norms determining who is the most obvious and natural caregiver. As these norms infiltrate both people's own sense of what

they should do and the potential social judgments of people around them, they can make it more difficult for women to refuse such an obligation<sup>13</sup> and for men to assert one.<sup>14</sup> If gendered expectations create a further layer of complexity in the decisions involving potential family donors like Annie, then healthcare professionals ought to acknowledge that some of the demands they make on families exacerbate existing social patterns of injustice in self-formation and flourishing.

The relationship between formal healthcare institutions and families has been complicated by the default social assumptions that, at least for close relatives, family caring is a natural phenomenon, not a negotiated and socially inflected set of practices, and that it is unbounded, except perhaps by the family's resources. Many families may well entertain such normative assumptions themselves, feeling obliged to provide to an ill relative all the care that they possibly can, even when it harms others within the family or the family overall.<sup>15</sup>

The default assumption that family care is natural and unbounded may account in part for the suspicion some care providers seem to feel toward families. If familial responsibilities for caring are assumed to be natural, unbounded and focused only on the patient, it is not surprising that care providers, like the transplant nurse, are unsure how to respond to family members like Annie who appear to resist such responsibilities. Equally, people like Annie are at a loss when confronted with a new and questionable instance of these responsibilities.

### FAMILIAL ROLES IN TREATMENT DECISION MAKING

Deciding what interventions ought or ought not to be provided for a relative can distort some families' basic understandings of what matters most or damage the moral relationships among family members. These threats stem in part from standing policies in healthcare widely endorsed by bioethicists. A prime example here is that healthcare decisions ought always to promote the 'best interests' of patients considered as individuals, ignoring the sometimes substantial harms incurred by family members along the way; another is basing family members' authority as surrogate decision makers solely on their understanding of the specific preferences or general values of the incapacitated patient. Both policies have been challenged by family-sensitive work on the ethics of decision making for almost three decades.<sup>16 17</sup>

Here we break new ground, explore another respect in which attention to families can reshape orthodox understandings of decision making. Familial connections can be experienced as less like reasons guiding action and more like demands compelling behaviour, and yet still be compatible with autonomous action. Suppose Annie could donate directly to Stewart. While she might have decided to part with her kidney as a result of pursuing relevant information and weighing conflicting considerations—the cost to herself, the benefit to her brother, her duties and his deserts—nothing of this sort may have gone on at all. It may just strike Annie that, if Stewart needs her kidney, she 'has no choice' other than to give it to him. Healthcare professionals scrupulous about respecting patient autonomy may be worried by this. If Annie is actually unable to consider alternatives (she *cannot* do otherwise), in what sense is she making a free choice? Is not the power to act otherwise than one does essential to autonomy?

As others have pointed out, this conception pictures the fully autonomous person as an essentially lonely soul without personal ties, that is, without what for many are key parts of their identity.<sup>18</sup> If our authority over ourselves is worth respecting, it must be compatible with having deep moral commitments to specific others that in some situations give you no other choice

than to act on them. What may be crucial for autonomy, as Frankfurt suggests, is how a subject relates to her commitments.<sup>19</sup> If Annie experiences her brother's need as a requirement to donate and endorses the moral authority this has upon her, then she is autonomous in a morally relevant sense, even if she cannot see any other option. A decision to call off the donation just because Annie is in a no-choice situation can therefore violate, not protect, her autonomous will.

Of course, direct donation is not an option for Annie. Though she might acknowledge impartial reasons to help a stranger, those reasons would likely present themselves to her without the kind of emotional requirement she might experience in donating to her brother. Lacking that sense of emotional necessity, Annie's reasons against donating in the paired exchange might well be strong enough to merit acknowledgement. In that case, if her brother's well-being hinges upon her donating to the donor pool, then her family ties under a paired exchange donation scheme might indeed be coercive.

### HEALTHCARE, FAMILIES AND JUSTICE

Annie's problem, like many in bioethics, first presents itself as a quandary confronting individuals. What should Annie decide? How might members of the transplant team best help her work through her concerns? Yet, like all bioethical problems, it arises against a backdrop that assigns various moral expectations to social roles and regards different roles as worthy of different forms of community response. Professional healthcare, for example, garners fiscal support and moral recognition; the informal care provided by family members gets comparatively little of either. How societies structure and support caring responsibilities are matters of justice.

Annie's situation exemplifies many of the ways in which contemporary medical practices transform the care responsibilities families face. Encountering what amounts to an expectation that she will agree to undergo major surgery resulting in one of her kidneys being transplanted into a stranger, Annie is saddled with moral as well as medical burdens. She has to deal with her reluctance to provide her brother with the help he needs. Further, the expectation addresses her as a sister, not merely as a sibling; women provide roughly two-thirds of living donor organs.<sup>20</sup>

The assumption that familial responsibilities are natural, unbounded, and target women and men differently contributes to the special features of Annie's problem. These same assumptions also help fuel healthcare's general demands on families and obscure how wrenching they can be. Healthcare problems other than organ failure confront families with prolonged care responsibilities. Family members may refuse to accept them, of course, yet the default assumption is that they will answer the call. Bioethicists have paid only scant attention to the costs of this assumption in terms, for example, of caregiver finances, shifting caregiver self-understandings and caregiver health.<sup>21</sup> Yet, these costs are central to assessing the justice of systems of healthcare: How should societies shape familial roles and enforce attendant expectations? How should family interests be counted if they conflict with patient interests? What role should the needs of family caregivers play in deliberations about allocating social resources for healthcare? It is reasonable to require that bioethicists reflect upon these pressing issues and that decision makers at different levels within healthcare take them into account when formulating new healthcare policies or take decisions to reallocate patients to home care.

What Annie is called upon to do for her brother remains beyond price. However, the continual growth of healthcare's capacities and costs has accelerated the transfer of care

responsibilities to family-based providers, with consequences that can in part be economically expressed. In the USA alone, the economic value of family care was estimated at \$450 billion in 2009.<sup>22</sup> The value of that care suggests strongly that societies should take steps to make adequate practical and emotional support available to family caregivers, including respite care, simply as a matter of prudence; family members need to be willing to provide prolonged care if medicine is to remain a public good. But beyond prudence, justice requires as much. Understanding healthcare as a social responsibility rather than a commodity for private purchase is often justified by the profound threat posed by illness and trauma to people's ability to pursue their conception of a good life.<sup>23</sup> Given that family care provision can trigger equally serious threats, providing health and social care for caregivers inherits that justification.<sup>24</sup>

**Acknowledgements** This paper is a contribution to the work of the Consortium on the Ethics of Families in Health and Social Care (<http://www.familyethics.net>).

**Contributors** All authors included on this paper fulfil the criteria of authorship. In addition, we assure you that there is no one else who fulfils the criteria but has not been included as an author. All authors have equally contributed to this paper.

**Competing interests** None.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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*J Med Ethics* 2015 41: 183-185 originally published online September 10, 2014

doi: 10.1136/medethics-2013-101783

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