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Moving Past Individual and “Pure” Autonomy: The Rise of Family-Centered Patient Care

Lee H. Igel, PhD, and Barron H. Lerner, MD, PhD

Over the past half-century, the central relationship in Western medicine—between patient and physician—has shifted from paternalism, in which the doctor decides what is in the patient’s best interest, to patient-centered care, in which decisions that support an individual patient’s needs, goals, and values are made in partnership. Now, a [family-centered approach](#) is contributing to the emergence of what might be called “post-autonomy” medicine. The goal here is not to restore decision-making power to clinicians; rather, it is to develop a more sophisticated version of self-determination—one that accounts for how autonomy occurs within specific social and cultural contexts. So, what are the merits and drawbacks of autonomy-based thinking in medical decision making today? What are ethically relevant consequences of making patients *and* families participate in this process?

Evolving Conceptions of *Autonomy*: From Individualist to Relational

Beginning in the 1970s, following a series of scandals in medicine—such as the revelations of the Nazi medical experiments during the Second World War and the United States Public Health Service’s Tuskegee Syphilis Study—and in the context of other movements toward equality, including civil rights and second-wave feminism, Western medicine began shifting away from paternalism [1, 2]. The long-standing model based on physician authority and passive patient acquiescence gave way to one that put an individual’s right to self-determination front and center. With the [prioritization of autonomy](#)—especially “pure autonomy,” in which the patient’s self-determining judgment prevails [3]—came greater attention to the patient’s and subject’s informed consent and advance directives that sought to ensure that the clinician would follow the patient’s wishes, rather than merely relying on his or her own views about a patient’s best interests. Shared decision making models, which became more prominent in the 1990s [4], have advocated more of a partnership between physician and patient but have not questioned the patient’s primary role in making health care decisions.

More recently, the emphasis on the patient as an individual acting separately from his or her loved ones has been questioned. This shift emerged in the mid-1990s and into the 2000s in the form of *relational autonomy* [5, 6], an outgrowth of the feminist movement’s attempt to meet the challenge of balancing individual choice and action within the push and pull of society. One ethically relevant consequence was a growing emphasis on

family members' input in decision making, based on their intimate knowledge of the patient. This development intertwined medicine and family, two age-old institutions that provide care to loved ones [7].

Technological and political factors promoting recognition of the important roles of family members. The transition to a "post-autonomy" medicine is a significant social transformation that can be explained in some measure by health care reform legislation that has alternately favored government-sponsored and privatized programs, with both physicians and patients having abdicated increasing numbers of health care decisions to health care organizations. It can also be explained in part by the associated frustrations over cost of and access to care on the part of physicians, patients, and family members. Finally, the literature about both the changing nature of health care delivery and human decision making [8-10] suggests that the traditional physician-patient relationship has disintegrated and been replaced by a "vast array of complex interrelationships among those who receive, provide, and finance care" [11]. This literature also helps explain growth in reliance on family involvement. In essence, the complexity of the system, with its demands for efficiencies and pooling of expertise, combined with the stresses and strains of understanding medical issues and treatment options, can lead patients to feel overwhelmed and attempt to resolve those feelings by seeking harbor in family input.

Related to this complexity of relationships is the broad dissemination of medical information through the Internet, mobile applications, and, more widely, the media [12]. This democratization of knowledge makes it hard to imagine family members not being involved in the health care decision-making process, in ways that are usually helpful (but occasionally intrusive) [13]. That means decisions about health care, which can be scientifically and emotionally complex to begin with, now require an even greater dependence on the skills of collecting, organizing, analyzing, and communicating information [14]. Relatives and friends can help their loved ones effectively and reliably manage some available literature and information [15].

Longer life expectancy. Another factor promoting the growing importance of families in health care decision making is the increase in average life expectancy at birth to 78 years of age in high-income countries [16], partly drawn from the technological ability to stave off certain causes of death for individuals who have access to that technology. This development has contributed to increased implementation of responses to technology, such as advance care planning, do-not-resuscitate (DNR) orders, and the use of health care agents and proxies to make decisions for incapacitated patients. While advance care planning does not always yield the result of patient and family wishes being honored, there is evidence that family involvement and presence in end-of-life care discussions can improve quality of care [17, 18].

Family involvement as beneficial and desirable. The fact that family involvement is often the default in advance care planning [19] suggests that the notion of family participation, to some extent, has existed all along. Some might assume that family members have the most regard for the values, wishes, and welfare of the patient. Another closely related assumption is that family members' involvement in the shared decision making process can be helpful, based on the belief that personal knowledge and experience are beneficial when serving as surrogate decision makers on behalf of incapacitated patients [20, 21].

Shifting medical culture. There are additional reasons for the growing role of relatives in medical decision making. These include shifts in thinking about: (1) culture and ethnicity, (2) the existing legal climate, and (3) the "best interests" standard.

In recent decades, there has been substantial growth in the use of both hospice and palliative care [21]. Both take a holistic approach to quality of life and continuum of care and encourage the participation of families in clarifying treatment goals, especially at the end of life [22, 23]. And as ethnic diversity has become a defining feature of the United States, the collectivist, family-centered values and perspectives of many different cultural groups have increasingly intersected with Western medicine [24, 25]. *The "family-centered care" that Western medicine regards as something new and different is actually an enduring value in many cultures. It is the norm and a tradition, for example, in [some Asian cultures](#), which place emphasis on strong family bonds and networks [26-28].*

Medical culture seems to be evolving in other ways, too, as suggested by apparently unsettled conceptions about relationships between individual and relational autonomy. Although courts of law have rendered legal decisions with policy implications, they have not often resolved the emotional and moral issues that are associated with—and usually underlie—some of the cases in question. Consider, for example, the 1980s case of Claire Conroy, in which the Supreme Court of New Jersey ruled that artificial feedings, like other life-sustaining treatments, concern the patient's best interests and that shared decision making by physicians and surrogate family members is an inadequate safeguard for an incompetent patient [29]. Given the close relationship between autonomy and decision making across the range of consent and refusal, respect for autonomy may too often be given disproportionate weight relative to other important ethical concepts, such as nonmaleficence, beneficence, and justice [3]. And, despite the prevalence of written directives, power of attorney documents, religious tenets, recorded patterns of prior medical treatment, and other expressions of autonomy-based values in clinical practice, there are questions about the degree to which this information actually expresses a patient's values. As the highly-publicized case of Terry Schiavo showed, conflicts of interest based on family dynamics and individuals' emotions can and do arise, and differences of opinion among family members about the patient's values and wishes can have a significant—and potentially deleterious—impact on courses of treatment and care [30].

Part of the explanation for this phenomenon is that human nature, despite individuals' best intentions, is often fraught with errors that influence how accurately people access a memory, recall an episode, and activate a "cognitive scene" for a particular purpose, especially when the circumstances are intense or complex [31]. A patient's stated wishes, family members' recollection of such, and our assessments of what others value can be similarly flawed. For example, the research on "[substituted judgment](#)," in which family members of an incapacitated patient are surveyed in an attempt to understand the incompetent patient's prior preferences, shows it is often not nearly as accurate as most people might imagine—or prefer—it to be [32]. In addition to incorrect inferences being made, the decision may be further complicated by cognitive biases, such as the "hot-cold empathy gap," in which people often "mispredict" and do not fully appreciate how they and others will think, feel, and behave across different affective states and environments [33, 34]. As a result, "best interests" standards, often involving family input, are increasingly being incorporated due to concerns about the inability of family to generate reliable substituted judgments [35, 36].

Conclusion

Despite the imperfections of implementing best interest and substituted judgment standards of decision making, allopathic health care still embraces family involvement and remains rather suspicious of "pure" autonomy. Signs of this appear in US-based research, such as the Institute of Medicine report, *Crossing the Quality Chasm*, which advocated for increased transparency so that patients and their families could make more informed health care decisions [37], and statements from nonprofit organizations promoting family-centered care [38]. They also appear in the bioethics discourse, which includes the argument that respecting the patient autonomy (in terms of the direction of medical care) can involve the influence of others, such as family members, as well as physicians [39, 40].

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Lee H. Igel, PhD, is a clinical associate professor in the Tisch Institute for Sports Management, Media, and Business and an associate in the Division of Medical Ethics at the Langone Medical Center at New York University in New York City.

Barron H. Lerner, MD, PhD, is a professor of medicine and population health at the Langone Medical Center at New York University in New York City and is the author, most recently, of *The Good Doctor: A Father, A Son and the Evolution of Medical Ethics* (Beacon Press, 2015).

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