

**ACCESSING GENETIC KNOWLEDGE:
A CASE FOR A HUMANIST VIRTUE ETHICS**

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ABSTRACT // This essay presents an ethical argument for the value of taking a theoretical perspective that privileges the particularities of individual lived experience over a priori categories of subjecthood. This argument is made through the examination of one practice – disclosure – among American patients who have recently been diagnosed with Huntington’s disease, a fatal genetic disorder. Disclosure is understood in this context as the expected sharing of a Huntington’s disease diagnosis by the patient with those close to her (primarily family). It is modeled on the practice in which a medical professional informs a patient of her diagnosis. Through advancing an account of disclosure that constitutes it as an ethically obligatory practice within the realm of bioethics, the essay demonstrates that a particular set of ethical priorities is assumed by insisting on the salience of disclosure in the lives of patients diagnosed with Huntington’s disease. Two case studies are presented to illustrate that patients’ lived experience in the wake of a Huntington’s disease diagnosis does not necessarily include disclosure as an ethically important practice.

In the era of genetic medicine, there exists the possibility of access to a new kind of knowledge: knowledge of the micro-physiology of your own, or someone else's genes. This new possibility provides the chance to know about future harm that may come to you or your blood relatives in the form of a genetic disease. How can we best understand the ethical questions entailed by this new possibility? Are patients who are given a genetic diagnosis also given new ethical obligations, for example, to share their diagnosis with their genetic relatives who may also be at risk? If so, how, and when are they obligated to do so, and what responsibility must they take for the outcome if they do choose to tell others that they are at risk? In considering this novel medico-ethical phenomenon, what kind of ethical framework is appropriate for capturing the situation of patients who receive a diagnosis of a genetic disease?

The individuals I study have recently been diagnosed with Huntington's disease (HD) and live in Southern California. In this essay, I draw on case studies that were collected by my supervisor Carole Browner and her colleague Mabel Preloran during their 2010 study of the meanings and uses of genetic testing for patients suffering from degenerative movement disorder symptoms, their family caregivers and their clinicians. HD is inherited in an autosomal-dominant fashion: if one parent is affected, there is a 50 per cent chance that it is passed on to the child. Although HD is congenital, it is typically a 'late onset' disease, and symptoms do not usually appear until middle age. First symptoms include movement disorder with loss of muscle control, shaking, memory loss, and personality changes. As it is a degenerative condition, the pathology aggravates over time. There is no cure, only palliative treatment, and it is ultimately fatal. Once symptoms start, individuals live for an average of 15 years.

When the individuals in this study were diagnosed, they acquired prognostic knowledge about their life course. Since the discovery of the first genetic test, the access to this kind of knowledge, both on the part of patients and on the part of those individuals the patient then chooses to tell has been the object of many studies in the social sciences. Very often, gaining access to this knowledge is framed as 'disclosure'. The first disclosure, between the medical professional and the patient, necessarily entails the possibility of future disclosures between the patient and others. Once patients are informed of their diagnosis, they face the choice of whether to inform genetically-related family members.

The question of what patients do in this situation is often explicitly framed as an ethical concern (Featherstone et al. 2006, Klitzman et al. 2007, Lehmann et al. 2000). The ethical dimensions of how, what, and when patients disclose their genetic disease have been problematised particularly in the case of disclosure to patients' genetic relatives, who may, unknowingly, have the disease as well. By taking disclosure *a priori* as an object of study, we assume a biomedical ethical framework that assumes

disclosure to be of ethical concern. However, this framework may or may not coincide with the ethical commitments and worries of the concerned individuals.

In this paper, I argue against a rendering of the ethical situation of patients diagnosed with a genetic disease that privileges disclosure as the focal point of ethical experience. I will suggest, in fact, that a focus on disclosure presupposes a moral framework that precludes an examination of the particular ethical experience of these individuals. In arguing for an investigation of the ethical valence of these individuals' experience, what these individuals consider to be of ethical concern for them must be examined. This examination attends first and foremost to their experiences as first-person selves always already in the midst of the risk and vulnerability of everyday action. I suggest that what might be seen from an outsider's perspective as being ethically-charged (a locus of ethical decision making) may from a more experience-near perspective not appear to carry any ethical weight at all. In doing so, I respond to Cheryl Mattingly's recent call for a more humanist ethical platform that is 'equally attentive' to *both* 'moral traditions and already articulated practices of subjugation' and to 'processes of ethical judgment grounded in singular events and the formations of selves who have their own particular history' (Mattingly 2012: 180). Here, I will strictly focus on promoting the latter, first-person component of this formulation, in an effort to re-balance ethical investigations in this field of inquiry that have largely focused on third-person analysis.

A HUMANIST VIRTUE ETHICS

Among the many voices that have come to the fore in the recent resurgence of directly attending to morality in anthropology is Cheryl Mattingly. In her 2012 piece 'Two Virtue Ethics and the Anthropology of Morality', Mattingly's call for a readjustment of anthropology's moral focus draws our attention to the divergent assumptions underlying two ethical frameworks commonly employed by anthropologists. These are two varieties of virtue ethics, which she argues have mistakenly been merged in recent approaches to the anthropology of morality.

The first of these two virtue ethics is 'third-person' post-structural virtue ethics, largely influenced by Foucault. The second is a 'first person' or 'humanist' virtue ethics, drawing largely on Aristotle. The post-structural virtue ethics, which she refers to as taking a 'third-person perspective' (Mattingly 2012: 169) is characterized by an ethical actor who is a *subject produced* by certain socio-cultural and historical conditions, whose 'self is not so much a cause as it is an effect' (Mattingly 2012: 173). In this tradition 'a dominant place [is given] to social structures in shaping the moral' (Mattingly 2012: 175). The ethical work for individuals in this model consists of the 'striving toward the occupancy of a 'subject position' (Faubion 2011 in Mattingly 2012: 172).

The ‘first person’ or ‘humanist’ neo-Aristotelean strain of virtue ethics, on the other hand, is concerned with a self ‘identified with the very first-personal *givenness* of the experiential phenomena’ (Zehavi 2008 in Mattingly 2012: 169). This model is concerned with the individual’s experience of what it is to be in the world from a first-person perspective, to ‘inhabit particular lifeworlds’ (Mattingly 2012: 170). In this model, the ethical work for individuals is done by building a virtuous character through *practice*, which takes the form of actions in ordinary, everyday life. Central to this position, however, is that these everyday actions are precarious and risky through and through, and that individual human actors will never be able to truly control the consequences of their actions or the circumstances in which they find themselves. I will next show that taking disclosure as an object of focus in studies of patients diagnosed with a genetic disease is a case of applying a third-person, rather than a first-person ethical framework to their situation.

THE ETHICS OF DISCLOSURE

‘Disclosure’ is a term native to biomedical ethics. Canonically taken in this framework to be an ethical imperative (Hertogh et al. 2004), disclosure is achieved when a patient is officially informed of her diagnosis by a medical professional. In the majority of studies of genetic diagnoses, this model, in which one individual delivers a discrete piece of information to another, has been implicitly laminated onto those who receive a genetic diagnosis and those they choose to tell or not to tell. In employing this term, authors index the biomedical ethical framework in which disclosure is an ethically pivotal action. This thrusts patients into a pre-established subject position in which they, upon receipt of their diagnosis, have a number of choices to make: who, when, and how to tell others of their diagnosis. Pre-determining that disclosure will be an ethically salient concern in these actors’ experience presupposes a particular subjectivity. In so doing, I argue, it takes the third-person perspective of post-structural virtue ethics.

I suggest that the cultural saliency of disclosure and the dominance of the bioethical framework in all questions regarding disease has steered social scientists and other scholars away from a humanist, first-person ethical analysis of the way genetic diagnostic knowledge shapes, or fails to shape, the ethical experience of the patient. Particularly, it presupposes that the receipt of diagnostic information is inherently a matter of ethical valence in that it necessarily changes patients’ ethical responsibilities and their understanding of their own ethical position. However, patients who gain access to such knowledge may not experience any shift in their ethical commitments or concerns. The institutionalised terminology of disclosure glosses over the possibility of ‘considering humans as “self-interpreting” moral beings whose perceptions, interpretations and actions help shape moral subjectivities’ (Mattingly 2012: 171). Following Mattingly, I argue for

attending to the singularities of each individual’s first person perspective to improve our chance of grasping what the true ethical struggles for them are.

Next I present the details of two cases of individuals recently diagnosed with HD in Southern California. While both of these individuals had just had their positive HD status disclosed to them, the access to that knowledge did not entail finding themselves in the midst of a new ethical problem. I outline their first-person perspectives by way of sketching, however briefly, their particular lifeworlds. It will be illustrated that for these two patients, as for many others in the study, the knowledge of their positive HD status was not ethically valenced and did not constitute a pivotal point in their ethical experience.

ANA¹

When Ana received her positive test result for Huntington’s disease, she was 37 years old. Recently divorced with two school-aged children, she had been searching for a diagnosis for 14 years. In 1990, 17 years before the study took place, Ana watched her father die of what had been clinically diagnosed as HD (the genetic test was not yet widely available). Ana described watching her father’s death with horror. The anxiety that she would one day suffer like him was a reason why she was searching for an HD test². But Ana was not afraid for herself. Her two children, and her ability to care for them in the future, were her utmost concern:

I was worried because I have the experience with my father and I know that HD could destroy you, and my main concern is who is going to take care of my children. Nobody even with the best intentions could take care of them like me. I am the mother. It is horrible to think about these things...

Ana was devoutly Catholic and considered her fate to be in the hands of the Lord. For example, when an appointment at the neurology clinic that she had been set on attending became available at the last minute, Ana explained this as proof that ‘nothing is impossible for the Lord.’ Ana was also considerably depressed. She frequently attributed her depression to her situation as a fatally diseased mother who would gradually become less and less able to care for her children. Ana recounted having felt this way even before she received her positive HD test result, a testament to how certain she was of having the disease. When Ana received her diagnosis, her deep, continuing anxiety was mixed with relief and a renewed conviction

¹ This case was originally discussed by Browner and Preloran (2010: 37–47).

² In the U.S., HD testing is never done as part of any routine clinical work-up. People are tested only if at least one blood relative is known to carry the Huntington’s gene or because they are manifesting symptoms consistent with the HD trajectory.

in her own ability to interpret her bodily experience. Previously, Ana had felt that everyone she consulted or even told about her symptoms ‘thought she was crazy’. As she explained, ‘I wanted to have it [the test] because I knew that I have HD, like my father, but I couldn’t prove it. Nobody believed me.’ Importantly, it’s likely ‘nobody believed’ her because Ana did not in fact show any physical symptoms. While she complained of ‘sensations’ in her arms and legs, and of trouble walking and keeping her balance, no professional she saw conclusively observed these phenomena. Ana seemed completely normal, although she was certain that she was not.

For her, disclosure of her disease was entirely expected. She had been searching for over a decade for a doctor who would take her claims of Huntington’s seriously so that she could have the test and begin treatment. Ana’s diagnosis did not provoke a new ethical problem, but precisely the opposite of what a bioethical or third-person virtue ethics might predict: instead of feeling burdened with responsibility, she felt vindicated and newly self-righteous.

ROLAND³

Roland was in his 50s when we met him at the clinic where he and his sister Mary had come to explore treatment options for his recently diagnosed Huntington’s disease. Roland had been suffering from movement disorders for many years, causing him to lose his job as a jazz musician and take up another as a taxi driver, until his rapidly declining memory forced him to leave that job as well. He became homeless for several years. It wasn’t until he was arrested for vagrancy that he called his estranged sister Mary to bail him out of jail. Since then, Mary has been Roland’s devoted caregiver.

Roland’s HD test result came when Mary, in her words, ‘converted the entire family’ into believing that their mother had died of HD. Roland and his brother had begun showing symptoms Mary recognised as similar to those of their mother in the early years of her illness. Mary had teamed up with their brother’s wife to monitor the men’s behaviour, and the women had decided together that all the blood relatives ought to get tested. In an interview with Roland, we can see the influence Mary had on Roland at this point in his life:

Int: Did the opinion of those close to you influence your genetic testing decision?

Rol: Yes, [Mary] was the one who thought I should get the test done in the first place.

Int: Can you tell me how it influenced you?

Rol: Well, she is the one who decided I should have the test.

Due to the experiential knowledge Mary acquired taking care of their mother in the last years of her life, Mary had, before having the family tested, begun bringing Roland to an HD support group. This is where Roland and Mary both learned most of what they knew about Huntington’s disease, including information about potential treatments, clinical trials, and generally how to best go about seeking treatment for this relatively rare disease.

By the time Mary decided Roland should be tested, his symptoms were severe. He had lost much of his memory and other mental capacities, and sometimes had trouble speaking. He also sometimes had difficulty controlling his movements. During interviews with Roland as well as during his neurological consultations, Mary played a significant role in navigating the interaction, often speaking for Roland or encouraging Roland to speak. Mary also kept track of all of Roland’s medical records, helped him fill out medical forms, and took notes during appointments.

Once Roland was diagnosed, Mary continued her pragmatic approach to his treatment, embodying a can-do attitude, focusing on the things that needed to be done over the inevitability of Roland’s eventual decline:

Int: Now that you have that information [the genetic test results] how do you feel?

Mar: I feel that we made progress because we can concentrate on looking for help; search for treatment, look for some clinical trials...I like the fact that everything seems to be moving now.

Roland’s attitude, while perhaps not as upbeat, was nonetheless in tune with Mary’s apparent level-headedness. As Roland recounted:

I just assume whatever the test you take, the results will be known, negative or positive (...) Whatever is out there is going to be out there. It’s kind of 50-50, so. The way I see it, if I have it, somebody else doesn’t have it, so it’s not a real mind blower to get the news.

Neither Mary nor Roland were shaken by the HD diagnosis; both considered it to be a predictable result that fits into the life trajectory, or at least one of a few acceptable life trajectories, that they already took themselves to be on. The moment of disclosure, for Roland, did not pose a significant ethical problem. Already in the midst of an incapacitating illness when he received his diagnosis, Roland did not experience this disclosure as a shift in his ethical responsibilities.

ACCESSING GENETIC KNOWLEDGE AS AN ETHICAL QUESTION

I have presented here two cases of individuals who were

³ This case was originally discussed by Browner and Preloran (2010: 86-87, 95).

recently diagnosed with Huntington's disease, a situation which might seem to weigh the patients with a certain ethical choice. What does one do with that knowledge, who does one tell, when, and how? I have argued that approaching the ethical question from this perspective is somewhat misguided in that it begins with the categories themselves instead of beginning with individual experience – a misstep, I believe, characteristic of a post-structural virtue ethics approach. The 'ethical' here cannot be captured by identifying subject positions that these individuals are striving toward, but rather only by attending to the unique specificities of each life and each character. Ana, depressed, horribly afraid of ending up like her father and putting her children through the same pain she experienced, asymptomatic to any observer, is faced with a different ethical struggle than Roland, even though the two might be considered to be in the same 'subject position.'

When approached from the perspective of a humanist first-person virtue ethics, it becomes clear that every case of accessing genetic knowledge, even in the case of a single disease like Huntington's, will pose a different kind of ethical struggle with different ethical considerations. It is not helpful, then, to gloss the further sharing of this knowledge as disclosure which indexes an ethical system (biomedical ethics) that shares with post-structural virtue ethics a foregrounding of the individual merely as occupying a certain subject role. Instead, we ought to attend to the access to this knowledge as part of the 'central human predicament of trying to live a life that one is somehow responsible for but is in many respects out of one's control' (Mattingly 2012: 179). 

ACKNOWLEDGEMENTS

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This research was partly supported by NIH grant no. 1 RO1 HG003228-01 (principal investigator Carole H. Browner) and by the UCLA Center for Culture and Health. I am indebted to Prof. Browner and Dr. Prelo-ran and grateful for the support from UCLA's Department of Anthropology. An earlier version of this paper was presented in July 2011 at the workshop 'Disclosing Subjects: Bodies, Selves, Intimacies, Politics', at the Thomas Coram Research Institute, organised by Mark Davis and Lenore Manderson.

REFERENCES

- Browner, C.H. & H.M. Preloran (2010) *Neurogenetic Diagnoses: The power of hope and the limits of today's medicine*. Oxford: Routledge.
- Featherstone, K., Atkinson, P., Bharadwaj, A. & Clarke, A. (2006) *Risky relations: Family, kinship and the new genetics*. Oxford: Berg.
- Flaherty, D., Preloran, H.M., & Browner, C.H. (In press.) 'Is it 'disclosure'? Rethinking Tellings of Genetic Diagnoses'. In M.D.M. Davis and L. Manderson, (eds.) *Disclosure and identity in health and illness* (Working Title). Oxford: Routledge.
- Hertogh, C.M. et al. (2004) 'Truth telling and truthfulness in the care for patients with advanced dementia: an ethnographic study in Dutch nursing homes'. *Social Science and Medicine*. 59 (8): 1685-1693.
- Klitzman, R., Thorne, D., Williamson, J., Chung, W. & Marder, K. (2007) 'Disclosures of Huntington disease risk within families: Patterns of decision-making and implications.' *American Journal of Medical Genetics Part A*. 143 (16): 1835-1849.
- Lehmann, L.S., Weeks, J.C., Klar, N., Beiener, L. & Garber, J.E. (2000) 'Disclosure of familial genetic information: perceptions of the duty to inform'. *The American Journal of Medicine*. 109 (9): 705-711.
- Mattingly, C. (2012) 'Two virtue ethics and the anthropology of morality'. *Anthropological Theory*. 12 (2): 161-184.