



Relational autonomy and the clinical relationship in dementia care

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Abstract

The clinical relationship (or doctor-patient relationship) has been underexplored in dementia care. This is in part due to the way that the clinical relationship has been articulated and understood in bioethics. Robert Veatch's social contract model is representative of a standard view of the clinical relationship in bioethics. But dementia presents formidable challenges to the standard clinical relationship, including ambiguity about when the clinical relationship begins, how it weathers changes in narrative identity of patients with dementia, and how the intimate involvement of family fits alongside a paradigmatically dyadic relationship. Drawing on work in recent feminist theory, a critique is offered of the standard clinical relationship in bioethics as underwritten by an individualistic conception of autonomy. An alternative view of the clinical relationship in dementia, one that embraces a relational account of autonomy, is put forward.

Keywords Doctor-patient relationship · Autonomy · Dementia · Caregivers · Family

Introduction

The dementia journey for many patients and families is long and winding and much of it happens outside the medical context, particularly early on in the disease. Changes in cognitive abilities, daily activities and responsibilities, and interpersonal interactions are experienced mostly in the home. But patients also have a relationship with a physician (or other clinical provider). Patients and clinicians come together to make decisions about diagnostic workup treatment, coordination of social and institutional care, advance care planning, and end of life interventions.

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Yet, despite being at the center of many of these important decisions, the clinical relationship in dementia draws little attention.

This is particularly evident in bioethics discussions surrounding dementia. Dementia raises a host of ethical issues, including those related to disclosure of diagnosis, capacity to drive or live independently, testing for genetic predispositions, and advance directives for aid in dying. But, in contrast to other areas of medicine, the clinical relationship in this context plays an undersized role in such discussions. Instead, appeals to dignity, beneficence, precedent autonomy, interests, welfare, and other concepts predominate.

In this paper, I argue that the lack of attention to the clinical relationship in dementia is not so much an oversight as it is a feature of how the clinical relationship has been articulated and understood in bioethics. In the first section, I present Robert Veatch's early and influential social contract model as a representative example of the standard view of the clinical relationship in bioethics. Then, I offer reasons why dementia seems to present formidable challenges to the standard clinical relationship. Drawing on work in recent feminist theory, I offer a critique of the standard clinical relationship in bioethics as underwritten by a problematic, individualistic conception of autonomy. Finally, I highlight how a reconceptualization of the clinical relationship based on a relational notion of autonomy could add value to discussions of dementia in medicine and bioethics.

The clinical relationship in bioethics

The clinical relationship (previously called the doctor-patient relationship) has been a fixture of modern bioethics. Various proposals have been offered to explain the significance of the clinical relationship [1–12]. Some proposals represent thick, normative accounts of the relationship, placing it at the center of biomedical ethics. For instance, Edmund Pellegrino [9] argues that the clinical relationship resides at the intersection of “the fact of illness” (i.e., that the patient experiences an existential threat and is as such vulnerable), the “act of profession” (i.e., a promise of clinicians to try to heal), and an “act of medicine” or “act of healing” (i.e., a scientifically sound action that accords with the patient's values). On his view, the clinical relationship has a kind of *sui generis* normative primacy. On the other end of the normative spectrum, and more commonly, the clinical relationship has been offered as a central, though limited concept, supporting a thin set of moral duties and concepts (e.g., confidentiality, veracity). Robert Veatch's view of the clinical relationship exemplifies this kind of account.¹

In his “Models for ethical medicine in a revolutionary age” [14], Veatch argues that the clinical relationship has been understood historically as conforming to one

¹ Veatch initially called this the doctor-patient relationship, but like many others, he came to change his terminology to recognize the primacy of the patient within the relationship as well as different types of professionals who enter into relationships with patients. Ultimately, Veatch settles on the term “patient-provider relationship” [13].

of three models—engineering, priestly, and collegial. In an engineering model, the physician is a technician, a “plumber” of sorts, capable of laying before patients a menu of value-free medical options. In a priestly model, the patient defers decision-making to the physician, treating the physician not just as a technical expert but as a moral expert as well. And in a collegial model, the patient and physician are “pals”, with mutual loyalty and goals, and with perfectly aligned shared interests. Veatch finds fault with each of these models in so far as they fail, in different ways, to share “ethical authority and responsibility” between patient and clinician [14]. In the engineering model, the physician lacks “moral integrity” by trying to subsume morally freighted medical decisions under “technical” expertise. In the priestly model, the patient abdicates responsibility for making morally weighty decisions by deferring these to a “priest” [14]. And he rejects the collegial model as pretending to offer an “uncontrolled and false sense of equality” between patient and clinician [14]. Drawing on both religious and liberal philosophical traditions and a rejection of a paternalistic Hippocratic ethics (which he thinks properly belongs on the “ash heap of history” [14]), Veatch argues for an alternative model of the clinical relationship—what he calls “the contractual model” [14–16].

For Veatch, the moral foundation of the clinical relationship is found within a “triple contract” [16, 17]. The first level of this triple contract is a hypothetical contract among members of society whereby the principles and basic institutions are implicitly agreed upon (akin to Rawls’ theory of justice). At a second level, a society contracts (often implicitly, but sometimes explicitly) with physicians as professionals to establish basic ground rules for the practice of medicine, including the role of physicians (e.g., as monopolistic prescribers of medications²). Finally, at a third level, individual doctors and patients contract (again, implicitly or explicitly) with each other over specific provisioning of health care (e.g., patients hiring or firing their physicians).

For Veatch, all three contracts give shape to the clinical relationship. The first level contract includes an acknowledgement that the clinician practices in a society that cannot presume a substantive theory of the good (in contrast, say, to the Hippocratic physician [15]). Clinicians cannot presume which medical goals patients value or prioritize; for instance, some may value longevity, others quality of life. Moreover, clinicians cannot presume how patients will trade off medical versus non-medical goods; some may prioritize religious commitments (e.g., Jehovah’s witnesses and blood transfusions) or economic considerations over medical goals (e.g., declining expensive treatment in order to preserve family assets). The second level contract involves the negotiation of the role of the medical profession within society. Whatever specific duties the clinician has derive from this arrangement with the

² This monopolistic power has evolved since Veatch’s early formulation of the triple contract view but continues to be a feature of the medical profession in many societies.

state.³ But it is Veatch's third level contract that gives the most definition to his view of the clinical relationship.

For Veatch, patients and clinicians are not just parties to the third level contract, they are equal parties. He explicitly rejects views of inherent patient vulnerability [18], and instead argues that patients are experts in knowing their own "beliefs, values, preferences, cultural commitments, and idiosyncratic inclinations" [15]. This patient expertise is no less important than the medical expertise that physicians and others bring to their side of the contract. It is not just that some or all physicians happen not to know these facts about patients; clinicians, particularly physicians, are not positioned to possess the kind of expertise that patients inherently possess.

The good of the whole person must include expertise having nothing to do with anything physicians have learned in medical school or professional practice. It requires art history, spiritual counsel, financial planning, and expertise in plumbing. More critically, it requires judgments about how much of one's resources should be devoted to these areas and therefore diverted from organic well-being. Physicians are in a uniquely poor position to help patients make these decisions designed to promote overall well-being. They cannot be expected to be wholistic healers. [18]

This view of moral epistemology has concrete, and controversial, implications for the clinical relationship as Veatch understands it. Clinicians should act, not as healers, but as "advocates or assistants in the medical realm" [15]. They should not recommend treatments, because doing so would presume, at some level, a full knowledge of the patient's best interest, a knowledge that clinicians cannot, on Veatch's view, possess [15].

Veatch's view exemplifies a kind of thin normative account of the clinical relationship. While the clinical relationship may be an irreducible part of the distribution of health care to individuals (after all, someone has to be the intermediary between the patient and health care resources), the relationship is not viewed as the first place to look for understanding ethically important decisions in medicine. Moral principles or concepts take precedence because the normativity of the clinical relationship is taken to be second order, drawing its moral importance from sources external to the relationship, such as Veatch's social contract theory.

³ For Veatch, the point is not that the interests of the state always trump (after all, there may be deontological constraints, e.g., principles of veracity or confidentiality arising from the first level contract that put additional limits on the contract between society and the medical profession), but just that the duties of the physician fall out of, and are exhausted by, this contract and do not have an independent source in the clinical relationship itself [13].

Dementia and the clinical relationship

The paradigmatic clinical relationship is one in which two people come together and voluntarily interact for some purpose related to health. Not all interactions between patients and clinicians fit this paradigm neatly. Dementia is one such example. Dementia is understood as a chronic or progressive syndrome of cognitive decline often affecting capacities for memory, orientation, comprehension, language, and judgment, among others. Individuals develop difficulties with daily functioning and can experience hallucinations, delusions, or other psychiatric symptoms. Dementia is a common disease affecting fifty million people worldwide [19]. As a cause of mortality and morbidity, it is a frequent topic around which clinicians and patients (and family) interact and make decisions. But various kinds, degrees, and manifestations of cognitive impairment complicate how, why, and when this interaction occurs. The paradigmatic voluntary meeting of the minds between patients and clinicians often does not occur in dementia. The reality is something short, sometimes far short, of the idealized picture of two individuals meeting, intentionally forming a relationship, and pursuing together some desired end (e.g., health, well-being).

There are ways in which this deviation from the ideal complicates the picture of the clinical relationship in dementia. The first of these relates to ambiguity as to whether a clinical relationship is established at all between a patient and clinician. In general, a clinician and patient with dementia meet under non-ideal circumstances. In some cases, the patient does not want or feel they need an evaluation. Problems with cognition, particularly memory, are often brought to the attention of a clinician by others, usually family, rather than by the patient themselves. This is unsurprising given that people with amnesic forms of dementia, in particular, often do not remember what they do not remember, and hence denial of problems is common (the clinical term for which is “anosognosia”). Sometimes family members persuade a loved one to get an initial evaluation, or even manipulate them to do so, but find that conversations about the need for evaluation are forgotten by the time of the appointment. This leads to conflict between patient and family at the outset about the very purpose of the evaluation, leaving the clinician and patient in a kind of relationship limbo.⁴ When cognition is more than modestly impaired, patients may not even understand the purpose of the evaluation [20]. Thus, as Blass notes, there can be an “absence of a mutually shared agenda for the physician–patient interaction” [21].

The problem can be a disagreement about what is desired (e.g., a family wanting an evaluation and a person with dementia not wanting this) but the disagreement often runs deeper. The patient and family interpret the past differently. They disagree over facts about the world. For instance, where a family member notes forgotten conversations, changes in driving patterns, or difficulties with new technology, the person with dementia denies such conversations have occurred (or how

⁴ This is not dissimilar to psychiatric evaluations in which the determination of capacity is a catch 22. Though everyone has a right to refuse medical evaluation, so long as they have the capacity to do so, the only way to determine if this capacity is present is to conduct a capacity evaluation.

they transpired), points to problems with other drivers rather than themselves, and laments poorly designed or explicated technology. And unlike in other contexts, the assumption that clarifying the facts of the matter will resolve the issue does not hold. Often no “aha moment” is in the offing once facts are laid bare. Rather, as Blass notes:

Full participation in any medical evaluation is generally predicated upon an understanding of and consent to the evaluation process itself, a mutual agreement as to the reason for the evaluation and the nature of the clinical problem to be addressed, as well as an understanding of and ability to consent to the recommended treatment. These aspects of participation may, to a greater or lesser degree, be lacking in the initial dementia assessment. [21]

Thus, a legitimate question is raised about whether it even makes sense to talk about the establishment of a therapeutic relationship absent agreement on facts central to the diagnosis itself. Or put another way, the effects of dementia on abilities needed to form relationships puts the very ontology of the clinical relationship into doubt.

An additional challenge for the standard clinical relationship in dementia comes from concerns that dementia leads to changes of identity in individuals with dementia. People with dementia change their preferences and even their values over the course of their disease. Some have argued that these changes can be so substantial as to constitute a change in identity. Such a change would have implications, for instance, for how advance directives are interpreted [22–24]. Should an advance directive be honored if a person whose name is attached to it is no longer the person, in some meaningful sense, as the person who previously formulated it? The question of identity leads to further questions about how best to understand personhood [25] and moral agency [26] in dementia. Putting some of these deeper questions aside (e.g., whether the identity at issue is metaphysical or narrative or something else), just acknowledging that dementia can lead to a meaningful identity change of some kind has implications for the clinical relationship.

No two clinical relationships are the same. A relationship between a patient and a clinician is a unique reflection of what each patient (and clinician) brings to the table. A person’s preferences, traits, values, commitments, and histories—in some sense their identity—determine the nature of their particular clinical relationship. A claim to the uniqueness of each clinical relationship is rather straightforward when talking about different patients. No one patient’s clinical relationship can stand in or substitute for another’s. But the question about identity change in dementia raises an interesting and a difficult question: if a person’s identity changes as a result of dementia, what does this mean for the clinical relationship? Is the relationship of a clinician and a patient formed early in the course of the disease the same as that between the clinician and patient later in the disease?

A third challenge for the standard clinical relationship relates to deciding whether family or others are part of or external to the patient-clinician relationship. The standard clinical relationship is dyadic: patient and clinician.⁵ Yet, the care of people with dementia always involves others, usually in a progressively more intimate way. Family or others provide collateral information to aid in the initial diagnosis, information that usually the patient cannot, or is even reluctant to provide, for instance, about specific memory lapses, or errors made in activities of daily life (e.g., vehicle accidents, forgotten bills). Over time, family or others collect and provide information to a patient's clinician necessary for accurate evaluation of disease progression and care needs. Is someone helping to remind or give medications at home, manage finances, drive or coordinate travel, obtain and prepare food, or effectively use technology? If so, how much help is being provided and in what ways? How has this changed over time? The "non-clinical relationship" between the clinician and family becomes increasingly important to the well-functioning clinical relationship between patient and clinician.

The level and trajectory of family involvement puts pressure on the adequacy of thinking about the separateness of these two relationships. As the family speaks more and more for the patient at clinic or hospital visits, they provide a substitute for the content once provided by the patient. At the same time, families provide information about how they are experiencing the patient's dementia. The value of this information, intended to improve the care of the patient, becomes increasingly difficult, in many cases, to separate from its contribution to the needs and experience of the family. The two become intertwined. For instance, an exhausted, sleep-deprived caregiver may be more likely to sleep through their spouse wandering out of the house at night but also themselves be more at risk for depression and other comorbidities.

Given all this, perhaps it is unsurprising that dementia plays a rather limited role in the articulation of the clinical relationship in bioethics. Again, Veatch illustrates this well. Veatch is a prolific writer, with at least 600 publications touching on almost every topic in bioethics. Yet, Veatch rarely talks about dementia or the clinical relationship in the context of dementia.⁶ He makes limited references to "advanced Alzheimer's disease" or the "severely demented" [28] or the "senile" [18]. His limited references to dementia or use of dementia-related case examples (e.g., Shirley Dinnerstein) are introduced in service of making a distinction between once competent and never competent adults who need decisions made on their behalf [29]. Beyond this, dementia is largely absent from his writings.

⁵ It is worth noting that there are other examples that run against the dyadic paradigm, including care of children, adults with developmental disabilities, individuals with disorders of consciousness, and some kinds of psychiatric illness.

⁶ This does not imply that just because dementia does not feature prominently in Veatch's work that he did not take it to be important. One might credit Veatch with contributing to a movement in bioethics and medicine that improved the lives of many groups previously disempowered in medicine and society, including those with dementia. Though he talks little about dementia specifically, he does discuss cognitive disability [27].

While the challenge discussed above may explain why the clinical relationship plays such a limited role in bioethics discussions about dementia, an alternative explanation is worth considering. Perhaps the reason has less to do with dementia and the limitations it imposes and more to do with how the clinical relationship itself has been traditionally envisioned. In what follows, I argue that individualistic conceptions of autonomy in bioethics (such as those that underwrite Veatch's view) might deserve more of the blame. Teasing out this idea may help clear the way to a view of the clinical relationship more suited to the challenges of dementia.

Clinical relationship and the relational critique of autonomy

Autonomy and the principle of respect for autonomy have been at the center of modern bioethics scholarship [30, 31]. Autonomy is generally understood to be the exercise of or the capacity to exercise self-governance such that one can live according to values and reasons that one takes to be one's own and not those imposed by others. Early work in bioethics, largely inspired by a Kantian view of personhood, interpreted autonomy in individualistic terms [16, 32]. Human beings are taken to be, in the ideal, free and independent agents, exhibiting self-sufficiency, self-determination, and freedom from constraint from others [33]. "The ideal of self-sufficiency rests on the idea that a good life is a life in which we do not need the help or support from anyone in meeting our needs and carrying out our life plan." [34]. More broadly, autonomy understood in terms of independence and individual rational agency has been central to the project of determining who owes what to whom in medicine [35, 36].

Such self-sufficiency notions of autonomy have come under criticism for not recognizing the deeply social and relational nature of persons. Feminist philosophers [37–39] and others challenge the underlying presumptions about this idealized picture of an "antecedently individuated" subject [40]. People are always "socially embedded" [41] and interdependent [39]. The "encumbered self" [42] is not an unfortunate deviation from an ideal, but a fact about what constitutes being a person living among others. Dependency and "patiency" are basic features of human experience [35], not just a state that children, older adults, or those with illness or disabilities find themselves in, but a spectrum of experience that all inhabit to various degrees at varying times [43].

This critique of autonomy has implications for the clinical relationship. As Donchin argues, the "standard" view of the clinical relationship is based on an idealized picture of rational, independent, autonomous patients and physicians.

Its standard formulation relies on an idealized image of the rational patient who calculates from a list of social goods and freely chooses among them. The physician's concern with the particulars of such a patient's life is limited to the bearing these particulars have on the amount of information she is obligated to disclose. Implicit in the model is an image of the kind of physician-patient encounter most likely to arise in acute illness where, it can plausibly be claimed, physician and patient meet as independent contractors. The model

patient in such accounts is typically a male in the prime of life who meets the physician as his intellectual and moral equal. The physician is ideally an independent agent too, perhaps initially reluctant to acknowledge the patient's moral right to decision-making authority, but otherwise free to act without external constraint. They meet episodically to confront the challenge of disease. Their relationship is structured around the need to decide on a course of treatment. Once the decision is made and implemented and the patient is restored to health, they go their independent ways again. Other autonomy-making considerations can be disregarded. The context within which care is provided (patient control over the conditions of care, and the ramifications of the decision for the patient's life projects) fades into the background. So do the disruptive effects of the patient's illness on the life plans and projects of family members who are expected to provide care until the patient can resume normal activities again. [44]

The standard picture of the clinical relationship, thus, is one that takes as the ideal a pair of independent and self-sufficient actors, patient and clinician, negotiating about medical decisions.

The relational critique of autonomy hints at why this picture of the clinical relationship is problematic. The standard picture of the clinical relationship presumes that the interdependencies of patients (and physicians) can and should be abstracted away when thinking about the clinical relationship. After all, if the idealized participants in the clinical relationship are self-sufficient and independent patients and clinicians—and more self-sufficiency and independence is the goal of the relationship—then interdependency becomes a deviation from the ideal, something not just to be tolerated but avoided. But if the relational critique of autonomy is correct, then this picture of the clinical relationship too is suspect. Dependency, vulnerability, cognitive or physical limitations, and disability are not just common but defining of how patients and clinicians encounter each other. Who is at the patient's side? Whom do patients live with or near? Whom do they rely on and for what? Who provides physical, emotional, or financial support? How are joys and burdens shared? Who provides back up to primary caregivers? Who does a patient choose to be their future surrogate? What organizations or institutions do patients rely on or contribute to? The answers to these questions are not just relevant to medical discussions, they are central to them.

Toward a relational clinical relationship in dementia care

An understanding of autonomy as relational may offer purchase on some of the challenges facing the standard clinical relationship. A relational approach to autonomy, for instance, will be less concerned with when relationships start and more concerned with how relationships evolve over time (e.g., how autonomy is shared). People find themselves in relationships. While the origin story of a relationship is not unimportant (e.g., how a person becomes a parent, a friend, a spouse, or a patient),

what typically matters more to understanding the relationship is how its constituents grow together over time. What are the many seemingly inconsequential decisions that sustain the relationship over time, that make it the relationship that it is?

This is important to keep in mind in dementia care. The patient who first comes to be evaluated is coming with a backstory. They have already been misjudging reality, remembering things that did not happen or forgetting things that did. They have already been experiencing a mismatch of the way they think things are and the way that others do. They are failing to accomplish things they want to. Given this background, what matters for the clinical relationship in dementia is not a stable and rational agreement on a set of facts. Rather, what affixes the clinical relationship within a person's life is that it fits into or grows out of a network of caring practices that are already part of how the patient gets along in the world. Caring practices are there to catch people with dementia when they fail. Spouses attend clinic visits to chime in or take notes, double-check bills, co-pilot in automobiles, answer questions in social situations, and so on. Friends bring in forgotten garbage cans, deliver groceries, or pretend not to notice repeated questions to save embarrassment. And clinicians are there to elicit histories and to evaluate often slipping cognitive capacities. They are there to inform patients and family about progression, offer therapies, and connect to social or other resources. Clinicians are one thread in the web of caring practices in dementia care.

A view of autonomy as fundamentally relational provides a different perspective on the problem of identity change in dementia. Hilde Lindemann has argued that one of the principal things that loved ones do for those with dementia is "hold" them in personhood. She argues that families do "the work of preserving, maintaining, and nurturing people" by telling and retelling stories about who the person with dementia is [45]. Understanding the changes in identity in dementia in this way offers an alternative view of the clinical relationship amidst the changes undergone by the person with dementia. The purpose of the clinical relationship is not to prop up an individualistic notion of the patient's autonomy, but to support the patient's relational autonomy. The best way to do this, in many cases, is to support the efforts of family and caregivers to hold patients with dementia in their identities.

What might a clinical relationship more attuned to relational autonomy look like? Much more will need to be said than can be provided here. But one thing it might require is a shift away from a strictly dyadic picture. Acknowledging that the clinical relationship is just one thread in a larger web of care practice for people with dementia (e.g., family, religious or community organizations, or social support services) does not diminish its importance. The clinician has a central role in keeping this support structure functioning and aligned. That said, the clinician's role within this scaffolding may need to shift, in some cases, away from a unitary focus on the needs and interests of the individual patient and toward caring for the relationships in which patients are enmeshed. Such a shift will feel both natural, particularly to families who care for those with dementia, and perhaps a little revolutionary in so far as it runs against the current of clinical practice based on an individualistic conception of autonomy. The clinical relationship is important in dementia care and a relational understanding of it may be an important step to acknowledging this.

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