Chapter Four

Health Care Decisions

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Health care decisions about investigation, diagnosis, and treatment (including decisions not to apply measures, or to stop applying ongoing ones) may involve, engage, or affect family relations and family members of a patient in a variety of ways. This complicates the assessment of how options affect patients, and may furthermore elicit independent effect on professionals through expected actions of family members. Moreover, due to the close and intimate nature of family relationships, *considerations* about such aspects may be concern both clinical professionals, patients, and family members independently of how they *actually* manifest themselves in terms of effects on length and quality of life, autonomy and so on. In particular, decisions can be expected to both be influenced by and affect family members’ conceptions of mutual responsibilities making up the basic moral web of families, as pictured in the outset of this volume.

Irrespective of how family responsibilities are allocated or what the legal requirements around medical decision-making are in place in different particular situations, health care professionals are almost always expected to play an important role in the decision-making process. The aim of this chapter is to outline how different relational aspects of families may ground obligations on behalf of health care professionals towards patients and their families in the processes of decision-making within health-care.

To initiate painting this picture, we start off from the core idea within person centered care of having patients’ general life situation, experiences, values and wants to become a substantial topic of concern in a process of shared decision-making (Luxford 2010; Munthe et al. 2012; Sandman and Munthe 2010). Many have observed that, since most people have families, this will in practice force care to become more relation- or family-centered (Committee on Hospital Care and Institute for Patient- and Family-Centered Care 2012; Goodrich 2009; Ells et al. 2011; Luxford 2010; Mead & Bower 2000; Munthe et al. 2012; Van Royen et al. 2010). The basic perspective of this book supports that observation and enriches it in several ways. One conclusion is that if the envisioned new decision making paradigms are to be minimally functional, professionals’ stance needs to involve complex schemes of including people closely related to patients, who will have to be recognized as legitimate stakeholders and partners in, as well as resources for, clinical care.

We will briefly outline different aspects of family relations and then h describe the normative implications these have for health care professionals in relation to health care decision-making. This overview is complemented by a case study, which illustrates some of the complexities involved, linking to observations of ethical moral psychological complications of clinical care of children and adolescents, made concrete by the context of care for diabetes type 1.

Relational Aspects of Person Centeredness and Shared Decision-making: A General Outline

The relational aspects of person centeredness and shared decision-making actualize a number of dimensions of relevance for ethical theory as well as for clinical practice. These will here be outlined briefly before some selected aspects are highlighted.

The demarcation between patient interests and the interests of others.

This is something noted already in ordinary clinical experience by many professionals, especially in areas where closely related persons usually are present in the care situation, such as obstetric and neonatal care, or terminal care of elderly persons. Family interests may upset, compete with or complicate attending to the interests of the patient in clinical decision-making. However, having person centeredness and shared decision-making be influenced by the core ideas of this book seems to undermine the otherwise traditional notion in clinical ethics and practice for such situations to always give the patient's best interests priority, and to potentially include family members as *co-patients*, or legitimate concerned parties. First, most patients will include among their interests many concerns about their family members. Second, family members’ interests and concerns may often go far beyond whatever biomedically defined health problem the patient suffers from. Third, due to these factors, when health care concerns are widened to include more general aspects of patients’ lives, the main basis for not considering effects of family members disappears. Fourth, this implies that health care decision-making also needs to consider potential effects on core family goods, such as established patterns of (perceived) relations of responsibility, strong emotional dependencies, and attached bases of security and safety. This issue is explicitly formulated as a main challenge to family centered care of children in the case study adjacent to this chapter.

The allocation of professional, patient, and family responsibilities.

This issue too is well known by health care professionals, especially those where the active assistance of family members is vital for the performance of (often outpatient self-) care; again, the cases of children and incapacitated elderly provide ample illustration. Emphasis on relational aspects of person centeredness and shared decision-making would here seem to highlight the idea of family members as *co-carers* (rather than co-patients), as the family situation of a patient will include considerations entering such clinical decision-making by family members. This leads to issues of what responsibilities family members can and should be given or even required to provide and on what conditions. Such matters become especially complex in view of the understanding of families as webs of responsibility webs, that is, closely knit social unities that already contain established perceptions of mutual responsibilities across a wide collection of areas, of which only a few relate immediately to health care, but which all may influence the potential consequences of chosen care measures. Consider, for instance, the case of a heavily smoking partner in a context of a patient who requests important surgery, where nonsmoking is a requirement. In the case study, this aspect is highlighted, as it point to how family will influence adolescent diabetes care performance, no matter what degree of their involvement in clinical decision-making is chosen by professionals.

The family as resource for clinical assessment and decisions

The indicated widened scope of clinical considerations means that the family becomes a possible positive resource for clinical decision-making in a number of ways, something the case study exemplifies in the context of pediatrics. This regards family members as individuals who may contribute relevant information and offer support services to enable new caring options. But it also includes the family seen as a social unit, which may provide what seems akin to the public goods produced by organized societies of importance to the care, such as feelings of belonging, security, acceptance, and closure in the face of a seriously impaired or changed life situation. Of course, in the traditional pragmatics of clinical practice, these aspects may be present to the extent that practitioners spot them and find reason to take them into account, but it is not a theme that is systematically applied or included in guidelines for good clinical care. In some specific areas involving gathering of biomedically relevant information this aspect has been openly and more systematically addressed, for example, in the case of communicable disease or genetic testing. However, most of this landscape of the family as a clinical resource seems to be passed over in silence or actively avoided in the literature on the ethics of clinical decision-making.

The family as threat to successful clinical decision making and care

Just as the family of patients may be a resource for care and decision-making, so too can it be a threat to it. The widened scope for having the interests of family members and the family as a psychosocial unit enter clinical decision-making created by person centeredness and shared decision making creates a much more far-reaching palette of scenarios and aspects to consider also in this respect. Again the case study of adolescent diabetes care lifts several examples of this. First, if the good of family members and of families need attention in the assessment of clinical options, this assessment may become impractical and too complex to be likely to be handled well by health professionals. Second, stark conflicts may appear between what a health professional considers responsible to do and what is desired either by the patient out of family concerns, or by family members affected by the situation, and the relational aspects makes it less obvious how such conflicts should be analyzed. Third, incapacities, structures or wants not of the patient, but of the patient's family may block otherwise available care strategies requiring family collaboration, and it is unclear how far health professionals may venture to change such situations, or even force changes.

A main observation regarding these four central areas is that they seem to require health professionals to systematically address issues for which they are not normally trained. Moreover, standard principles in clinical bio- and health care ethical frameworks provide scant support, as they usually rest on assumptions that the areas described above are unusual exceptions, rather than the quotidian ones they become if a family-centered approach to person centeredness and shared decision-making is adopted in earnest.

Relational Normativity and Patient Interests

So far, we have touched on solely empirical and practical complications of taking seriously a family centered care approach. These all have to do with the multiplication of interests, parties, and stakes that follow if the conception of a family as a moral web of responsibilities that may contain goods of its own is applied to notions of person centeredness and shared decision-making. However, the emphasis on relational aspects of patients’ autonomy and goods prominent in this book also raises underlying conceptual concerns regarding the very notion of *patient interest*.

One aspect of this notion that needs to be considered links to the inherently normative nature of family relations. Such relations are in part constituted by responsibilities, commitments, and entitlements that hold between those standing in a familial relationship to each other, even though it might be unclear or controversial exactly which those are. A sign of this normativity is the way in which people may justify actions toward family members, well known, for example, in the case of organ donation. Suppose that Annie’s brother Stewart has a renal disease that reached end-state and that he is in need of a kidney. He asks her, who is a biologically fitting donor partly because they are siblings, to consider a donation and Annie agrees to donate one of her kidneys. According to her, this is what she ought to do, and if someone were to ask her why, it would make perfect sense for Annie to reply: “He is my brother.” That is, she would express a moral commitment to and responsibility for Stewart in virtue of their familial relationship, and this commitment constitutes her reason for donating a kidney to him. Now, certainly, part of this story is about the pragmatics of biological relatedness that makes Annie a particularly fitting donor for Stewart, but this is not all of it. Without the mentioned commitments and recognized responsibilities, Annie would have no more reason to donate a kidney to Stewart than to any other person she would biologically match in a similar way, and it is the presence of these normative relations which make Annie and Stewart *family* in the sense applied in the present volume. None of this is to say that these normative relations need to be ethically sound or that perceptions of such responsibilities cannot be reasonably disputed.

When we regard the relations defining families as normative, the notion of *the patient’s interest* becomes less sharply demarcated than commonly assumed in health care and related ethics. One context in which this difficulty of separating a patient’s interests from the interests of his or her family and its members may surface when the patient forms his or her notions of what care to prefer out of consideration of perceived family interests. Think of an elderly patient with his reasoning capacities intact and in the end of his life, who after some years at a nursing home requests an ongoing life-sustaining treatment to stop because he wishes to relieve his children from the burden of worrying about him and visiting him on an almost daily basis. Or, similarly but other way around, the patient prefers further life-sustaining treatment for his children’s sake, although he would otherwise just as well have it discontinued. In such cases, we may, of course, worry about manipulation or undue emotional pressure, say, due to content or discontent expressed by the children. We might also, on a more societal level, be concerned about the causes of such a burden, if it arises out of poor public support or from scant value given to older lives. However, these types of considerations may be made quite regardless of that. It is not in any way strange if the man wants to die for his children's sake, although the children harbor no such wish, and he may want to survive for their sake, although they would prefer him to die.

Either way, these kinds of considerations are bound to cause some uneasiness among health care professionals caring for a person in such a situation, as well as some bewilderment of ethicists supposed to assist them, and rightly so. As indicated, there are good reasons to be cautious and attentive when motivations such as these are at play. Patients in the end of life are often vulnerable to manipulation and susceptible to conditions such as depression, which may cause irrational self-disregard. However, other-regarding motivations are not as such excluded from properly belonging to the patient’s *own* interests. A patient, or any person for that matter, may take her other-regarding concerns to trump her self-regarding ones without losing the ownership, as it were, of those interests. We will in the next section return to the question of how the distinction between the interests of person and family can be understood and the implication for family centered decision-making. But before that, we make one final point about the relational normativity brought to the fore of a family centered approach to clinical decision-making.

Boundary Problems

When acting towards a family member we may find ourselves in situations that may be experienced as no-choice situations, where our place in the web of family responsibilities creates a kind of moral necessity. The case of Annie above may exemplify this. Her perception of the situation may well be that to donate her kidney is something she *must* do—there “really” is no other option. This type of response is probably quite common whenever an important health care measure requires the participation or assistance of family members; these tend to agree to such a role immediately, without much deliberation, and are quick to embed this new role into their daily life, as when a partner helps with mobility and exercise in the home, remembering medication and diet, or tends to simpler care tasks (such as changing bandages). In practical action, they thereby accept such roles, and certainly do not object to it, but neither do they ever actively endorse it or consciously make a resolution to take it up. Rather, they are morally compelled by their family responsibilities.

With a single-minded application of a traditional conception of freedom to such a response pattern, one may well end up with the conclusion that people thus responding to a perceived moral necessity of family responsibilities are coerced by circumstances outside of their control. The lack of conscious choice due to moral pressure and the lack of perceived alternatives may be thought to support the idea that people in such circumstances therefore cannot be fully exercising their autonomy. On a standard view, freedom is roughly a matter of having the power to act otherwise than what one in fact does, and a very common notion is that such power presupposes that the subject of the freedom believes it to be in place—what is sometimes referred to as the *epistemic condition* of freedom and responsibility (Eshleman 2014). But when a person feels morally compelled, not able to see any real alternative in the sense here exemplified, the presence of such a belief may be doubted. And if that is the case, the acting parties in such situations cannot, by the standard formula of “ought implies can,” be responsible for whatever moral valence befalls their actions.

However, this line of reasoning has been questioned, as in the case of organ donation between siblings (Crouch and Elliott, 1999). The web of strong emotional ties between a sister who donates a vital organ, her brother who receives it, and their parents who thereby have the life of one of their children saved, cannot by itself undermine autonomy and moral responsibility. The notion of ruling ourselves in the way required for moral agency and responsibility must be compatible with having strong emotional and moral commitments to specific others, also in situations when they create a sense of having no choice besides acting on them. Simply put, if the possession of normative moral reasons presuppose freedom, this freedom cannot in turn exclude that people possess such reasons. At the same time, coercion and undue influences do occur within families and are then usually exercised through the web of emotional as well as moral relations that constitutes them—emotional blackmail being a familiar example of a source of family members experiencing having no choice in a way that is obviously problematic from an autonomy standpoint. Thus, the challenge is to recognize that people who act out of strong concern for each other or their shared community may very well act just as freely as those who act out of a classic notion of self-interest, while simultaneously recognize that such interpersonal concerns and sentiments may constitute risk factors for undue influence that may undermine autonomy and responsibility.

One influential way to account for these distinctions is to say that it is a matter of how *I*, as a subject or person, *relate to* my interests and commitments—how well they cohere with each other and other aspects of my view of myself and my life in the world. The immediate, strong motivation of normative reasons experienced as a "must" by a subject, that originates from and is endorsed by him- or herself, has by Harry Frankfurt (1971) been coined *volitional necessity*. This type of experienced necessity is easy to imagine influencing a person like Annie, or any other possible donor to any sort of family member, to set aside what she would otherwise have wanted for her own sake (even to the point of silencing it altogether) when facing the vital need of her brother. We may assume that anyone in such circumstances acknowledges and accepts such a vividly experienced normative requirement: we *want* to do what we experience that we must do for the sake of those close to us. In this way, by endorsing our commitments and their motivational pull, our concerns for others can be said to be proper parts of our own interests. Thereby, we remain autonomous in the morally relevant sense also when, in light of such commitments, we have an experience of having to donate organ or tissue to others (to take one instance), as long as we endorse the moral authority it exercises on us, and this holds even if we perceive no alternative and may thus be argued to fail, technically, the epistemic condition of moral responsibility.

Suppose that someone who is continuously assisting in the care of a partner, a child, a parent, a sibling, for reasons of the type just described starts to be less comfortable with the arrangement, even outright disliking it, yet continues to provide care out of the strong feelings of obligation. Would this person now act less autonomously, even be a victim of (inner) coercion? For the same reason as before, it seems plausible to deny such a suggestion, as deciding to act against personal desires for moral reasons is a part of our ordinary struggling with competing considerations, some of which are moral. This is not to deny that when the situation changes in this way, things begin to get morally more complicated. If starting to doubt whether the caring effort should continue, would it be acceptable for others to put pressure on us to continue, and insist on the moral reasons to care for family members? This, it seems, depends more on *why* caring for our family member has become less of a sure thing, than on *how uncomfortable* or *how compelling* we find it to act on what we see as our moral duty.

Now, suppose that the very *commitment* to care for our close one gradually weakens over the years. This may occur in two ways. One is that we change our perception of the balance of reasons; we still embrace a commitment and experience a duty of care for our family member, but now find the cost to ourselves to be too high. The other is that we let go of our commitment to care for our family member; that is, we dislodge some of the nodes in the web of responsibility making us family in the first place. Other members of our family may then react by putting pressure on us to remain within what they see as an adequate balance of reasons and web of responsibilities, which we no longer subscribe to. Such pressure may then approach what is clearly undue influence, especially if it contains elements of threatening to withdraw personal and emotional contact and this has us go on with the caring against our own best judgement. This action will no longer be exercised from within our personal commitments but from external forces and fear of sanction.

However, even if no such obvious situation of compliance due to threat occurs, and even if a person very much embraces his or her relational commitments to family members, we may still find the situation ethically problematic. Again, the decisive thing seems to be what explains *why* a person entertains a commitment (or not), and what may worry us is that it may result from an oppressive or manipulative context, as in the case of religious or political sects, dysfunctional families, and so on. Whether a person is autonomous cannot merely be due to the internal coherence of a set of wants and commitments, as such sets may arise out of circumstances that bypass the emotional and cognitive mechanisms supposed to be involved in autonomous decision-making, thus undermining autonomy even in the absence of outright threat or coercion.

At the same time, it may be argued that families contain such oppressive and manipulative structures much more often and strongly than usually acknowledged, for instance, regarding gender and age roles. Suppose that John needs a kidney and his younger wife, Emma, is a suitable donor. John is in his sixties and Emma has just turned 40 and they have a daughter of 5 that suffers from idiopathic nephrotic syndrome, indicating risk of future renal problems. Suppose also that they are part of a typical patriarchal (paternalist, sexist and ageist) family structure, where the expectation is that Emma, whatever hardships implied, will stand by her man. When, in a private consultation with a nephrologist, Emma says that she wants to donate, the nephrologist is worried and points out that their daughter might need a kidney in the future. But Emma remains unmoved. She fully endorses the family's relational moral requirement to donate her kidney in order to be a loyal wife for better or for worse—even if that implies becoming less ready to care for her daughter in the future.

One way to try to pinpoint what in the explanation of Emma's commitment to her husband grounds a suspicion of undue influence is to identify her apparent unresponsiveness to reason. To be autonomous one must arguably have a capacity to navigate among different norms and values and to somehow respond to them—this is a part of the cognitive and emotional apparatus indicated earlier. But for such responsiveness to be attainable to people who perceive themselves as having responsibilities towards one another, they have to mutually acknowledge and respect that each may have reason to reconceive these responsibilities; the relational structure has to make room for its web of responsibilities to change. If John and the rest of Emma's social environment does not allow for this, her values may not properly be her own and her autonomy may be impaired due to her relational environment's blocking her access to what she would otherwise recognize as important reasons. Coercion and undue influence may, hence, be structurally embedded in some common responsibility webs making up families, and constantly have some of its members suffer persistent loss of autonomy regarding certain choices they make out of relational concern. The challenge is to pinpoint when this is the case and when it is not.

The Ethics of the Family as *Co-Carer*

As indicated, besides being active parties in decision-making, or being part of a context that requires advanced attention in clinical decision-making, family centeredness opens considerable space for a patient's family to be included not only as assistants (as in the case of organ donation) but as actual performers of care: *co-carers*. Again, this phenomenon has always been present in various forms of outpatient care, but the family-centered move creates both more transparency around how this is done, a wider space for professionals to systematically consider family members as co-carers, and an implied shift of power and responsibility to family (besides the one toward patients implied by the person centered approach), with regard, for example, to what they are prepared to accept in terms of work required, financial sacrifices, changes of internal family structures and traditions, accountability for the outcome of care, and so on. This also means that care solutions where the family and its members are made co-carers become both possible and necessary to assess more systematically from an ethical standpoint. In the chapter to follow, relevant issues of social justice and responsibility will be addressed. Here, we will mention four more immediate ethical aspects of this.

First, the more of a co-carer the family becomes, the more critical becomes the issue of how well prepared it and its members are to take on that responsibility, and what responsibility health professionals have to facilitate or guarantee that requirements in this area are met. This has been highlighted as a central ethical issue of person centered care and shared decision making with regard to patients (Munthe et al., 2012), but also family co-carers will be expected to independently perform continuous clinical assessment, decision-making and execution of measures, but at the same time lack the overall specialist knowledge and skills of a trained and experienced health professional. At the same time, the person centered shift opens up room for considering solutions and plans where family is included as co-carer. Which arrangements are defensible and why, and what responsibility for such arrangements and their outcomes befall family and health professionals respectively? It makes sense to claim that if health professionals actively pursue family involvement that expands the co-caring role, they also have a responsibility to secure the quality of this delegation of decision-making and service. But to what extent? And to what extent is the ethics of such allocations of responsibility for co-caring dependent on the extent to which they arise at the behest of the patient and her family themselves?

The next two aspects both link to the assumption of family relationships to involve particular intimacy, implying close and strong emotional relatedness, knowledge about personal details, shared assumptions about what is expected and of value in the family situation, and so on. This feature of a patient’s family has an immediate instrumental importance, in that it may be mobilized for both good and bad, as elaborated in earlier sections. The intimacy may, of course, be a great resource than can improve care, and in some respects makes the co-care of family superior to that delivered by an occasionally visiting health professional. However, the same intimacy may also serve to harm patients, since a role as co-carer may make family members cross boundaries they should not cross, as well as reinforce abusive or oppressive family structures already in place, even providing new tools for family members to exploit the intimacy for getting at each other or upset internal relationship structures to the detriment of patients. Second, the intimacy also connects to the mentioned difficulty of keeping apart the interests of patients and of the family (and its members). Depending on how co-caring of family members is organized, it may give more or less room for patient interests flowing out of internal family relationships, such as a will to avoid burdening one’s intimates, or the opposite tendency of making those close to oneself increasingly dependent on a continued co-caring relationship.

The final aspect we want to highlight comes out of the idea of families producing special relational goods (or evils) accessible to family members, akin to the public goods usually assumed to be produced by organized societies. Many of these seem to link to the way in which families assemble themselves into an informal social organization, where members unassumingly occupy and play specific roles to co-produce goods available to all family members to make life valuable and meaningful (or the opposite), e.g., senses of belonging, safety and identity (or lack of such). The role as co-carer in organized health care efforts, however, seems to pull out of and break these qualities of the typical family web of relationships, as the *informal* relations are now transformed and linked to a formally institutionalized external web of norms, standards and evaluators (the health professionals, who deliver the verdict on how the care is proceeding). The question is what this means for the family’s internal production of relational goods and how that is to be factored into the ethical assessment of various ways in which family can be made co-carer in family centered health care decision-making.

Implications for the responsibilities of health care professionals

In light of the different aspect outlined above, we might now turn to the question of what normative expectations are reasonable to put on health care professionals in the context of health care decision with patients and their families.

First, there is a process oriented task to facilitate deliberation and decision-making. Obviously, reaching decisions about medical treatment is a process rather than a single action or event. This means, at least, that there is a route to the decision that stretches over a period of time, and that this route includes a number of steps that leads to the decision – steps that involve smaller decisions, meetings, exchanging and processing information, and reasoning, etc. Experienced clinicians often talk about the importance of creating a deliberative space when facing a serious clinical decision – to put the decision on hold while grounding it in different ways. Time-wise, a deliberative space can in the clinical setting vary between minutes and months. Above the temporal aspect, there are conceptual, emotional as well as discursive aspects of a deliberative space. Such a space may allow the parties to conceptualize the alternative actions, to reflect emotionally on the alternatives, and discuss feelings and attitudes towards the decision. Properly articulated, such a space may also allow for relatives and close ones to take part in the deliberative process. We might think of decision processes in health care as involving a number of deliberative spaces where each precedes a decision of varying magnitude. Deliberative spaces are no novelty, but there are reasons to stress that healthcare professionals are crucial in framing the decision process properly. It is, therefore, their responsibility to create or to foster deliberative spaces that allow a number of relational aspects to be brought to the forefront of the decision-making. The extent to which health care professionals should be active or even authoritative in the deliberation is highly dependent upon contextual features of the patient, the family, the disease, treatment etc.

Among the relational aspects that need to be identified in such a process of ‘family centred’ decision-making are, as indicated above, shared interests – family interests. Without in an depth entering issues in social ontology, we might state that these belong both to single individuals as well as to collectives. The sorting out of what interests are shared with others or more solely belongs to an individual is an important deliberative task, both central for the patient–family constellation and for the health care professionals. If this accomplished to a satisfactory degree, the identification of responsibilities is more easily addressed. For health care professionals, it will also be important to identify what emotional leverage close relations may equip family members with in cases of decision-making. As described above, undue influence and emotional coercion may go in different directions.

In summary, as well as respecting this sense of relational autonomy of the patient and family, health care professionals have a significant responsibility to promote variants of patient centredness and shared decision accommodating for these aspects. Such processes are crucial both for clarifying necessary aspect in single cases, and for health care professionals to determine underlying conflicts between family interests and clinical values.

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