

2014

Neither Father nor Doctor “Knows Best”: From Tradition to Choice in the Family and on the Wards

Janet L. Dolgin
Maurice A. Deane School of Law at Hofstra University

Follow this and additional works at: https://scholarlycommons.law.hofstra.edu/faculty_scholarship



Part of the [Law Commons](#)

Recommended Citation

Janet L. Dolgin, *Neither Father nor Doctor “Knows Best”: From Tradition to Choice in the Family and on the Wards*, 6 J. FAM. THEORY REV 62 (2014)

Available at: https://scholarlycommons.law.hofstra.edu/faculty_scholarship/1281

This Article is brought to you for free and open access by Scholarly Commons at Hofstra Law. It has been accepted for inclusion in Hofstra Law Faculty Scholarship by an authorized administrator of Scholarly Commons at Hofstra Law. For more information, please contact lawlas@hofstra.edu.

JANET L. DOLGIN *Hofstra University*

Neither Father nor Doctor “Knows Best”: From Tradition to Choice in the Family and on the Wards

This review article analyzes 3 developments within the world of health care that involve concomitant changes in the scope of family and the form of family relationships. The first follows from construction of the informed-consent doctrine and its implementation, the second stems from stunning innovations in reproductive technology, and the third involves the increasing significance of genetic information for medicine. The article suggests that an analysis of changing relationships within the world of health care may offer insights about shifts in the meaning of family. As social domains, the world of family and the world of health care have undergone similar transformations during the past half century. Shifts in the foundational assumptions in each domain—that of the family and that of health care—inform shifts in the other domain. Examining the actualization of these shifts can assist scholars and practitioners in guiding discourse and in resolving disputes among family members and among those who populate the world of health care, including clinicians, patients, and patients’ family members.

Parallel transformations in key assumptions about personhood and about relationships among

people have reshaped relationships within families and within the world of health care in the past 4 or 5 decades. More precisely, relationships within families and relationships between clinicians and patients increasingly resemble relationships in the marketplace. Fixed roles and statuses have largely been replaced by demands for choice as the terms of relationships are increasingly open to negotiation, and paternalism is no longer widely valued in either social domain. Unsurprisingly, these changes have been accompanied by controversy. Moreover, the changes have resulted in significant uncertainties about the shape of relationships and the meaning of personhood, both within families and between clinicians and patients. Confusion has been especially disconcerting in situations that simultaneously challenge traditional family relationships and traditional understandings of the clinician–patient relationship.

This review examines three health-care developments that have reshaped the roles of clinicians, patients, and family members to illustrate the character of parallel—and often synergistic—changes in the worlds of family and health care. In each of these contexts, conflicts between the goals of individualism (privileging individual autonomy) and those of community (privileging paternalism and group solidarity) have energized new understandings of relationships that were once understood through the lens of hierarchically organized communities. These developments have affected relationships among family members and relationships in the

121 Hofstra University, Hofstra University, Hempstead, NY 11549 (lawjld@hofstra.edu).

Key Words: assisted reproduction, family law, genetics, health care, informed consent.

world of health care. Underlying shifts in both social domains have encouraged more flexibility and choice, which may prove fruitful for understanding new forms of family and for providing new understandings of relationships among clinicians, patients, and patients' family members. Construction of the informed-consent doctrine, for instance, has dramatically reshaped relationships between patients and physicians (Schuck, 1994). Similarly, the increasing use of reproductive technologies has further challenged concepts of family as society and the law increasingly have relied on autonomous choice and intention to define families (Garrison, 2000).

THE DOMAIN OF THE "TRADITIONAL FAMILY"

The so-called traditional family in the United States developed in the early years of the 19th century, largely in response to the demands of the Industrial Revolution (Grossberg, 1985). During the 19th century and most of the 20th century, Americans viewed the family through fixed, hierarchically structured roles and attendant statuses, such as gender and age (Demos, 1986). In contrast to society's vision of the traditional family, Americans imagined the marketplace of the Industrial Revolution as populated with putatively equal, autonomous individuals who were expected to negotiate the terms of their own relationships. American society viewed the marketplace as structured through reference to money, not love, and those who populated it were *not* expected to develop lasting, committed relationships. Rather, relationships were expected to continue as long as—and only as long as—the negotiated bargains on which they were shaped continued (Demos, 1986).

Mainstream American society seemed most unhesitatingly to embrace the notion of a traditional family during the middle decades of the 20th century, just before the appearance of new forms of family that more resembled the autonomy of the marketplace. For example, Schneider's (1968) classic study of American kinship described the mid-20th-century family as a unit grounded in love, not money; loyalty, not bargains; and community, not individualism. In these traditional families, family members were not viewed as autonomous individuals; rather, the identity of each depended on the hierarchical structure of the whole (Maine, 1917; Schneider, 1968). Values such as individualism,

clearly reflected in American economics and politics almost from the nation's beginning, largely eluded many families until the late 1960s (Grossberg, 1985). However, by the last several decades of the 20th century, the ideological distinctions that separated the world of home from the world of work began to blur. Family members (or at least adults within families) increasingly began to define one another as autonomous individuals, joined together as long as (and only as long as) they chose to remain connected. Some segments of the public vehemently rejected this new vision of family, but even among many of those who preferred traditional visions of family, the notion of choice (e.g., the choice to be a certain kind of wife or husband) displaced the presumptive inflexibility of traditional family relationships. Moreover, various subcultures in the United States entertained somewhat different visions of family.

Concomitant shifts in family law in the United States, began—hesitantly at first—in the mid-1960s. Changes in the law reflected the process through which adult family members were redefined as autonomous individuals, each *vis-à-vis* the others. For example, in *Griswold v. Connecticut* (1965), the U.S. Supreme Court invalidated a Connecticut birth control law. Yet the reasoning behind the Court's ruling mostly relied on traditional understandings of family. In particular, the Court stressed the right of a married couple to make decisions about contraception without state intrusion. The Court described marriage in the most traditional terms:

Marriage is a coming together for better or for worse, hopefully enduring, and intimate to the degree of being sacred. It is an association that promotes a way of life, not causes; a harmony in living, not political faiths; a bilateral loyalty, not commercial or social projects. Yet it is an association for as noble a purpose as any involved in our prior decisions. (*Griswold v. Connecticut*, 1965, p. 486)

Then, in 1972 the Court expanded the protection offered in *Griswold* and, in doing that, voiced a nontraditional understanding of family. The ruling in the case *Eisenstadt v. Baird* (1972) invalidated a Massachusetts law that prohibited the distribution of birth control to unmarried adults. In *Eisenstadt*, the Court jettisoned the presumed distinction between relationships at home and relationships at work and granted

adults the right to make choices precluded by traditional understandings of family. The Court wrote:

It is true that in *Griswold* the right of privacy in question inhered in the marital relationship. Yet the marital couple is not an independent entity with a mind and heart of its own, but an association of two individuals each with a separate intellectual and emotional makeup. If the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child. (*Eisenstadt v. Baird*, 1972, p. 453)

Thus, by 1972 the US Supreme Court assumed a vision of family relationships—or at least of relationships among adults within families—that looked much more like relationships in the marketplace and the public sphere more generally than those in the traditional home. In this regard, the portrait of spouses painted in *Eisenstadt* contrasts strikingly with that assumed 7 years earlier in *Griswold*.

Other changes in family law in the 1970s echoed this shift toward viewing family members as independent persons who choose to relate to each other in various ways—or not to relate—and thus, for instance, to separate or divorce. During this period, courts also began to recognize cohabitation agreements between unmarried partners (e.g., *Marvin v. Marvin*, 1976; *Morone v. Morone*, 1980). Similarly, the law granted potential spouses the right to enter into prenuptial agreements. Such agreements delineate the details of a possible future separation or divorce (*Sherer v. Sherer*, 1982). In short, American law and the society of which it is part have come increasingly to expect family members (and particularly adult family members) to shape the parameters of their relationships and, if desired, to shape the terms that end those relationships.

DOES DOCTOR STILL KNOW BEST?

A process that began to transform the family from a hierarchically structured community to a collection of autonomous individuals who choose their relationships and the terms of those relationships found its analogue in the world of health care during the same decades. Both domains, long imagined as distinct from the marketplace and from most public arenas,

largely abandoned their traditional presumptions over the course of the second half of the 20th century.

Throughout the 19th century and much of the 20th century, medicine was identified as a “profession” that participated in, but stood at the margins of, the world of commerce. Unlike relationships in the commercial marketplace, relationships between patients and health-care professionals were expected to be paternalistic, trusting, and loyal (Dworkin, 1988). Society presumed that the world of health care was structured hierarchically—that, in a nutshell, “doctor knew best. (Dworkin, 1988, p. x). By the start of the 21st century, another model—one resembling that which is operative in the commercial marketplace—had largely displaced the traditional model. In Dworkin’s (2003) phrase, the conclusion “doctor knows best” was replaced by the assertion “It’s *my* body.” The development of the informed-consent doctrine in the United States illustrates the scope of the transformation of relationships in the world of health care. Previously, patients did not assume a right to participate in their health-care decisions. Doctors made medical decisions, and for the most part, patients accepted those decisions gratefully. In 1914, for example, New York’s highest court obliged surgeons to obtain a patient’s consent before operating, but there was no presumption that the patient was entitled to information explaining or justifying the physician’s decision (*Schloendorff v. Society of the New York Hospital*, 1914). Patients had a presumptive right to consent to or refuse to consent to care, but Judge Cardozo, who wrote the New York court’s opinion in *Schloendorff*, did not impose an obligation on physicians to inform patients about the details of proposed care before patients agreed to or refused that care.

Not much changed for almost 6 decades, until, virtually at once, courts and legislatures began to require a patient’s consent to or refusal of care to be premised on information about the care in question. Soon, the informed-consent doctrine became the governing law in almost every jurisdiction in the United States. This doctrine assumes the autonomous individuality of patients. Beginning in the 1970s, patients were given the right not only to refuse treatments suggested by their health-care providers but also to be given adequate information about their condition and possible modes of treatment so as to make an *informed* decision about whether to

consent to care (Beauchamp & Childress, 2001; *Canterbury v. Spence*, 1972).

In parallel fashion, health-care practitioners, especially physicians, dramatically altered their approach to conversations with patients about treatment options. Whether particular changes in practice reflected or were reflected in changes in the law (or both), the shift in law and practice by the 1970s was undeniable. An article published in *Journal of the American Medical Association* in the early 1960s reported that about 90% of physicians refrained from informing a patient about a cancer diagnosis (Oken, 1961). An article published in the same journal 18 years later, reported that 98% of physicians surveyed did inform a patient about a cancer diagnosis (Novack et al., 1979). In that 18-year period, a universe governed by paternalistic presumptions had largely evaporated. The expectation that doctors, not patients, should make health-care decisions because doctors, not patients, understand illnesses and how to treat them was replaced with the expectation that patients were partners in medical decision making.

By the 1980s, transformations in the social world of medicine clearly paralleled those in the family arena. In both contexts, a world that prized individual autonomy had largely replaced one that had prized hierarchically structured relationships and that had assumed long-term trust and loyalty. More particularly, both relationships in the family arena and those in the world of medicine came increasingly to resemble relationships in the commercial marketplace.

CHANGES IN HEALTH CARE AND FAMILY RELATIONSHIPS

Many developments in the world of health care in the past several decades have reflected and, in turn, fostered new understandings of relationships among family members. Three such developments and their implications for relationships among family members and between patients and clinicians are reviewed in this article: (a) construction and elaboration of the informed-consent doctrine in clinical settings and the related development of rules about medical decision making for patients lacking capacity; (b) the advent of reproductive technology and responses to families created through reliance on it; and (c) genetics and genomics, which holds stunning implications

for understandings of personhood and of family.

Development and Elaboration of the Informed-Consent Doctrine

The first of these developments involves the construction of the informed-consent doctrine. The *Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), a foundational bioethics document that provides ethics guidelines for human-subject research, identifies “respect for persons” as a core moral value. The report specifies that implementation of respect for persons as a value should entail construction of an informed-consent process for research subjects. That understanding has been widely appropriated and applied to clinical medicine as well.

Yet only a half century ago, neither individual patients (in relation to clinicians) nor family members (in relation to one another) were considered autonomous. Health-care choices usually reflected physicians’ conclusions, sometimes in consultation with certain, but not all, family members. Under Roman law, a family’s paterfamilias voiced the family’s choice. That person, typically the “father of the family” or “owner of the familial estate,” had absolute control of family matters. The term continues to be used to refer to the authority of the “father” (generally the oldest, male member of the household). Moreover, the choice of the paterfamilias was often enough his choice rather than that of the patient (Deftos, 1997; *Tooley v. Provident Life & Accident Insurance Co.*, 1963). Indeed, well beyond the reach of health-care decisions, courts generally avoided interfering with decisions of the paterfamilias in cases involving family relationships, even in cases in which those decisions did not seem compassionate or wise (*McGuire v. McGuire*, 1953). Thus, determination of patient capacity was far less relevant with regard to medical decision making than it is today. Physicians handled decisions for most patients, and to the extent that the physician consulted “family,” the paterfamilias was that family.

During the last 3 decades of the 20th century, social norms and legal rules have recognized the right of an autonomous patient to make his or her own medical decisions. As noted, this trend harmonized with shifts

in society's understanding of families as collections of autonomous individuals rather than as communities with prescribed roles and statuses that transcended the significance of individuals' choices, at least with regard to adults in families.

Society and the law remain conflicted about the shape of childhood and the rights that should be accorded at different stages of childhood (Segadelli, 2010). In general, uncertainties about the meaning of childhood and the scope of the parent-child relationship are legion and can complicate medical decision making for and about children. Although the law has granted children some of the rights of autonomous individuality in the past few decades (*In re Gault*, 1967; *Tinker v. Des Moines Independent Community School District*, 1969), U.S. society continues to view children as vulnerable and dependent (*Bellotti v. Baird*, 1979). Contradictions abound, and legal rules about medical decision making for and by children vary widely from state to state. In particular, society has been ambivalent about the extent to which its commitment to equal rights for everyone determines the rights we accord to children. In fact, contemporary society has been far more reticent about leveling the status difference between children and adults. Children, explained law professor Steven Shiffrin (1980), are the Achilles' heel of liberalism.

Thus, by the end of the 20th century, society and the law encouraged capable patients to rely on family members—and on clinicians—only insofar as they chose to do so. Rather, the law generally required clinicians to share medical decision-making tasks with the patient involved. To that extent, patients gained a central role in directing the course of their own health care. This is a stunning recognition of individual autonomy as a value in the world of health care.

However, the presumption that patients have the right to choose whether to consent to suggested treatments or to refuse those treatments assumes a capable patient. Patients without capacity are not deemed autonomous. Such patients are treated more or less as the law and the health-care system treat very young children. (More deference is often paid to older children, depending on the issue at stake and the child's maturity.) In short, for adult patients without advance directives and without capacity, as for children, a need

developed to determine by law what had previously been determined by unselfconscious assumptions about the parameters of family relationships. Increasing success with keeping terminal patients alive on life-sustaining care augmented the urgency of defining surrogate decision makers in hospital and nursing home settings.

Cases involving incompetent patients in need of medical decision making occasioned considerable dispute in the last decades of the 20th century. Old patterns that relied on the authority of the paterfamilias to make decisions for other family members had largely been abandoned and replaced with patterns presuming patient autonomy. This worked well enough for competent patients but not for those without capacity (who had not left advance directives). State lawmakers responded variously. A few states, including New York, entered a long period in which certain medical decisions, especially end-of-life decisions, for patients without capacity could not be implemented. For instance, in *In re Storar* (1981), New York's highest court mandated that treatment be continued for a dying man who had been severely retarded since birth. John Storar's mother had asked that treatments be stopped, but the court concluded that in the absence of evidence of John's own wishes, it could not order an end to care. About 20 years later, New York's legislature followed the vast majority of states in providing for surrogate decision making for patients without capacity and without an advance directive or some equivalent. The legislation (considered in more detail later in this article) rested on the widespread presumption that incompetent patients would have wanted medical decisions made by particular relatives and others (listed in the law in order of priority).

New York's statute, the Family Health Care Decisions Act (FHCDA) of 2010, a latecomer to this bailiwick of lawmaking, is illustrative. It provides a prioritized list of surrogate decision makers for patients deemed to lack capacity. Under the law, health-care surrogates for adult patients without capacity (and without advance directives) are identified in this order: a spouse or domestic partner; a child who is at least 18; a parent; a sibling who is at least 18; and, finally, a close friend (FHCDA 2010, § 2994-d). The law defines both "domestic partner" and "close friend" broadly (FHCDA 2010, § 2994-a). The latter term is defined

to include relatives not classed among those expressly enumerated (i.e., relatives other than a spouse, child, parent, sibling) (FHCDCA 2010, § 2994-a(4)). The inclusion of domestic partner at the same level of priority as spouse is of enormous moment, and again suggests the breadth of changes in traditional visions of family and their implementation in health-care settings. The Code of Ethics of the American Medical Association (2001) explains, “Physicians should recognize the proxy or surrogate as an extension of the patient, entitled to the same respect as the competent patient” (n.p.). In cases in which adult patients have nominated health-care proxies while competent, the surrogate’s identity reflects the patient’s pre-incompetence wishes. In other cases, surrogates are usually chosen by reference to state laws (e.g., New York, FHCDCA) that prioritize family members in a list of possible surrogates.

The need to establish and implement a process for choosing surrogate decision makers and attending to their decisions has led to the institutionalization in hospitals and other health-care facilities of mechanisms for resolving disputes among patients, patients’ relatives, legal surrogates, and clinicians. The proliferation of ethics committees in hospitals reflects a need to resolve conflicts about medical decisions for incompetent patients among family members or between family members and clinicians (Council on Ethical and Judicial Affairs, 2001). A half century ago, the privileged familial status of the paterfamilias would have precluded public acknowledgment of disputes about medical decision making among a patient’s family members. That is no longer the case. Yet it is not possible to rely equally on the presumption that autonomous, individual patients are alone responsible for medical decision making. Thus, lawmakers and professional groups have had to contemplate the contours of family, and they have had to devise institutional responses to intrafamilial disputes that would once have been resolved, for better or for worse, by the inherent authority that traditional understandings of family bestowed upon particular family members vis-à-vis others in the family group and that society bestowed upon clinicians, and in particular, upon physicians.

Alongside the new rules about medical decision making constructed during the past few decades, some concern has developed about when, if at all, autonomy should be limited

in the name of a patient’s best interests. This has resulted in a countermovement of sorts (favoring beneficence over autonomy, at least some of the time). It is not likely to eviscerate the central principles of the informed-consent doctrine. But it does call for more nuanced attention to patients’ welfare, sometimes at the expense of their autonomy (Levy, 2012).

In summary, the transformation of patient-physician relationships mostly paralleled the transformation among family members beginning in the second part of the 20th century. Yet a more recent concern with limiting patient autonomy to safeguard a patient’s welfare suggests an effort to mediate the demands of individualism with those of community. Perhaps a similar effort will eventually reshape family relationships. In some part, concern about limiting patient autonomy is reflected in concern about the extent to which society and the law are ready to grant autonomy to children older than 7 or 8 years of age.

Medicine, Reproduction, and the “New” Family

Legal responses to family disputes occasioned by reproductive technology increasingly privilege individualism and choice over traditional family values. Reproductive technology generally implicates family relationships, and far-reaching questions about the shape of family and about the determinants of the parent-child relationship, in particular, have followed advances in reproductive technology and their implementation. In recent decades, the use of reproductive technology has led to a wide variety of disputes about parentage. In the United States, legislators have responded slowly. Courts, however, asked to entertain the discrepant claims of litigants seeking to resolve specific disputes about parentage or potential parentage occasioned by reproductive technology, have fashioned guidelines that have redefined the scope of parentage. A set of late 20th- and early 21st-century California cases, for instance, suggests increasing readiness to abandon understandings of family grounded in presumed biological “truths” in favor of parental intention and choice (*Buzzanca v. Buzzanca*, 1998; *Johnson v. Calvert*, 1993; *K.M. v. E.G.*, 2005). In the United States, adoption law (first constructed in the 19th century) foreshadowed the notion that the parent-child relationship need not rest on

“biology.” However, adoption was long grounded on an agreement that the adopting relationship was tantamount to the parent-child relationship, based on the presumed biological “facts” of the reproductive process (e.g., birth certificates have named adopting parents just as they name biological parents) (Papke, 1999).

The increasing use of reproductive technology has rested on society’s readiness to abandon traditional family patterns. And legal (especially judicial) responses to disputes occasioned by the use of reproductive technology have reinforced that social trend. By the last decades of the 20th century, stunning new developments in reproductive technology offered infertility patients unprecedented reproductive options. Each new reproductive option stimulated new questions about how best to determine legal parentage. Although the process of answering these questions has been uneven, social and judicial responses have increasingly diluted concern with identifying presumptive biological truths with concern for parental intention and choice.

This history can be dated to the middle of 19th century, before most people could have imagined in vitro fertilization or gestational surrogacy. At that time, an American physician named J. Marion Sims began to offer assisted insemination to patients anxious to conceive children. At least one of these inseminations resulted in a successful pregnancy (Shalev, 1989; Swanson, 2012). The practice gained wider use, although few pregnancies resulted during the following few decades. Nevertheless, reports about the use of donor sperm in the first decades of the 20th century led to a social outcry that deplored assisted (then called “artificial”) insemination as sinful and adulterous (Shalev, 1989). Still, by the middle of the 20th century, the procedure was securely medicalized, and soon this form of medicalized reproduction was legalized. States throughout the United States recognized its legitimacy, at least in the case of married people. State legislatures widely provided that children conceived through assisted insemination using donor sperm became the “natural” children of the husband as a legal matter, assuming that the husband had consented to the insemination (Shalev, 1989).

The novel presumption that the law had the authority to determine “natural” parentage even in cases in which the claim of “natural” parentage conflicted with long-standing and unquestioned assumptions about family was

remarkable. Even more, it presaged a pattern that flowered during the last decades of the 20th century. Increasingly, the law allowed social preferences, rather than old-fashioned assumptions about “blood” or “genes,” to define families, at least with regard to families occasioned by reproductive technology.

Soon, developments in reproductive technology led to more and more innovative options for reproduction and new forms of family. Louise Brown, born in Oldham, England, in 1978, was the first child conceived in vitro. Within a couple of decades after this birth, zygotes conceived in vitro were being cryopreserved for future use; a child, conceived from the ovum of one woman, could be gestated by a different woman; and it became possible to effect posthumous conception, or children conceived after the deaths of their biological parents. Posthumous births, the birth of a man’s children after his death, were as old as time. Posthumous conception was entirely new.

Each of these possibilities led to confusion and to disagreements among progenitors, clinicians, tissue banks, and/or third parties (e.g., “surrogate mothers”) involved in the reproductive process. And each required courts to reinterpret traditional understandings of family and of the parent-child relationship. The result has been a vision of family as firmly linked with notions of choice as with notions of biological “fact.”

Although court decisions in the 1980s involving cases of assisted reproduction, such as those of the New Jersey courts in *Matter of Baby M.* (1987/1988), mostly reinforced traditional understandings of family, that approach did not predominate for long. By the first decade of the 21st century, courts in several states had recognized families that reflected increasingly novel reproductive facts. In many of these cases, courts looked to relationships rather than to biology in determining legal (sometimes even referred to by courts as “natural”) parentage.

Matter of Baby M. (1987/1988), decided in New Jersey, received widespread publicity and, in many ways, was the first important state-court decision responsive to the challenges of reproductive technology. Interestingly, however, the story at the center of the case involved no technology. But the case was a harbinger of those that did because it posed the central question at stake in disputes occasioned by reproductive technology: What role would biology play in defining

families in a universe that was ready to challenge traditional assumptions about the significance of biology in identifying family relationships?

Matter of Baby M. (1987/1988) involved a married couple, William and Elizabeth Stern. They wanted children but were unwilling to risk Elizabeth's becoming pregnant (for medical reasons). The couple hired a surrogate, Mary Beth Whitehead, who agreed to gestate a baby conceived through assisted insemination using Stern's sperm and, at the baby's birth, to yield maternal rights to the Sterns. In fact, William Stern, Mary Beth Whitehead, and Whitehead's husband, Richard, signed the contract at issue in the legal case. Richard Whitehead signed the contract so as to deny any claims to paternity to a child that might be born as a result of the insemination of his wife with Stern's sperm. And Elizabeth Stern (an "intending," but not a biological, mother) did not sign the contract for fear that doing so might violate laws prohibiting the purchase or sale of a child. After the birth of the baby—a girl, born in March 1986—Mary Beth Whitehead, unable to hand the child over to the Sterns, fled to Florida with the child. The Sterns commenced litigation, seeking return of the child and a declaration of their parentage.

The trial court sided with the Sterns on almost all fronts. In effect, it upheld the contract (although the judge framed his decision as one serving the "best interests" of the child rather than the legal rights of the Sterns). The court terminated Whitehead's parental rights, granted custody to William Stern, and arranged for a speedy adoption of the child by Elizabeth Stern. On appeal, New Jersey's highest court overturned the ruling of the trial court judge. It identified William Stern and Mary Beth Whitehead as the baby's parents. The court conceptualized the case as one might conceptualize any custody dispute, as, for instance, between divorcing parents. The court granted custody to William Stern and visitation rights to Whitehead.

In the decades since *Matter of Baby M.* (1987/1988), courts have determined the implications for parenthood of genetics, gestation, and reproductive intention. No settled pattern of legal responses in the United States as a whole has emerged. However, a number of states have provided for determinations of parenthood by balancing assessments of the role of biology and intention in particular cases. In one of the first cases of this sort decided by a state's

highest court, the Supreme Court of California concluded that maternity can be grounded on evidence of maternal intention plus some cognizable biological link to a child. That link could be either genetic or gestational.

Johnson v. Calvert (1993) involved a dispute between a "gestational surrogate" (the woman who gestated and gave birth to the disputed baby) and a couple, who contributed the sperm and egg from which the baby was conceived in vitro. The couple, Mark and Crispina Calvert, had entered into a contract with Anna Johnson, the surrogate. For a fee, Anna agreed to gestate and give birth to a child, conceived from the Calvert's gametes, and, at the baby's birth, to give the child to the Calverts (the "intending" parents). Thus, the case resembled *Matter of Baby M.* (1987/1988) except that the intending parents were both related to the child genetically, and the surrogate was not.

Before the birth of the baby, a boy, the parties had gone to court in a dispute about the child's legal parentage. Three California courts entertained the case. All held for the Calverts. The three decisions, viewed as a set, are particularly fascinating in that the trial court held for the Calverts because they were linked to the child through genetics; the state intermediate appellate court held for the Calverts, on the basis of its interpretation of state statutory law. And the Supreme Court of California organized the pieces within a novel legal frame and declared that in cases involving two women, each presenting cognizable claims to biological maternity, the state would identify the intentional mother (the woman who, from the start, intended to raise the child) as the legal mother. In some cases that woman would presumably be the gestational mother, and in others (such as *Johnson*), she would be the genetic mother. This decision, now almost 2 decades old, established an innovative approach to the identification of the mother-child relationship. It provided for the recognition of "natural" maternity even though it elided traditional assumptions about what makes a woman a mother.

Then, a little more than a decade later, the same court seemed to upend its assertion in *Johnson* that a child can have "only one natural mother" (*Johnson v. Calvert*, 1993, p. 781). In one of three companion cases decided in 2005, California's supreme court named two women (who had been same-gender partners) as the mothers of twins conceived from the

eggs of one of the women and gestated by the other. Even more, it would seem that had the court looked to the *Johnson* intent test, it should have rejected the genetic mother's legal maternity. On an ovum donation form prepared by the fertility clinic where the children involved were conceived, the woman who donated the eggs so that her partner could become pregnant expressly denied any intention to become a mother to any children who might be conceived from her eggs (*K.M. v. E.G.*, 2005). The court in *K.M.* and its companion cases (*Elisha B. v. Superior Court*, 2005; *Kristine H. v. Lisa R.*, 2005) stressed the importance of adults' parenting choices rather than their intentions pre-conception in determining legal and natural maternity. Most important, for understandings of family, this trilogy of cases (of which *K.M.* was one) stands for the proposition that "natural" maternity need not entail biological maternity.

This proposition is, and for some time will likely remain, a point of contention among states in the United States and among nations. For instance, in 2006 the British House of Lords expressly privileged biology over maternal behavior in a custody dispute occasioned by the breakdown of a relationship between two women (*In re G (Children)*, 2006). The children involved had been conceived through assisted insemination. The court overturned the decisions of two lower courts, both of which granted primary custody to the nonbiological mother on the grounds that the biological mother had attempted to preclude her onetime partner from visiting the children. The House of Lords began by explaining: "In reaching its decision the court should always have in mind that in the ordinary way the rearing of a child by his or her biological parent can be expected to be in the child's best interests, both in the short term and also, and importantly, in the longer term. I decry any tendency to diminish the significance of this factor" (*In re G (Children)*, 2006, p. 1).

Thus, with respect to families created through reliance on assisted reproduction, some courts continue to privilege biology over intention and behavior. But others, such as the California court in *K.M. v. E.G.* and its companion cases, look at parental choices and conduct as the hallmarks of legal parentage.

In summary, families that valued individuality and equality more than community and hierarchy provided the cultural grounding for the implementation of reproductive technology.

Yet that implementation inevitably resulted in disputes about legal parentage and the scope of family. For the most part, responses to those disputes further privileged families of "choice" over traditional families. For researchers and social theorists, these disputes and responses to them provide a fruitful context for assessing the changing shape of family relationships.

Genetic Testing, "Familial" Conditions, and Genomics

The notion of family discussed in the previous section—that being elaborated by society and the law in the context of families occasioned by reproductive technology—stresses choice and intention. In contrast, a focus on genetic information results in a different notion of family. This understanding of family is framed by the presumption of shared substance ("blood" or genes). For families faced with disease and disability associated with genetic alterations, for example, the biological components of familial relationships can become particularly compelling. They may even trump the modern concern with choice and the actuality of relationships in families. What is the potential significance of genomic information in reshaping understandings of family?

Both the genetic family and the traditional family are based on a notion of inevitability grounded in biology. Yet even as the genetic family (as a theoretical construct) differs from the family of choice, it differs quite as certainly from the traditional family. But the genetic family abandons the social components of family to become essentially an ahistorical construct.

As a theoretical matter, the construction of a "genetic family"—a family identified primarily through reference to information about shared genetics—raises perplexing questions. However, the notion of a genetic family is not only theoretical. The advent of genetic testing and of genomics (which focuses on many genes and on interrelations among them) has startling implications for the meaning of family. As a practical matter, those implications have had consequences in only a few situations, most of which involve familial illnesses and conditions.

The ability of science to identify genetic alterations associated with what were once called familial conditions has resulted in the medicalization of families. Should one family member test positive for a deleterious genetic

alteration, that test may transform individuals or groups of people who are not sick into patients (Elliott, 2003). In short, should one or a few members of a family group show symptoms of a genetic disease or test positive for a genetic alteration associated with a particular disease or condition, the implications extend beyond that person to others in his or her family. For many people who are told that they have tested positive for a deleterious genetic alteration, significant questions may develop about whom to tell and what to relate. In many states, the law requires physicians to tell a patient with a genetic condition or a genetic alteration that increases the risk of developing such a condition that others in their kin group are also at risk and should be informed of that risk.

In 1995, the Florida Supreme Court entertained a case that raised important questions about a physician’s obligation to communicate information about a genetic condition. The court held that a physician’s obligation to provide information did not include an obligation to communicate directly with a patient’s relatives (*Pate v. Threlkel*, 1995). Heidi Pate initiated the case by suing her mother’s physician, Dr. Threlkel. The physician had treated Heidi’s mother for medullary thyroid carcinoma. Heidi, who had subsequently been diagnosed with an advanced form of the same condition, argued that had Threlkel warned her about the risk to her (in light of her mother’s diagnosis and the genetic character of the condition), she would have been diagnosed and obtained care early enough to achieve a cure. More specifically, Heidi argued that her mother’s physician had a duty to warn his patient’s daughter that she was at risk for developing the cancer with which his patient had been diagnosed. In effect, Heidi argued that Threlkel’s obligation to provide information extended beyond his patient to that patient’s children (and, presumably, to other close relatives).

Heidi’s claim suggest that a doctor’s patient group, at least for purposes of providing information about a genetic condition, extends beyond the individual patient to family members. It would, thus, seem to conflate the patient and his or her genetic relatives, at least in the specific context of medical care. The Florida Supreme Court, acknowledging a possible duty to warn, rejected the suggestion that the doctor was required to warn his patient’s relatives. The court explained:

If there is a duty to warn, to whom must the physician convey the warning? Our holding should not be read to require the physician to warn the patient’s children of the disease. In most instances the physician is prohibited from disclosing the patient’s medical condition to others except with the patient’s permission. See § 255.241(2), Fla. Stat. (1989). Moreover, the patient ordinarily can be expected to pass on the warning. To require the physician to seek out and warn various members of the patient’s family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus, we emphasize that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient. (*Pate v. Threlkel*, 1995, p. 282)

In a troubling twist on this conclusion, a New Jersey court—in a case not unlike *Pate v. Threlkel*—imposed on a physician precisely the sort of obligation that Heidi Pate had claimed, unsuccessfully, that Dr. Threlkel owed to her. Donna Safer initiated the case in question by suing Dr. Pack’s estate, the deceased physician who had treated her father, Robert Batkin, during his final illness. Almost 3 decades after Batkin died of a hereditary form of colon cancer, Safer was diagnosed with the same condition (*Safer v. Pack*, 1996). The case preceded the identification of any genetic alterations associated with colon cancer. However, the court presumed that physicians were, or should have been, aware of the hereditary character of the condition. Donna Safer, like Heidi Pate, argued that a physician was obliged to warn a patient’s child about a hereditary condition from which the patient suffered and for which the child was thus at risk. Donna was 10 years old when her father died. Thus, presumably the obligation at issue involved informing Donna’s mother of the risk. The mother, Ida Batkin, testified that she had not been informed about a risk to her children or even about her husband’s cancer diagnosis. She explained that Dr. Pack had described her husband’s condition to her as a “blockage” or “infection,” and that when asked about the possibility of a risk to her children, Dr. Pack told her “not to worry” (*Safer v. Pack*, 1996, p. 1190). Judge Keston, writing for a New Jersey appellate court, recognized the duty that Donna Safer had delineated. He explained that a “duty to warn of avertable risk from genetic causes, by definition a matter of familial concern, is sufficiently narrow to serve the interests of

justice” (*Safer v. Pack*, 1996, p. 1192). The court further asserted that a physician’s duty to warn a patient’s family members about the genetic component of a patient’s condition might be “owed not only to the patient himself but that it also ‘extend[s] beyond the interests of a patient to members of the immediate family of the patient who may be adversely affected by a breach of that duty’” (*Safer v. Pack*, 1996, p. 1992, quoting *Schroeder v. Perkel*, 1981, p. 65).

The judicial decision in *Safer* was soon limited by the state’s legislature, which provided that clinicians can reveal genetic information about a patient to that patient’s relatives only if the patient has consented or has died (Genetic Privacy Act, 1996). However, the case carries far-reaching implications for social constructions of family. In particular, it poses the image of family as an undifferentiated whole (from the perspective of genetic information). As a practical matter, this construction of family suggests that a physician’s patient may be a familial group rather than an individual. That suggestion, in turn, carries serious implications for understandings of confidentiality and privacy. Robert Wachbroit (1993) noted that asking, “Who is the patient?” may be more complicated than one generally assumes:

[I]f the idea of the patient were to include [a close genetic relative], then the health professional’s informing the [relative] of . . . genetic information [about the patient] would not constitute a breach of confidentiality. Indeed, one might argue that the health professional is not simply permitted to inform the [relative], but is actually required to do so, given the duty to disclose relevant medical information to the patient. (pp. 1401–1403)

In effect, Wachbroit’s suggestion (much like Donna Safer’s in her case against Dr. Pack) conflates the individual patient with his or her larger genetic family. Each individual in the group can be viewed as substitutable for each other because, from the perspective of DNA, they are fungible, or at least potentially so.

In practice, clinicians will surely distinguish between individual patients and familial groups. However, the notion of the patient as a group of people (joined by putative genetic similarities) could eventually transform rules about privacy and confidentiality that now focus on the individual person, not his or her familial group. That shift, even if initiated only with reference to

genetic information, could affect legal responses to privacy and could eventually affect modes of thinking about families more generally.

CONCLUSION: USING THEORY IN PRACTICE

In the late 20th and early 21st centuries, assumptions about family and assumptions about relationships in the world of health care have shifted in parallel fashion. In each social domain, choice and autonomous individuality have largely replaced fixed roles and communal hierarchy. Changing assumptions about family relationships and changing assumptions about relationships in the world of health care have facilitated, reinforced, and sometimes challenged one another. This review has examined three examples of these processes.

The following concrete examples are intended to explore the implications for practice. In particular, these examples suggest how awareness of and attention to assumptions about family relationships and about relationships in the world of health care can be of use to practitioners in resolving conflicts about health care. The two examples both involve patients asking for care that is at odds with clinicians’ recommendations and with family members’ wishes. In both illustrations, the goals of individualism (which, as noted earlier, privilege autonomy) conflict with the goals of community (which, as noted earlier, privilege paternalism and loyalty).

In the first illustration, an 82-year-old patient named Gertrude has rejected her physicians’ strong recommendation that her gangrenous leg be amputated. Gertrude’s doctors have concluded that without the recommended surgery, her chance of survival is very low. Gertrude’s husband, Jack, assumed that Gertrude would follow her doctors’ recommendations. He is now distraught to find that that is not the case. In fact, he has become quite angry at Gertrude. During most of Gertrude and Jack’s 60 years of marriage, Jack made the family’s important decisions.

The task of mediating the conflicts underlying this case may require hours of conversation and mediation (Dubler, 2011). Among other things, it would be important to explore the parameters of Jack’s anger. A professional (e.g., a social worker, a psychologist, a nurse, a hospital ethics committee) involved in this case should be able to identify the parties’ conflicting visions of the role that autonomy and paternalism

(viewed here as beneficence) play in shaping medical decision making for and/or by Gertrude. It would be useful to help the parties understand that their differences flow, at least in part, from their divergent views about the extent to which Gertrude's decision making should be shaped (if at all) by Jack's assumption that he is responsible for Gertrude and by the clinicians' discomfort at sacrificing beneficent care in the name of patient autonomy. It will be easier for all those involved to focus on the medical decision that must be made once they see that the intensity of disagreement among them flows as much from their divergent assumptions about who should decide as about what should be decided.

The second illustration falls under a subset of cases involving patients who refuse care recommended by their clinicians. In these cases, the patients involved seem to enjoy significant capacity, yet a capacity determination has been requested largely because the patient's medical decision does not seem rational to the clinicians. (It should not be assumed that clinicians who call for capacity determinations in such cases are simply attempting to exercise control. Rather, most would seem to fear that the patient will fare badly without the treatment at issue and either genuinely question the patient's capacity or see a capacity determination as the only way to protect a patient from a "bad" decision.) Imagine a patient, Bill, who refuses chemotherapy even though his physicians tell him that he has a 70% to 80% chance of long-term remission if he undergoes chemotherapy. Bill, age 23, saw his cousin (who was also a dear friend) die horribly of cancer, and he is unwilling to undergo the travails of treatment and then perhaps die anyway within a few years. Bill's siblings—a younger brother, Bob, and two older sisters, Jane and Ann—with whom he is very close, are now at odds with one another about whether to try to convince Bill to agree to chemotherapy. They have always gotten along fairly well, but Jane has proclaimed that she'll never talk with Bob again because she wants to convince Bill to try the treatment being offered, and Bob is adamant that Bill has a right to make his own decision without his siblings' interference.

Bill's case poses patient autonomy against clinician beneficence. Under the law, Bill, if deemed capable, has a right to refuse care. Yet at least two parameters of the case

demand careful consideration. The first involves assessments of Bill's capacity. The second involves the concerns of Bill's siblings and his clinicians, who want to provide what they consider good care. The conflict about Bill's care could be resolved by a determination (presumably well-intentioned) that Bill lacks capacity. This would be terribly hard on Bill. Alternatively, the conflict could be resolved by deeming Bill capable and autonomous and requiring his clinicians to cede authority without more discussion. This could leave the clinicians frustrated and uncomfortable. And neither of these approaches is likely to ease the anxieties of, and disagreements among, Bill's siblings. A better course, for everyone, would allow the parties (helped by a social worker, a hospital ethics committee, or some other professional) to explore the divergent assumptions about autonomy and beneficence that underlie the conflict. Then, most felicitously, Bill, if deprived of the power of autonomy, might at least understand the beneficent motives of his clinicians. And the clinicians, if unable to treat Bill as they would like, might, again most felicitously, understand Bill's assumptions and motives and thus respond to Bill's medical decision more sanguinely than they might otherwise respond. Bill's siblings would almost certainly benefit as well from this sort of approach to the conflict between Bill and his clinicians.

Understanding conflicting assumptions about autonomy and community (beneficence, in these cases) is not likely to obliterate underlying differences in approach. But identifying and revealing such underlying assumptions can help each party involved in cases such as Gertrude's and Bill's to more fully appreciate the others' viewpoints and perhaps even encourage those involved to reach a compromise that will give solace to everyone (e.g., waiting a few days, if that is possible, before making a definitive decision). In short, for family researchers and theorists, parallel (often synergistic) changes in the worlds of family and health care offer a wealth of data for exploring the social and cultural implications of shifting visions of personhood and of relationships. And for the clinician and other practitioners, changes in each domain offer a field of comparison, a laboratory of sorts, from which to contemplate the benefits and risks of changes in the other domain. This laboratory provides a locus for gaining insights

that may prove of great use in helping resolve disputes that implicate both family relationships and relationships among clinicians, patients, and patients' family members.

REFERENCES

- American Medical Association. (2001). *Opinion 8.081, Surrogate decision making—Code of Medical Ethics*. Retrieved from <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion8081.page?>
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (5th ed.). Oxford, UK: Oxford University Press.
- Bellotti v. Baird*, 443 U.S. 622 (1979).
- Buzanca v. Buzzanca*, 72 Cal. Rptr. 2d 280 (1998).
- Canterbury v. Spence*, 464 F.2d 772 (1972).
- Council on Ethical and Judicial Affairs. (2001). *Surrogate decision making* (Report 4-A-01). Retrieved from <http://www.ama-assn.org/resources/doc/code-medical-ethics/8081a.pdf>
- Deftos, L. J. (1997). Genomic torts: The law of the future—the duty of physicians to disclose the presence of a genetic disease to the relatives of their patients with the disease. *University of San Francisco Law Review*, 32, 105–137.
- Demos, J. P. (1986). *Past, present, and personal: The family and the life course in American history*. Oxford, UK: Oxford University Press.
- Dubler, N. D. (2011). See you out of court? The role of ADR in health care—A “principled resolution”: the fulcrum of bioethics mediation. *Law and Contemporary Problems*, 74, 177–198.
- Dworkin, G. (1988). *The theory and practice of autonomy*. Cambridge, UK: Cambridge University Press.
- Dworkin, G. (2003). Can you trust autonomy? *Hastings Center Report*, 33, 42–44.
- Eisenstadt v. Baird*, 405 U.S. 438 (1972).
- Elisha B. v. Superior Court*, 117 P.3d 660 (Cal. 2005).
- Elliott, C. (2003). *Better than well: American medicine meets the American dream*. New York, NY: Norton.
- Family Health Care Decisions Act. (2010). N.Y. Pub. Health L. §§ 2994-a to 2994-gg (McKinney Supp. 2011).
- Garrison, M. (2000). Law making for baby making: An interpretive approach to the determination of legal parentage. *Harvard Law Review*, 113, 835–923.
- Genetic Privacy Act. (1996). N.J. Stat. Ann § 17B:30-12, P.L. 1996, chap. 126. Retrieved from http://www.state.nj.us/health/irb/documents/nj_genetic_privacy_act.pdf
- Griswold v. Connecticut*, 381 U.S. 479 (1965).
- Grossberg, M. (1985). *Governing the hearth: Law and the family in 19th-century America*. Chapel Hill, NC: University of North Carolina Press and American Society for Legal History.
- In re G* (Children), [2006] UKHL 43, 1 WLR 230.
- In re Gault*, 387 U.S. 1 (1967).
- In re Storar*, 420 N.E.2d 64 (N.Y. 1981).
- Johnson v. Calvert*, No. X-633190, (Cal. App. Dep't Super. Ct. Oct. 22, 1990), *aff'd sub nom.*, Anna J. v. Mark C., 286 Cal. Rptr. 369 (Cal. Ct. App. 1991), *aff'd* 851 P.2d 776 (Cal. 1993), *cert. denied*, 114 S. Ct. 206 (1993).
- K.M. v. E.G.*, 117 P.3d 673 (Cal. 2005).
- Kristine H. v. Lisa R.*, 117 P.3d 690 (Cal. 2005).
- Levy, N. (2012, February). Forced to be free? Increasing patient autonomy by constraining it. *Journal of Medical Ethics*. doi: 10.1136/medethics-2011-100207.
- Maine, H. J. S. (1917). *Ancient law*. London, UK: Dent.
- Marvin v. Marvin*, 557 P.2d 106 (Cal. 1976).
- Matter of Baby M.*, 217 N.J. Super. 313, 525 A.2d 1128 (1987), *aff'd in part and rev'd in part*, 109 N.J. 396, 537 A.2d 1227 (1988).
- McGuire v. McGuire*, 59 N.W.2d 336 (1953 S.C. Neb.).
- Morone v. Morone*, 413 N.E.2d 1154 (N.Y. 1980).
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979, April 18). *Belmont report: Ethical principles and guidelines for the protection of human subjects of biomedical and behavioral research* [44 Fed. Reg. 23 192]. Washington, DC: Department of Health and Human Services.
- Novack, D. H., Plumer, R., Smith, R. L., Ochitill, H., Morrow, G. R., & Bennett, M. (1979). Changes in physicians' attitudes toward telling the cancer patient. *Journal of the American Medical Association*, 241, 897–900.
- Oken, D. (1961). What to tell cancer patients: A study of medical attitudes. *Journal of the American Medical Association*, 175, 1120–1128.
- Papke, D. R. (1999). Pondering past purposes: A critical history of American adoption law. *West Virginia Law Review*, 102, 459–476.
- Pate v. Threlkel*, 661 So.2d 278 (Fla. 1995).
- Safer v. Pack*, 677 A.2d 1188 (N.J. Super. 1996).
- Schloendorff v. Society of the New York Hospital*, 105 N.E. 92 (N.Y. 1914).
- Schneider, D. M. (1968). *American kinship: A cultural account*. Chicago, IL: University of Chicago Press.
- Schroeder v. Perkel*, 87 N.J. 53, 432 A.2d 834 (N.J. 1981).
- Schuck, P. H. (1994). Rethinking informed consent. *Yale Law Journal*, 103, 899–959.
- Segadelli, J. M. (2010). Access to justice—Minding the gap: Extending adult jury trial rights to adolescents while maintaining a childhood commitment to rehabilitation. *Seattle Law Review*, 8, 683–721.

- Shalev, C. (1989). *Birth power: The case for surrogacy*. New Haven, CT: Yale University Press.
- Sherer v. Sherer*, 292 S.E.2d 662 (Ga. 1982).
- Shiffirin, S. (1980). Government speech, *UCLA Law Review*, 27, 565–655.
- Swanson, K. W. (2012). Adultery by doctor: Artificial insemination, 1890–1945. *Chicago-Kent Law Review*, 87, 591–633.
- Tinker v. Des Moines Independent Community School District*, 393 U.S. 503 (1969).
- Tooley v. Provident Life & Accident Insurance Co.*, 154 So. 2d 617 (La. Ct. App. 1963).
- Wachbroit, R. (1993). Rethinking medical confidentiality: The impact of genetics. *Suffolk University Law Review*, 27, 1391–1409.