



## A Feminist Bioethics Approach to Diagnostic Uncertainty

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diagnosis is always provisional in a more fundamental way than most other diagnoses in medical practice.

It's for this reason that I disagree with the practical implications of O'Leary's argument demanding clarity about the need (or not) for biological care. In ideal circumstances, clarity about the need (or not) for biological care is preferred. But in the case of psychogenic diagnoses, the lack of robust support for the diagnosis, the warranted epistemic humility about the diagnosis, preclude such clarity. When a practitioner attributes MUS to psychogenic causes, this attribution is uncertain in fundamental ways noted in the preceding. As a result, the practitioner cannot, with a high degree of confidence, determine that a patient does not need biological care. At the same time, the practitioner has some reasons to conclude that the patient does not need biological care. To make an appropriately epistemically humble claim, the practitioner should not offer clarity to a patient about whether or not the patient needs biological care when the conclusions of medical science don't support it.

The implication of my disagreement with O'Leary is more strategic than fundamental. I share with O'Leary concerns about the gravity of the problem of MUS and psychogenic diagnoses, the likely overconfidence in psychogenic diagnoses, and the historic (and likely continuing) sexism in psychogenic diagnoses. The immediate needs regarding practitioner confidence in and communication of psychogenic diagnoses, as I see it, involve two complimentary goals.

First, a positive marker for psychogenic diagnoses: As O'Leary points out, there are limits to the quality of the research into erroneous psychogenic diagnoses. Rather than looking, as previous studies have done, at whether an alternative diagnosis has been given to the patient, future research should focus on distinguishing patients for whom nonbiological treatments were and were not effective at treating their symptoms. Given the tools of registries and large data sets, it sits within the grasp of medical science to identify the common characteristics across these groups. By providing robust demonstrations connecting particular patient characteristics with effective and noneffective nonbiological

treatment, medical scientists could provide practitioners with good reason to be confident in identifying the patients that psychogenic diagnoses will help.

Second, in the meantime, practitioners should incorporate strategies for communicating uncertainty while making clear their diagnostic perspective. One temptation will be to maintain vagueness about whether or not the practitioner believes there may be a psychogenic diagnosis. As O'Leary points out, this temptation may result from concerns about usurping of patient autonomy. Such vagueness, however, is more likely to undermine patient autonomy than protect it. When a patient is not clearly informed about a practitioner's reasons for recommending a certain course of action, that patient's ability to be self-determining in any informed sense is limited. The patient may simply trust the practitioner: call it "deferential autonomy." In itself, this is not problematic. By being unnecessarily vague about their perspective, however, practitioners keep patients in the dark about the grounding of their perspective and the uncertainty of their diagnosis. They preclude the informed autonomous judgment of patients. Instead of turning uncertainty about psychogenic diagnoses into a vague diagnosis with vague notions of confidence, practitioners have a responsibility to make clear their diagnosis to patients, and, at the same time, to be epistemically humble about it. ■

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# A Feminist Bioethics Approach to Diagnostic Uncertainty

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In addressing the lack of attention paid to the significant clinical and ethical risks involved in the context of

diagnostic uncertainty, O'Leary (2018) argues that "no area of that oversight is more clearly problematic than

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when psychogenic diagnosis is entangled with an assumed lack of autonomy in women" (9). This is due largely, O'Leary argues, to the *prima facie* assumption that medically unexplained symptoms (MUS) are "hysterical" in origin. That is, what is known about MUS in the context of Western biomedicine comes via its association with the nineteenth-century gendered diagnostic construct of hysteria. According to O'Leary, the infantilization of hysteria patients during this time manifested in a "doctor knows best" mentality that is patterned in current medical practices involving MUS. For this reason, O'Leary insists that bioethical engagement with MUS must occur through considerations to gender. I agree and offer a friendly extension of O'Leary's work by proposing a feminist bioethics approach to diagnostic uncertainty rooted in relational autonomy and a politicized understanding of the power imbalances and testimonial injustice that permeate the clinical encounter.

O'Leary's cogent analysis of MUS and their disproportionate representation in women finds favor in a large body of feminist bioethics scholarship that reconceptualizes autonomy in ways that are socially contextualized and perceptive to paternalistic and oppressive aspects of interpersonal encounters (Dodds 2000). By articulating a feminist critique of autonomy through the dimensions of informed consent and truth-telling, O'Leary embraces a formulation of autonomy—understood as informed, rational, free choice—that has dominated early bioethical theory (Dodds 2000; Donchin 2001). In the context of clinical medicine, this approach is useful since it demands bioethicists challenge gendered assumptions and biases that limit the scope of patients' medical treatment choices and attends to various obstacles in the effective communication of medical information that threaten patients' capacity to "make self-governing medical decisions" (O'Leary 2018, 9). However, O'Leary's approach also raises the question of whether a traditional conceptualization of autonomy equated with informed consent accurately depicts how decisions are made in medical practices fused with diagnostic uncertainty. On the one hand, O'Leary's approach has a tendency to elide the relationship between individual patients and the social world by neglecting the fundamental ways that "intensification of dependency is a normal concomitant of illness" (Donchin 2001, 375). On the other hand, conceptualizing autonomous choice in this way seems to embrace an unrealistic understanding of autonomy that assumes all patients with MUS are fully and equally well-positioned to make medical choices. For many people with contested illness, decision making takes place in a social context of vulnerability, and the chooser is influenced by a number of external and internal pressures. Not only do patients bear the burden of incredulity when their symptoms cannot be substantiated by biological markers, they also describe, for the first time or for the umpteenth time, feeling powerlessness and in a position of subordination in their encounters with doctors. Moreover, in extreme cases, the experience of disabling illness can disrupt a patient's biography—usurping life plans and

shifting relationships—resulting in loss of self-identity (Bury 1982).

The power and authority of doctors to act as gatekeepers raise a somewhat different set of issues about limitations on the capacity for autonomy as it relates to the invalidation of patients' bodily knowledge. Institutionalized medicine basks in cognitive and social authority (Wendell 1996). By virtue of their authority position and professional knowledge, clinicians act as gatekeepers to medical care, where they are treated as "experts" in the medical management of patients' bodies (Malterud 1999). Patients, on the other hand, usually lack such authority, and therefore, their voices are constantly underrepresented and even silenced in health care practice. In medical practice, patients with MUS experience testimonial injustice (Fricker 2007) in their interaction and communication with doctors who dismiss or disbelieve their direct testimony. That is to say, they tend to not be believed or given due credence about the seriousness of their complaints specifically because of views about the credibility of women or the seriousness of their complaints. This is reiterated in frequent and strikingly similar accounts of patients with MUS who describe having their individual lived experience and bodily knowledges delegitimized by doctors (Werner and Malterud 2003; Lian and Robson 2017), especially when those experiences are not congruent with a prescribed set of symptoms for a particular condition. Thus, the testimonial injustice and silencing in doctor-patient relationships nullify the agency of the patient by failing to acknowledge an epistemically privileged position that is informed by her knowledge, values, and preference.

Surely for patients with MUS, the freedom of choice is critically important and deserves to be defended. But autonomy does not exist in a vacuum. It exists in relation to the complex social, cultural, and political realities that shape our lives with equal force. When autonomy is defended without adjacent calls for social and economic justice, it sets up false and pernicious oppositions between persons and the community to which they belong. Thus, rather than a narrowly idealized understanding of autonomous choice, the feminist bioethics approach I propose is perceptive to the prevailing influence that power and knowledge have on both the exercise of patient agency and the ethical landscape of medical practice (Dodds 2000; Donchin 2001). This approach demands attention to the effects of not only gender, but race, ability, class, and sexual orientation—as well as the ways these ascribed identities crosscut with one another in potentially compounding ways—in the distribution in medical practices involving MUS.

Coming to see autonomy as relational in this way requires pushing beyond dominant principlist idealized conceptions of autonomy emphasizing independence in medical decision making, and critically rethinking the ways that autonomy is threatened and enforced for patients with MUS in actual medical practice. This approach requires recognition of the complex historical context and social location in which autonomous actions

are made, and enables a more in-depth analysis of the ways in which autonomy is fostered or threatened by various interpersonal, social, and institutional relationships (Donchin 2001). Importantly, it reflects the embodied experience of illness and the concrete social context of health care decision making. We can see these elements of relational autonomy in O’Leary’s discussion of gender bias, insofar as O’Leary emphasizes the ways that cultural norms, gendered stereotypes, and access to information and knowledge stand in relation to one another—influencing how both doctors and patients with MUS contemplate, evaluate, and reflect on the choices they have available to them in medical practice.

Awareness of the conditions of autonomous choice is essential to understanding gendered oppression. The asymmetrical power relations between doctors and patients, rich and poor, men and women, abled and disabled, become significant features for understanding the concrete particularities of everyday medical decision making in the territory of diagnostic uncertainty. This approach resonates with the analysis offered by O’Leary, which, all things considered, is a contention that the first and central task of doctors is to medically treat patients who face significant possibility of medical harm or suffering. Such is integral to promoting the agency of patients with MUS and ensuring they receive the medical treatment and care they require. ■

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