Why Families Matter

abstract

Serious illness puts pressure not only on individual family members but also on the family itself. The care of an acutely ill child requires the family to channel many of its resources toward a single member—an arrangement that can usually be sustained for a while but that cannot continue indefinitely while the other members do without. Illness disrupts ordinary familial functions and, if it is serious enough, threatens to break the family altogether. In this article, I argue that there are situations in which the threat to family integrity is so real and serious that the interests of parents or siblings or sometimes grandparents may override the interests of the pediatric patient. *Pediatrics* 2014;134:S97–S103
That treatment decisions are not always guided by what is in the medical best interests of a pediatric patient is not in doubt: consider the badly damaged neonate whose parents painfully decide they must not consent to a costly course of treatments involving repeated hospitalizations that might prolong the infant’s life another year or 2, because they live a half-day’s journey from the hospital and have 3 other young children at home. Such decisions have been defended by appeals to the principle of justice; John Hardwig, for example, has argued that a patient’s right to treatment is circumscribed, like all rights, by the harm it inflicts on others. Considerations aside from justice could also motivate the thought that important interests of individual parents or siblings or sometimes grandparents may override the interests of the pediatric patient. But this focus on what is owed to individual family members obscures attention to what is owed to families—considered, not merely as the sum total of the individuals within them, but as morally valuable entities in themselves. Although there is little enough mention in the bioethics literature of the husbands, wives, parents, or grown children of patients (except, perhaps, as proxy decision-makers or informal caregivers), almost nothing has been written about the moral relationship between families themselves and medicine. I find the exclusion of the family’s perspective from health care ethics peculiar; very widespread, and in need of remedy.

Accordingly, in this article I offer some theoretical underpinnings for the idea that familial considerations must be taken into account in medical decision-making, and that sometimes these considerations have a greater claim on health care professionals than do the best interests of the pediatric patient. I begin by identifying morally valuable functions that families perform for their own. I then consider what is of intrinsic value in families. And finally I argue that a family’s ability to provide these goods, and indeed its very existence, can be put at risk when too many demands or the wrong kind of demands are made on it.

FAMILIES AS ENTITIES IN THEMSELVES

Families come in many configurations and sizes, and the term means different things in different contexts. What I mean by it here is the structure of intimacy in which most people live out their lives, characterized by relationships that are more or less ongoing and close, usually (but not always) involving long periods of living together in the same household. Ordinarily (but not always) they are structures of love and trust, although even when these are absent, the vulnerability produced by the intimacy within them gives rise to special responsibilities of care, consideration, and commitment.

On a liberal view of persons as free autonomous individual agents, it could be assumed that families are nothing more than the sum of their individual members, and that they have no identity apart from that. I argue the contrary. Families are social institutions with their own histories, features, and functions. Ferdinand Schoeman calls the family an “intimate arrangement having its own goals and purposes,” “an organic and enduring entity” and it is all of that. Families endure by shape-shifting; people are born into and die out of them, abandon them, enter them by marriage or other long-term commitments such as adoption, and reconfigure them by divorce and remarriage. But while families change shape over time, they also have their own distinctive characteristics. A family might, for example, be Amish or Roman Catholic, even though not everyone in the family fits that description. It might be working class or wealthy, descended from the Mayflower, or Boston Irish. Some families produce athletes in every generation, others tend toward the arts, some have a strong work ethic, and still others are blended or interracial or queer or farm or refugee.

It could be objected that “family” is simply shorthand for the web of interrelationships among the individuals who form one, valued only insofar as the people in them are valued. But sometimes, it seems, we act for the sake of the family even when we don’t value some of the individuals in it. Nobody likes Grandpa Schulz much—he is an ill-tempered bully and selfish to boot, and how Grandma Schulz puts up with him nobody can understand. But today is his birthday, and although 12-year-old Sally protests that she has a soccer game she has to go to, her parents insist that she come with them to the party. “Why do I have to?” Sally wants to know. “Because he’s family.”

FUNCTIONS OF FAMILIES

In a pediatric context, the family that matters is that of the pediatric patient. This may consist (paradigmatically) of the child’s biological mother, father, and siblings, but it may not; many children live in single-parent families, others live with a grandmother or aunt and perhaps cousins, and still others live in reconfigured families with a biological parent, a stepparent, and step-siblings, with or without visits to the other biological parent. However that may be, from the time of the child’s birth, the family plays a number of crucial roles in the child’s life. What follows is by no means an exhaustive list, but it serves as a reminder of why families are instrumentally valuable.

First and most obviously, families are responsible for preserving the child’s life. This duty comprises not only feeding, clothing, and sheltering the child, but also keeping her from harm. Parents or other adults in the role of parents must provide as secure an environment as their resources allow, which includes (among other things) teaching older
siblings to “be gentle with the baby,” making sure the child’s immunizations are up to date, fastening the child’s seatbelt if the family has access to a car, and taking her to the doctor when she is ill. Siblings must keep sharp implements away from the child, refrain from slamming doors in her face or involving her in dangerous play, protect her from neighborhood bullies, and keep her from running out into the street.

Second—this is also obvious but often overlooked—the family is the foundry in which the child’s identity is forged. It’s the family that establishes a proto-identity for her before she is even born; she is Candle Smith, daughter of June Smith and Maria Garcia, little sister to Carlos, native of North Carolina. These and other important facts about her are woven into the stories and fragments of stories that parents, siblings, and other family members create or draw on to depict the child as she grows and changes over time, and it’s that narrative tissue that constitutes the child’s identity. As the child acquires a self and then becomes self-aware, the third-person stories that were all the identity she originally had are gradually augmented by the first-person stories that constitute her own sense of who she is, but this probably doesn’t happen until she is at least 6 years old. Before then, those who are intimately connected to her both construct her identity and then maintain it—hold her in it—by treating her according to their narrative sense of her. Although many people hold us in our identities, the ongoing intimacy of families makes them particularly well suited to perform this function for their own. That is why, when Carlos teases little Candle until she cries, or Maria is laid off from a job that has been important to her self-conception, or June is suffering from a serious illness that loosens her grip on herself, they look to the others in the family to reassure them as to who they really are.

A third function of families is socializing children. Consider what this involves. It includes teaching them to talk, walk, feed, and dress themselves, and interact in a civilized manner with others. But it’s also a matter of giving children their second nature and thereby initiating them into a specific form of life. Second nature, as Aristotle understood it, is human nature, the disposition to virtue instilled in us on top of our animal nature by good upbringing, so that we are fit to take our place in human society. Where Aristotle thought of it largely as moral formation, for John McDowell, our second nature also comprises our disposition to rationality; to acquire second nature is to acquire the concepts that let us connect our minds to the world. Because of our second nature, we can simultaneously be of the world and know the world, acting in it according to the moral (and other) reasons we see there. Like McDowell, I believe that an absolutely central element in the acquisition of our second nature is learning language. It’s in speaking to children: singing, commanding, exclaiming, making jokes, employing sarcasm, “requesting, thanking, cursing, greeting, praying” that families not only open the gates for children to the rational and moral world, but also show them what to do when they get inside. Stanley Cavell explains what we learn along with language acquisition this way:

When you say “I love my love” the child may learn the meaning of the word ‘love’ and what love is. I.e., that (what you do) will be love in the child’s world, and if it is mixed with resentment and intimidation, then love is a mixture of resentment and intimidation, and when love is sought that will be sought. When you say “I’ll take you tomorrow, I promise,” the child begins to learn what temporal durations are, and what trust is, and what you do will show what trust is worth. When you say “Put on your sweater,” the child learns what commands are and what authority is, and if giving orders is something that creates anxiety for you, then authorities are anxious, authority itself uncertain. Of course, hopefully, the person, growing, will learn other things about these concepts and ‘objects’ also. They will grow gradually as the child’s world grows.

Acquisition of language is thus also initiation into how “we” do things—a particular culture’s socially shared behavior and ways of understanding. For as we learn language, we also learn “shared routes of interest and feeling, modes of response, senses of humor and of significance and of fulfillment, of what is outrageous, of what is similar to what else, what a rebuke, what forgiveness, of when an utterance is an assertion, when an appeal, when an explanation—all the whirl of organism Wittgenstein calls “forms of life.” As it’s a child’s family that initiates her into language, with all that entails, we can see her family gives her not only her self, but also her world.

A fourth function of families is to nurture children. This is a matter of giving the emotional, intellectual, and spiritual support that allows them to grow well. Families nurture their adult members too, of course, a good husband nurtures his wife by coming to hear her first solo performance with the church choir. Good siblings nurture with financial assistance and perhaps shelter when a grown sister or brother needs help exiting an abusive relationship. The nurture of the young proceeds on much the same lines; the child’s parents, siblings, grandparents, and other intimates encourage her to try new things, affirm her curiosity and creativity, help her overcome her fears, nourish her imagination, give her hope.

A fifth function of families is to nurse children (and of course adult members too) when they are ill, joining forces with health care professionals when the illness is too serious for home remedies. When the child is nursed at home,
siblings participate in giving the needed care; they bring Daddy the bottle of Tylenol or cough syrup, find and start the child’s favorite movie, wake Mama in the middle of the night when the child has vomited. Grandparents or other family members who are not part of the household are often recruited as informal caregivers as well, especially when the child’s parent or parents must be away for large parts of the day. When the child is hospitalized for a lengthy period of time, however, it’s the parents alone who divide the responsibility for the child’s care with health care professionals. That parents are visible to the child is hospitalized for a lengthy period of time, however, it’s the parents alone who divide the responsibility for the child’s care with health care professionals. That parents are visible to the health care team while the rest of the family has receded into the background may account, in part, for the relative inattention to the family as a whole in the bioethics literature.

FAMILIES’ INHERENT VALUE

If, as this partial list of familial functions suggests, families are valuable for what they can do for us, they are also valuable for what they are in themselves. Again, I’ll focus on the family of the pediatric patient, and again, what follows is not meant to be exhaustive, but rather to serve as a reminder of what good-enough, imperfect families are actually like.

First, families are places of love. It’s often said that children need love just as much as they need food, clothing, and the other goods and services families provide, so it might be thought that love makes families instrumentally, not inherently, valuable. But that is to mistake the nature of love. It is not a service like clean clothes in the drawer or a good like a hot dinner. It is, rather, a specific kind of interpersonal connection. When the child is an infant, the connection is one-sided; the parents give and the child receives. But what they give is themselves. They open their lives and hearts to the child, offering it the best of who they are. It’s an invitation, which, if the connection is to remain loving rather than degenerating into exploitation, must be reciprocated as soon as the child is old enough—otherwise the child is simply using her parents for what she can get. As the child grows, those in the family who love her teach her how to love them back until, in time, she learns to love maturely. Because familial connections are human, the love that informs them is always mixed with less desirable elements: selfishness, inattention, domination, fear, indifference, anger. Nevertheless, love is prized and sought after for its own sake, and that much of it is to be found in families is a partial explanation of their inherent value.

Second, families are also the site where lives are shared. The activities, routines, and events that are the stuff of family life tie its members together in an ongoing history that is common to all, although each person experiences it differently. What happens to one affects the others, particularly the children who are entirely dependent on the rest. Indeed, the intertwining of lives is essential to the identity-formation and maintenance that goes on in families; it’s the people you share your life with who are often directly implicated in the important acts, experiences, roles, relationships, characteristics, and commitments around which your identity-constituting stories are woven, and that’s part of the reason why these people are so important to you. For better or worse, in good-enough families the sense of security that comes from knowing that we do not navigate this world alone can be worth a great deal. We value the ability to share our lives and selves, and we find it tragic when a child cannot do that. Because identities are part of what we value when we value people, and these are bound up with the people whose lives we share, that sharing is itself inherently valuable.

Third, as they live out their lives together, family members encumber their children with a “thick” conception of the good—a specific understanding of what makes life worthwhile. It’s important not to romanticize this; the family might live by a code of honor that requires avenging any insult, no matter how slight, or “protecting the purity” of female members by sequestering them. That is a danger that can’t be helped, though. Wherever there is enduring intimacy, there will be value-infused outlooks, attitudes, priorities, and ways of proceeding that are shared in common and that give a specific shape to the child’s life. These thick conceptions of the good are necessary for what Charles Taylor calls strong evaluation—evaluations that involve “discrimination of right or wrong, better or worse, higher or lower, which are not rendered valid by our own desires, inclinations, or choices, but rather stand independent of these and offer standards by which they can be judged”. Taylor links strong evaluation to the formation of second-order volition: the ability we have to reflect on our first-order desires and determine whether we find them worthy of moving us to action. The power to regulate our first-order desires in this way, according to Harry Frankfurt, is what frees our will so that it’s we ourselves, and not those desires, that determine what we want to do. The weak evaluator, whose will is not free, evaluates her first-order desires and chooses the one that produces the most satisfaction; the child wants the Star Wars Legos for her birthday but also the Iron Man costume and picks the Legos because she thinks they’ll be more fun. She takes her desires for granted, and they are what move her to action. The strong evaluator, by contrast, understands that her desires themselves can be evaluated in terms of their worth, and endorses or repudiates them with the aim of making herself into a morally good person. The adult who once played Star Wars and Iron Man reflects on the institutionalized, sexist violence that pervades her society and does not want to be the kind of person who is complicit in it in any way, especially not as a form...
of entertainment, so she judges her desire to play Grand Theft Auto to be unworthy of her and goes bowling instead. If Taylor is right, adults engage the values that inhere in their conception of the good not only to regulate their first-order desires but to strengthen their moral character. For a child to learn how to do this, she must make use of such conceptions of the good as are available to her: namely, those of her family. That is why it matters that families encumber their children with their own sense of what is valuable. In opening them up to the range of values that are found in the world, families are the conditions for the possibility of their children's moral agency. And as agency is valued for itself, so are the conditions for it.

And fourth, her family is the child's home. As that, it is the security and stability that grounds the child's life. Again, it's important not to romanticize this. In concrete practice, alcoholism, parental death or abandonment, serious illness, domestic violence, constant fighting, sexual abuse, and other evils can make a nightmare of a child's home. Idealized, the notion of home has often been insufferably petit bourgeois and oppressive of women. But Iris Marion Young, among others, has defended home as "the material anchor for a sense of agency and a shifting and fluid identity,"11 an anchor that is particularly necessary for the rapidly growing and changing child. Home surrounds us with the objects, artifacts, rituals and practices that configure who we are in our particularity12 and give context to our lives. To be sure, for Young, home is conceptually distinct from family, as it also includes the domestic space inhabited by individuals living on their own. But for children, home and family are one. For them, home consists of the family that makes the domestic space the child's own. Family members do it when they care for their possessions and transmit the value of that care to the younger generation. They do it when they look after and love one another in that place. They do it when they use that place for the daily routines, familiar rituals, and special celebrations that affirm their identity as a family. It's these people that Robert Frost had in mind when he wrote, "Home is the place where, when you have to go there, they have to take you in." They have to because you belong there; you are one of them. When the child is old enough to make a new home for herself, home and family are no longer coextensive, but even then, and perhaps especially in times of need and dependency, home is still her family. However it may reconfigure itself over the years, her family is her rightful place in the world, the ground of her life and being. And once again, because her life and being is inherently valuable, its ground is too.

It's always difficult to make a case for a thing's inherent value, and I can't hope to persuade everybody that families should be valued in this way. I think they should, but even if I am wrong, it's enough for the purposes of my argument if I have shown that they possess instrumental value, as that alone gives us reason to care for them and keep them safe from harm.

THE FAMILY UNDER PRESSURE

Serious illness puts pressure not only on individual family members but also on the family itself. The care of an acutely ill child requires the family to channel many of its resources toward a single member: an arrangement that can usually be sustained for a while but that cannot continue indefinitely while the other members do without. Illness disrupts ordinary familial functions and, if it is serious enough, threatens to break the family altogether.

When a child is seriously ill, the familial function of nursing is ordinarily turned over to health care professionals, which means that families no longer have primary control over how it is done. Yet some of that care cannot be provided in the same way by even the most attentive professional staff, precisely because the staff are not part of the family. It is 1 thing when a hospital nurse gives medication that makes the pain go away and another when Mama does it at home, as Mama transmits the comfort of love, familiarity, and connection along with the dose. The inability to give familial care in a hospital setting, even when the family recognizes the need for professional help and is grateful for it, may leave family members feeling helpless and at a loss, frustrated by not being able to do what they do best.

It's not only the nursing function that is disrupted in times of serious illness. When parents must spend every spare moment at the hospital, the child's siblings or frail elderly relatives may find themselves less well protected than they are in happier times. They may be frightened by the long parental absences, unsettled by the change in their routines, less well supervised by people not thoroughly familiar with their needs and proclivities, more prone to engage in dangerous activities. At the same time, the parents may feel guilty that they cannot be at home, worried about the other children's well-being, and frustrated by their inability to look after frail elders who need them. Grandparents, aunts and uncles, or family friends who are close to the children can go some distance toward taking the parents' place at home, but unlike professional caregivers who can be replaced by equally qualified others, family members are not interchangeable, as children in particular know only too well.

Identity-maintenance undergoes a special strain when a child is hospitalized for long periods of time. If the patient is an infant, the family's function of creating her identity is disrupted as the infant is torn from the nest of relationships in which this work takes place. If she is an
older child, her sense of herself may be threatened, first by her illness and then by her isolation from the familial intimates who hold her in her identity. Nor is she likely to be the only one who faces difficulties here. Her parents may find their own identities under siege because they cannot perform their parental roles in the usual way; stress, worry, and sleeplessness can contribute to their sense of inadequacy or anger and reduce their ability to maintain either their own or their loved ones’ identities. And once again, those at home may be less able to cope and find that their grip on themselves has weakened.

Serious illness likewise retards socialization and nurturing. The pediatric patient may be slow to muster the linguistic and social skills of healthy children her age, or may be emotionally immature or destructively self-centered. Siblings may pick up on tensions in the home and regress on some or all fronts. And as money and time may be scarcer than usual, middle-class families may be forced to curtail music lessons or soccer practice, whereas low-income families might have to do without decent food, clothing, or health care.

All that is bad enough, but health professionals and medical ethicists who do not well understand the relationship between families and medicine can make matters even worse. For example, providers tend to treat families of pediatric patients primarily as sources of unpaid care. High-tech treatments that can be given at home, such as ventilator care or dialysis, thrust family members with no medical training into positions of serious responsibility. When an infant born at 25 weeks’ gestation is discharged from the NICU that has saved her life but left her with serious damage to lungs and brain, neonatologists may take it for granted that her family will just naturally provide the years of unrelenting care that will now be required. Parents may be called on to learn how to insert a nasogastric tube or perform high-frequency chest wall oscillation, or to devote significant amounts of time providing physiotherapy. And if a kidney or liver lobe is required, health care providers may assume that family members will just naturally volunteer.

This cavalier attitude toward families is arguably born of nothing worse than misunderstanding—or forgetting—what families are for. Another more pernicious attitude arises out of the clash between health care ethics, which is patient-centered and individualistic, and the ethics of families, which is neither. In families, where the ethos is much more communal and relational, people will sometimes behave in ways that, from a professional, patient-centered perspective, may seem flat-out immoral. And medical ethicists, trained in the individualist, individualist moral theories originally designed to govern interactions in the public sphere, have been deeply suspicious of families as well. As a result, there is what amounts to a default setting of distrust, a presumption on the part of clinicians and bioethicists that a family is just as likely as not to be neglectful, abusive, or selfish. A parent’s decision not to visit the patient every day because her energy and attention are also required at home can be seen by the staff as uncaring, or possibly even neglectful. A parent’s insistence that a testing child participate in a clinical trial by giving blood can be seen by the ethicist as abusive, rather than as holding the child to the family’s conception of the good. A clinician’s assumption that the only kind of futility that matters is medical futility can keep her from appreciating that families might request a treatment to further valuable ends of their own—such as keeping the patient within the circle of their love as long as possible. It’s not that families should always prevail in such disputes. My point is merely that the expression of a distinct, family-oriented perspective strikes many professional caregivers as illegitimate, as undermining familial claims to care. Such distrust can add to the strain families are already under, posing a threat to their identities. It can call into question everything that is inherently valuable about them, casting doubt on how well they love, whether the lives in them are exploited rather than shared, whether their conception of the good is good enough, and how adequately they function as a home. When coupled with greatly heightened demands on families’ capacity for care, this attitude on the part of clinicians, as bolstered by medical ethicists, can damage families’ own sense of what they are and why that matters. Like the people within them, families under pressure need to be held in their identities by caring others who recognize what is valuable about them and treat them on the basis of that recognition. Otherwise, they are at risk for losing their integrity, perhaps to the point where they cease to be families at all.

We bioethicists may be forgiven for not having developed a robust account of the moral interface between families and medicine. The moral theories on which we standardly draw aren’t particularly well equipped to handle relations of intimacy and dependence, and although almost all of us have families of our own, we mostly just appreciate them without stopping to think very much about why that is so. In this article I’ve only been able to provide the merest sketch of the sorts of things about families that matter, but I’ve also tried to show why we all, bioethicists and clinicians alike, might need to take families more seriously. What’s at stake is the well-being not only of our sickest children, but of the social entities in which they live.

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