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**Publication Date**

2013

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UNIVERSITY OF CALIFORNIA

Los Angeles

The Genetic Subject Reconsidered:  
An Argument for a First-Person Approach  
to Patients with Huntington's Disease

A thesis submitted in partial satisfaction of the requirements for the Degree of Masters of Arts in  
Anthropology

by

Devin Saint Clair Flaherty



## ABSTRACT OF THE THESIS

The Genetic Subject Reconsidered:

An Argument for a First-Person Approach to Patients with Huntington's Disease

by

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Master of Arts in Anthropology

University of California, Los Angeles, 2013

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Recent work in the anthropology of moralities has evidenced two divergent notions of the “subject”. One takes the subject, or “self” to be a locus of experience, emotion, and action. The other takes the subject to be a product of contemporary regimes of truth and the occupant of various subject positions which determine her ethical and existential possibilities. These positions can be identified as a “first-person, humanist” and “poststructural” approach respectively. In this essay, I argue that although poststructural approaches can be useful, more attention to a first-person, humanist approach is warranted. Through case studies of patients in the United States recently diagnosed with Huntington's disease, I demonstrate that the particularities of each individual's first-person perspective are extremely relevant to an account of their moral experience. I contrast this approach to the poststructural account of the “genetic subject,” a theoretical framework which disables an examination of these individual particularities.

The thesis of Devin Saint Clair Flaherty is approved.

C. Jason Throop

Douglas Hollan

Carole Browner, Committee Chair

University of California, Los Angeles

2013

To my parents—of course.

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### Acknowledgments

The original research on which the case studies in this thesis are based was supported in part by NIH grant 1 RO1 HG003228-01, Carole H. Browner, Principal Investigator and by the UCLA Center for Culture and Health. The cases used here are discussed in Carole H. Browner and H.

Mabel Preloran's monograph, *Neurogenetic Diagnoses: The power of hope and the limits of today's medicine* (Routledge, 2010). These cases are also discussed in Devin Flaherty, H. Mabel Preloran and Carole Browner's chapter "Is It 'Disclosure'? Rethinking Tellings of Genetic Diagnoses" in *Disclosure and Identity in Health and Illness* (working title), Mark D.M. Davis and Lenore Manderson, eds. (Routledge, in press). A much earlier version of this paper was presented at the *Disclosing subjects: bodies, selves intimacies, politics* symposium, Thomas Coram Research Institute, Department of Education, University of London, July 9-10 2011, organized by Mark Davis and Lenore Manderson. An abbreviated version of the argument presented here can be found in Devin Flaherty's "Accessing Genetic Knowledge: A case for a humanist virtue ethics" *The Unfamiliar* (in press).

I was supported in various stages of this project by the following organizations, to whom I am grateful: UCLA's Department of Anthropology, Graduate Division, Institute for Society and Genetics, International Institute, and Center for the Study of Women. I am also grateful to UCLA's *Mind, Medicine and Culture* working group who generously read an earlier draft of this paper and provided me with many helpful insights. My advisors, Carole Browner, Jason Throop, and Douglas Hollan, have each helped me greatly in advancing my thinking and my writing. I am thankful for what each of them has done for me. Thank you also to Elinor Ochs, for her comments and support. Additionally, I am deeply grateful to Cheryl Mattingly who generously shared her time with me and whose work was the inspiration for this thesis.



What is a subject? This is a question central to the contemporary anthropology of moralities (Fassin 2012; Faubion 2010, 2011; Lambek 2010; Robbins 2004, 2007, 2010; Throop 2008, 2010, 2012; Zigon 2007, 2010). Here is a sketch of the two predominant paradigms<sup>1</sup>: One position takes a subject to be a locus of experience, emotion and action—an “experiential self” (Hollan 1992). A subject experiences itself as having subjectivity, with some meaningful capacity for moral choice. It is opposed to an object that does not act but is only acted upon. The subject is a cause<sup>2</sup>. This first position tends to hold that minimally this subjectivity consists in a certain psychological interiority, a unique and complex “unity of a human life” as lived, and a meaningful emergent biography (MacIntyre 1981:204). The second version of the nature of the subject denies that these features of selfhood—those that subjects take themselves to have and attribute to others—are anything more than the products of contemporary regimes of subjectification<sup>3</sup>. This position takes the subject itself to be a product, created by these processes of subjectification, particularly through the processes of creation and maintenance of subject positions. A subject is defined by the subject position she inhabits, a position which determines the possibilities available to the subject and, importantly for my purposes here, orients the subject to those possibilities in an ethical mode. A subject is that which is “subjected to”; a subject is an effect. According to this view, subjects act upon themselves and upon others *as if* subjects had psychological interiority, some kind of lived unity through time, and meaningful, emergent biographies, due to the subjectifying forces in play in our contemporary moment.

It is not difficult to see why the answer we give to this question is important for an anthropology of moralities. The answer we give entails drastically different ontologies of the human being and thus differing understandings of what morality is, consists of, and entails. This distinction is nothing new; it is familiar. Nor is it usually so clean. Byron Good, for example, in his recent (2010) Marrett Memorial

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<sup>1</sup> By no means are these the only meanings of the “subject” that have currency in anthropology today. I am here isolating two of the most prominent, but see, for example, Humphrey (2008) for a different formulation.

<sup>2</sup> This distinction between the self being a cause versus the self being an effect was inspired by Mattingly (2012a):173.

<sup>3</sup> Note that Obeyesekere uses this term very differently, to designate “the process whereby cultural patterns and symbol systems are put back into the melting pot of consciousness and refashioned to create a culturally tolerated set of images” (169).

Lecture “Theorizing the ‘subject’ of medical and psychological anthropology” suggests the need for anthropologists to take on ethnographic projects that attend to “the most intimate forms of everyday experience” in the context of the “theoretical frames” of poststructuralism, *despite* “the post-structuralist suspicion of the ‘humanist subject’ and the focus on ‘subject position’ over lived experience” (Good 2010:517). These “ethnographic investigations of subjectivity require” according to Good, “combining studies of the cultural phenomenology of the subject and practices of self-cultivation with historical and ethnographic investigations of the genealogy and meaning of the modern subject” (2010:523). Although these kinds of mixed approaches are common, they are rarely made explicit.

A recent article by Cheryl Mattingly (2012a), however, seeks not only to make the distinction explicit, but to argue that the two positions may be fundamentally irreconcilable<sup>4</sup>. In “Two Virtue Ethics and the Anthropology of Morality,” Mattingly distinguishes between what she terms a “first-person, humanist virtue ethics” derived from neo-Aristotleanism and a “third-person, poststructural virtue ethics” which is derived largely from Foucault’s later work in which he drew from Greek ethical thought to develop an ethics of self-care (Mattingly 2012a:163; Foucault 1990). (The “first-person, humanist virtue ethics” is consonant with the first position described above; the “third-person, poststructural virtue ethics” with the second.) While Mattingly contends that the two versions of virtue ethics have much in common, she argues that they exist in contradiction to one another due to a basic difference in how they conceive of the subject<sup>5</sup>.

According to Mattingly, a first-person, humanist virtue ethics takes the subject to be “an enduring individual who experiences” and to whom we can accurately attribute “a very robust notion of the narrative arc of a life and some kind of biographical integrity” (Mattingly 2012a:170). This is similar to MacIntyre’s conception of “the unity of a human life,” whose “unity resides in the unity of a narrative

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<sup>4</sup> See also Mattingly (2010) and Mattingly (2012b) for similar argumentation to that presented in Mattingly (2012a).

<sup>5</sup> I depart from Mattingly terminologically here. While her language indicates that a third-person, poststructural virtue ethics is concerned with “the subject” and that a first-person humanist virtue ethics is concerned with “the individual” or “the self” my claim is that her “individual”/“self” is isomorphic with the first notion of “the subject” I provide here (this claim is supported particularly by Mattingly’s argument regarding “basic human self experience” (2012a:169).

which links birth to life to death as narrative beginning to middle to end” (MacIntyre 1981:205)<sup>6</sup>. This ethics takes as basic the understanding that subjects (or “selves”) have “first-person access to [their] own experiential life” which is itself a unique perspective on the world; we do not experience anything else (other people, chairs, church bells) in the same way that we experience our selves, and the perspective that is always already embedded in that experience is thus qualitatively singular (Zahavi 2008:106 *in* Mattingly 2012a:169). A third-person poststructural virtue ethics, on the other hand, is concerned precisely with “dismantling (...) the notion of an ‘I’ and a ‘we’ who are a locus of agency, experience, the unity of a life” (173) in favor of a subject who is *defined by* “inhabiting a particular social location” (176). Mattingly cites James Faubion’s recent work, *An Anthropology of Ethics* (2011) as representative of this third-person perspective that takes “‘the population of [the] interpretive universe’” to be not individuals with first-person perspectives, but rather “‘subjects in or passing through positions in environments’” (Faubion 2011:119 *in* Mattingly 2012a:176).

From the poststructural, third-person virtue ethics perspective, what is crucial is determining *where* in the moral landscape a certain subject is positioned at any given time. From this perspective, “the human being (...) is not an entity with a history, but the target of a multiplicity of types of work, more like a latitude or longitude at which different vectors or different speeds intersect” (Rose 1996:37). Furthermore, two subjects found in the same position in this landscape, occupying the same “where” are identical subjects, of which there could be “indefinitely many” (Faubion 2011:4 *in* Mattingly 2012a:172). These identical subjects have the same *telos*, as in this view *telé* are connected with particular subject positions, not with particular individuals: “[t]he telos of one’s ethical striving is here defined in advance by the telos that belongs to that particular subject position” (Mattingly 2012a:172). From the humanist, first-person virtue ethics perspective, it is the *who* that is crucial. This approach to morality foregrounds the singularity of individual biographies as lived by “an enduring individual who experiences” (Mattingly

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<sup>6</sup> Indeed, the humanist notion that as human selves we perceive ourselves and others as enduring in a meaningful way that allows the creation and living out of unique biographies enables another, slightly different use of “subject.” As MacIntyre writes, “I am the *subject* of a history that is my own and no one else’s, that has its own peculiar meaning” (1981:217, emphasis in original). In this sense of the subject as main character, “[t]he self inhabits a character whose unity is given as the unity of character (1981:271).

2012a:170)<sup>7</sup>. From this perspective, a subject's *telos* involves a processual becoming that is deeply vulnerable and exposed to circumstances out of her control. The moral striving of cultivating virtue, from this perspective, is fraught with the contingent, ever-changing potentialities and possibilities of social life (Mattingly 2012a:167). Central to the distinction Mattingly is arguing for in this article is the categorical nature of the poststructural *wheres* (my terminology) versus the singularity of the humanist *whos*. Notice that in the poststructuralist virtue ethics as described by Mattingly, subjects pass through certain positions that pre-exist them: the position predates the subject that comes to inhabit it. There is a heterogeneity of subject positions (Rose 1996:27), but there are nevertheless categories of subjects. In a humanist first-person virtue ethics, the subject herself, not the subject position, is the starting point of the moral<sup>8</sup>.

Although the discussion I have described thus far is addressed to a particular critique of two versions of a particular moral framework, virtue ethics, which Mattingly argues have been conflated in recent work in the anthropology of moralities, the argument she puts forward is part of a much broader debate. While rarely explicitly stated, I argue that at its most basic, this is a debate between subjectivity and subjectification: a debate over the nature of the self. Much of Mattingly's recent work explicitly addresses this broader debate (2011, 2012b). In this work, she "seek[s] to 'write against structure' in the sense of offering an alternative vision to structural determinisms that make personal lives and small events mere epiphenomena" (Mattingly 2011:45). This approach is also championed by Arthur Kleinman (1998, 2006) whose notion of "moral experience" places the feeling, perceiving, experiencing individual (the subject in the humanist sense) firmly at the center of moral analysis. Both of these authors, and the position they represent, take the experiential human self as ontologically fundamental to morality.

This second position is by far most famously represented by Foucault's oeuvre, and has since been taken on by many, but again has perhaps been most famously and most explicitly developed

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<sup>7</sup> The difference between the "ethical" and the "moral" is variously theorized by Kleinman (2006), Rose (2007), Zigon, (2010), and others. James Faubion (2010, 2011) rejects the terminological distinction due to the "thick and inconsistent mass of forays that have preceded it" (in Lambek 2010: 86), exchanging the "moral" for the "themetical," a neologism. Here, following Lambek (2010) and Mattingly (2013, personal communication), I take the terms to be synonymous.

<sup>8</sup> This is not to downplay the inherent sociality of moral life that is fundamental to the humanist first-person perspective. Indeed, both positions described here take the moral as "a communal enterprise" and "an integral and pervasive aspect of social life" (Mattingly 2012a:164).

theoretically by Foucault scholars James Faubion (e.g. 2011) and Nikolas Rose (at times in collaboration with Carlos Novas) (1996, 1998, 2007a, 2007b; Novas and Rose 2000; Rose and Novas 2003). In this view, “the human being is that kind of creature whose ontology is historical” (Rose 1996: 42): the self as we know it is a historical construct. We find in Rose’s writings a continuation of Foucault’s genealogical project that seeks to explain our contemporary relationship with ourselves and others in terms of contemporary forms of governmentality and the entailed techniques of self. This genealogy is crucially *not* a genealogy of subjectivity; the project is indeed to show that subjectivity as we know it has only arisen under contemporary regimes of subjectification. Rather, it is a *genealogy of subjectification* that seeks to reconstruct “all those heterogenous processes by means of which human beings come to relate to themselves and others as subjects of a certain type” (Rose 1996:25). This genealogy, furthermore, “requires only a minimal, weak, or thin conception of the human material on which history writes” (Rose 1996: 24). In the contemporary sociohistorical moment, that “certain type” of subject that we take ourselves and other to be is a “self with autonomy, choice, self-responsibility, equipped with a psychology aspiring to self-fulfillment” (Rose 1996:33). From this perspective, there are not selves that predate regimes of subjectification that they are then submitted to, but rather it is the case selves are themselves formed *by* regimes of subjectification<sup>9</sup>.

In what follows, I too, following Mattingly, will seek to “write against structure” by exploring what a first-person, humanist approach might have to offer for understanding the experiences individuals at risk for, or diagnosed with, a genetic disease—a population that, has already been much explored from a third-person poststructuralist vantage point by Carlos Novas and Nikolas Rose (Rose 1996, 1998, 2007a, 2007b; Novas and Rose 2000; Rose and Novas 2003). In our era of genetic medicine (the “post-genomic” era), there exists the possibility of access to a new kind of knowledge: knowledge of the micro-physiology of our 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

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<sup>9</sup> It is important to make clear here that Rose’s arguments are only intended to apply only to “advanced liberal democracies” (Novas and Rose 2000:491). Thus, while some cross-cultural criticisms may be warranted, much cross-cultural data on the self is simply outside the scope of Rose’s argument.

best understand the ethical questions entailed by this new possibility? What kind of ethical framework is best suited to capture the ethical work facing patients who receive a diagnosis of a genetic disease, and the moral worlds they inhabit? Drawing primarily on Nikolas Rose and Carlos Novas's concept of the "genetic subject" (Novas and Rose 2000; Rose and Novas 2003; Novas 2003) which is a product of the theoretical groundwork of subjectification I have sketched above, I argue that while this third-person poststructuralist approach illuminates some important aspects of the moral position of individuals facing a diagnosis of a genetic disease, there is still much to gain for an anthropology of morality by engaging with the first-person perspectives of these particular individuals. This position has much in common with Douglas Hollan's argument that experiential selves (selves from the first person perspective) are not identical to cultural models of selves (selves from a third person perspective) which inevitably "present a simplified and often idealized conception of objects and processes in which much of the blooming, buzzing complexity of phenomena is either suppressed or ignored" (Hollan 1992:285).

To illustrate my argument, I use case studies of individuals recently diagnosed with Huntington's disease (HD) living in Southern California. Huntington's disease is a monogenetic autosomally dominant disease. Practically, that means that if one of your parents has it, there is a 50 per cent chance that you have it too. Individuals are born with HD, but because it is typically a late onset disease, symptoms don't usually begin until middle age (the average age of onset is 40 years [Evers-Keiboom 2000]). Huntington's disease is a movement disorder, with typical symptoms including loss of muscle control, shaking, memory loss, general cognitive decline, and personality changes. It is also degenerative: once symptoms start, they only get worse. There is no cure, only palliative treatment, and it is ultimately fatal. Once symptoms start, individuals live for an average of 15 years<sup>10</sup>. The study that I draw on investigated the trajectories of individuals who attended three different neurology clinics to seek consultation for symptoms they were experiencing that were identified by the research team as consonant with a movement disorder (including mood changes, declining mobility, and fading memory). The case studies I

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<sup>10</sup> For an excellent treatment of the discovery and history of Huntington's disease, see Wexler (1996). Novas (2003) also presents a detailed account.

present here are drawn from a subset of these individuals whose consultations led to genetic testing for Huntington's disease, which the test then showed them to be suffering from.

My intention in this paper is to demonstrate the difference that theoretical perspective makes for the way that we conceive of human beings as moral actors. I do this primarily at the level of data interpretation. Taking Mattingly's recent explicit intervention (Mattingly 2010, 2012a; 2012b) into the anthropology of morality as a starting point, I provide divergent interpretations of empirical cases to demonstrate what a first-person, humanist perspective makes possible that a third-person, poststructural perspective prevents. Namely, I seek to show that the experiential self, the self from the first-person perspective, escapes categorization, be it by cultural models (Hollan 1992) or sociological theory, a claim that can only be made productive by taking a first-person, human approach to research (and here specifically, to data interpretation). In my discussion, I focus on one phenomenon in particular that has garnered much attention in the sociological literature of genetic disease: the phenomenon of "disclosure" (Hallowell 1999, Cox & McKellin 2001, Almqvist 1999, Evers-Kiebooms et al. 2000, Chapman 2005, Bloch et al. 2005, Huggins et al. 2005, Etchegary 2006, Koenig and Stockdale 2011, Burgess and d'Agincourt-Canning 2011, Klitzman 2007, Forrest et al. 2003, Finkler 2000). I proceed by exploring which aspects of disclosure particular ethical frameworks bring into being, the third-person poststructural, articulated by Rose and Novas, and the first-person humanist, articulated by Mattingly. I thus draw attention to the differential consequences of these two approaches for one specific phenomenon that is generally understood to have great ethical import in the contemporary moment.

### **Rights-based Disclosure and the Complication of Genetic Medicine**

Before discussing these two possibilities for studying the ethical dimensions of disclosure among individuals who have received a genetic diagnosis, I will first situate disclosure as a practice within clinical medicine. In the clinical field, disclosure is constituted as a practice by the governing framework of bioethics. Specifically, clinical disclosure is embedded in a "rights-based health care ethics" as the right of the patient to be informed about matters pertaining to her state of health by her attending medical professional (Hertogh et al. 2004:1692). In this rights-based ethical framework, "respect for autonomy" is

“a moral principle of central importance,” and disclosure between medical professional and patient is prescribed as a crucial way of adhering to that principle (Hertogh et al. 2004:1685). Thus the patient’s “right to know” provokes an ethical obligation on the part of medical professionals to disclose: disclosure is constituted as both an obligation and a right. Furthermore, because the patient also has a right to confidentiality, medical professionals have an ethical obligation to disclose to the patient and to no one else.

Genetic medicine, however, inherently complicates this model, as one patient’s positive genetic test indexes potential diagnoses for the patient’s blood relatives. The idea that “the family is the patient” is integral to genetic medicine (Etchegary 2006 Petersen 2006, Chapman 1992, Finkler 2000). Marcus Pembrey, in the now classic edited volume *The Troubled Helix* (Marteau and Richards eds, 1996) captures the problem:

Family ties can take on a new meaning in genetics and challenge our usual view of confidentiality. To whom does genetic information belong: the individual or the family? What right does one family member have to learn the genetic results or another member? What obligation do people have to tell others in the family of their own tests results and inform other family members that they are at risk? (76)

This novel characteristic of genetic disease shifts the bioethical terrain, putting into question the central values that supported the traditional model of disclosure. The value of patient autonomy and confidentiality is now weighed against the value of a family-centered treatment, and—most dangerously for a rights-based model—against the “right to know” of the patient’s blood relatives. Within this new ethical framework, the nature of disclosure shifts, taking on new meanings.

These novel ethical complications have spurred a focus on disclosure in the social sciences literature on genetic risk and genetic disease. In these studies, the clinical practice of disclosure between medical professional and patient serves as an implicit model for framing how, when, and why a patient discloses her genetic disease to others (particularly blood relatives)<sup>11</sup>. Of particular interest, however, is how some authors have sought, given this new ethical landscape, to explicitly problematize otherwise

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<sup>11</sup> See Flaherty, Preloran and Browner (in press) for a deconstruction of the assumptions of this model.



implicit aspects of the clinical model of disclosure. Particularly, these authors, most notably Katie Featherstone and her collaborators (2006) and Monica Konrad (2005) call into question both the temporal discreteness and the neat packaging of information that are assumed in clinical models of disclosure, but which may not be applicable outside of the clinical context. As write Featherstone and her collaborators in their ethnography of Welsh families affected by genetic disease: “There can be no assumptions that in the everyday world family members ‘share’ information in an explicit fashion, if at all. It is nearer to the truth to think in terms of fragmentary disclosure, partial disclosure, or even “family secrets” (Featherstone et al 2006:52). Konrad comes to similar conclusions (though derived from a different theoretical perspective) describing disclosure as a best understood as a

pragmatic kind of ‘drip by drip’ approach to truth-telling that is sensitive to the timing of disclosure and to how knowledge is conveyed, rather than to any pure ontological sense of unmediated substance. An ethics of disclosure, in other words, works itself out over time as a series of staggered revelations (2005:101).

Both Konrad and Featherstone and her colleagues seek to emphasize the pragmatic contexts of family life and the psychological complications brought on by life’s everyday vicissitudes to bring to light the idealized nature of the clinical model of disclosure, that assumes a discrete information transfer from one individual to another.

As we will see, this manner of complicating the act of disclosure itself is much closer to what I will be offering as a first-person, humanist perspective on disclosure. These authors, however represent a minority: in studies of genetic disease, the clinical model of disclosure is rarely problematized, reflecting a tendency to implicitly conceptualize disclosure as a one-time event in which a discrete piece of information is communicated between two individuals who then both “know” the same thing<sup>12</sup>. In either case, however, the ethical framework has changed from the traditional bioethical model embraced before the advent of genetic medicine. Disclosing one’s diagnosis to blood relatives or potential partners has become strongly recommended on ethical grounds, confusing “an individualistic rights paradigm and

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<sup>12</sup> Indeed, it is this model that Featherstone et al. and Konrad are writing against, which speaks to its considerable ongoing influence.

traditional bioethical framework which prioritizes the autonomy principle and privileges the rights of one individual over another” (Taylor 2004:148). This tension, which is conceptualized as being between the right of the patient to autonomy and confidentiality and the right of the patient’s blood relatives to know of their risk of disease (often termed simply the “right to know”) is particularly problematic when the disease is severe or fatal, as is the case for Huntington’s disease<sup>13</sup>.

### **Meta-ethical approaches to studying disclosure**

I have above presented two approaches social scientists have taken to studying disclosure among individuals who have been diagnosed with a genetic disease. I have argued that both of these approaches can be understood as engaging with the clinical/bioethical model of disclosure. The main approach is to implicitly calque a clinical model of disclosure to the disclosure practices of diagnosed individuals. A minority approach critiques this model (in terms of the temporal discreteness and packaged information it assumes) by attending to the processes of disclosure in non-clinical ethnographic contexts. Neither of these approaches, however, provides a framework for studying the relationship between the clinical model of disclosure and the disclosures engaged in by the individuals being studied. How are we to understand the relationship between the disclosure that occurs in clinical settings and the rights-based bioethical framework that underpins that practice, and the disclosure that individuals engage in outside of this context, in the midst of their everyday lives? Much evidence indicates that at least some patients who have received a genetic diagnosis are indeed concerned with disclosure as an ethical obligation (one that is often difficult to fulfill). How does this concern come about? What is the relationship between the ethical concern to disclose felt by individuals in their everyday lives, and the bioethical framework that constitutes it as an ethical recommendation? Answering these questions requires shifting to a meta-ethical perspective.

Both the poststructural and the first-person humanist approaches take a critical stance toward studies that presume disclosure as an ethical concern without exploring the relationship between the individuals studied and the broader bioethical framework. These two approaches each offer contrasting views of this

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<sup>13</sup> This tension has been recognized as affecting patients and practitioners alike (e.g. Biesicker 1998).

relationship—contrasting meta-ethical stances—that are derived from their divergent perspectives on the nature of the subject. The poststructuralist approach of Nikolas Rose and Carlos Novas (both drawing heavily from Foucault) takes both the biomedical ethical model of genetic disease *and* the individual's ethical concerns and the actions motivated by those concerned to be two different components of the same contemporary regime. From the perspective of a “geneology of subjectification,” (Rose 1996) Rose and Novas aim to demonstrate that the kinds of individuals that exist today, with the kinds of ethical orientations and concerns that they have, are intertwined with the particular way genetic medicine has emerged as a practice. Evoking Rose's account of Foucault's concept of “pastoral power,” Novas argues decisively that the values of *both* biomedical professionals *and* medical patients can be understood by attending to “the diverse modes in our culture through which human beings are turned into subjects” (Novas 2003:140). Novas continues:

Rather than conceptualizing persons as rational actors who autonomously make decisions, as is common in the bioethics literature, pastoral power suggests that we take notice of the specific conceptions of personhood that are employed in the field of biomedicine and the forms of truth through which knowledge is produced about each and every subject who falls within its ambit. (2003:140)

Without getting sidetracked into the details of the mechanisms of pastoral power here, the important thing to note is that in this approach there is concurrence between the ethical values of patient and medical professional because they are co-created as subjects under the same regime of truth. While the medical professional is a different kind of subject than is the patient (there is, in this account, a heterogeneity of subjects), in both cases the subjects that they are, are created so as to be able respectively to effectively take care of (the medical professional, the “pastor”) and be taken care of (the patient, a member of the “pastorate”). Thus, they share ethical values. This approach constitutes disclosure as ethically valenced due to the kinds of subjects that have been created. Elsewhere, in an argument we will examine in depth momentarily, Rose has developed an even higher-level account of the co-creation of contemporary subjects that seeks to historically explain the very existence of the “selves” we take ourselves and others to be. This account shares with Novas's account of pastoral power an explanation of the complementarity

between bioethics and the ethical concerns of individual patients as a complementarity in subject production.

A first-person humanist perspective takes a decisively different approach to the relationship between bioethics and the ethical concerns of individuals. Mattingly (2012b) provides us with a blueprint for this approach in the context of her work with African-American families with chronically ill children in the urban United States:

Rather than foregrounding a habitus, social structure, or regime of truth as a kind of collective container of practical agents and practical action (...) I focus primarily upon the agents themselves, on the ground and in their particularity, examining their efforts in situational and personal detail, treating these larger macrostructures as powerful cultural resources (including highly negative resources) that inform but do not determine their actions, their experiences, and their deliberations. (2012b:46-47).

The concurrences between bioethical imperatives and individual ethical concerns are not taken as given, then, but rather are derived (if existent) through close attention the individuals themselves. In the context of disclosure, for example, if an individual recently diagnosed with a genetic disease was experiencing concern about when and how to tell their family members (as we saw was the case for many of the patients in the study conducted by Featherstone and colleagues) taking a first-person, humanist perspective would lead us to explore questions of the particularity of that concern: what does it mean for this person that she is experiencing this kind of distress, in regards to the history of her relationships with her family members? How does she experience this distress from moment to moment, what does she feel shifts her feelings about the possibility of disclosing? What is she afraid will happen if she does disclose, or is she perhaps more concerned about what will happen if she doesn't? Where does she feel the desire to disclose is coming from? Attention to these kinds of "situational and personal detail[s]" does not mean feigning ignorance of a bioethical regime that prescribes certain ethical concerns (such as disclosure, in the case of genetic medicine). Rather, it takes seriously the idea, as articulated by Hollan (2012) in an argument for the potential of psychoanalysis to contribute to cultural phenomenology, that "it is a mistake to presume that people who enact similar behaviors, no matter how common or repetitive *from a*

*third-person perspective*, have the same experience of motives for those enactments” (Hollan 2012:46, emphasis mine). This approach constitutes disclosure as something that is *constituted* by the first-person perspective of each individual, not merely as a common practice that whose meaning is easily knowable by an outside observer.

### **The Genetic Subject**

After this introduction to the contrast between these different approaches, I would like to zero in on an argument that is an outgrowth of the third-person, poststructural approach to the subject, but that speaks directly to the phenomenon of disclosure among genetic patients. This is Nikolas Rose and Carlos Novas’s analysis of “the genetic subject” (Novas and Rose 2000, Novas 2003, Rose 2007a, Rose 2007b)<sup>14</sup>. The genetic subject is one of these “certain type[s]” of subjects that has been formed under the contemporary regime of truth, which includes, in this analysis “a new ethics of biomedical subjectivity”. The genealogy of this particular subject position can be accounted for, argue Novas and Rose, by the way that biomedicine in general, and genetic medicine in particular, has functioned to create “mutations in personhood” that have resulted in a “kind of person” with a new set of obligations and responsibilities (Novas and Rose 2000:486). As Rose puts in a later exposition of the argument: “Biomedicine, over the 20<sup>th</sup> century and into our own, has thus not simply changed our relation to health and illness. It has helped make us the kinds of people we have become. Or, to put it differently, it has changed the kinds of human beings we take ourselves to be” (Rose 2007:13). In this new “mode of personhood,” “forms of subjectivity generated by genetic risk are bound up with new ethical problematizations and concerns that complement already dominant forms of personhood” in which the patient is expected to become “skilled, prudent and active, an ally of the doctor, a proto-professional—and to take their own share of the responsibility for getting themselves better” (Novas and Rose 2000:489). The emergence of genetic medicine has further modified these expectations, has changed the subject position and thus the telos of biomedical subjects: “The responsibility for the self now implicates both ‘corporeal’ and ‘genetic’

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<sup>14</sup> This example was prompted by Mattingly’s citing of Rose as a paradigmatic proponent of this approach (2012a)—although due to the subject of her argument Mattingly does not include Rose’s account of the genetic subject.

responsibility: one has long been responsible for the health and illness of the body, but now one must also know and manage the implications of one's genome" (Novas and Rose 2003:5).

The concept of this "genetic responsibility" is central to apprehending the place of disclosure in Novas and Rose's account. For Novas and Rose, "genetic responsibility" explains both the concern (often distress) over the felt imperative of disclosure social scientists find among patients and patients' families as well as the behavior and recommendations of medical professionals regarding the importance of timely disclosure (especially, for example, genetic counselors<sup>15</sup>). In terms of pastoral power, it seems that genetic responsibility is "a power relation that works through the very freedom of the subject to shape individual conduct in socially desirable directions" (Novas 2003:81). It is a key member of the "multiplicity of projects, strategies, tactics and social agencies that have constituted the regulation and management of hereditary illness as their object" (Novas 2003:82). Novas and Rose describe the emergence of genetic responsibility in terms of "the new genetics" (the advent of genetic medicine):

[G]enetic forms of thought not only give life strategies a genetic coloration, but also create new ethical responsibilities. When an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family history and potential family futures. In this way genetic thought induces 'genetic responsibility'—it reshapes prudence and obligation, in relation to getting married, having children, pursuing a career and organizing one's financial affairs (...) [T]hese descriptions do not merely form the judgements, calculations and actions of agencies of control—they shape the self-descriptions and possible forms of action of the genetically risky individual. (Novas and Rose 2000:487)

We see here that genetic responsibility is conceived of as a "new ethical responsibility," a new normative force in the lives of individuals that orients practical choices.

One of the ways the "prudence and obligation" of the "genetically risky individual" (elsewhere called the "genetic subject") is reshaped is by a new orientation to the problems, implications and imperatives of disclosure. As we see in this passage below, the problem of disclosure emerges as a product of different governing (self-governing) forces that place different demands on the genetic subject—or, more accurately, have the genetic subject place different demands on themselves:

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<sup>15</sup> Novas (2003) presents a detailed single-authored analysis of the co-emergence of the genetic subject and the profession of genetic counseling.

The genetically at risk individual *must engage* with a communicative problem space. When should they tell siblings or children that are also at risk (...)? As genetic information is familial, it has the potential to affect our relations with others. Hence the governance of one's own risky genes intersects with the governance of one's communicative relations with others. In our age of authenticity, the norm of truthful speech increasingly infuses familial relations. How then, should we shape our communicative conduct with regard to potentially life-altering information? For those genetically at risk, genetic knowledge is valuable in life planning decisions concerning careers, relationships and children. And once choice is seen as paramount, knowledge is required to make informed decisions. (Novas and Rose 2000:505, emphasis mine)

Disclosure is thus a practice that emerges from the dual obligations of the contemporary “norm of truthful speech” and “the governance of one's own risky genes,” or genetic responsibility. That is, genetic responsibility *takes the forms that it does*, in practices like disclosure, because of other forms of governance that have created and maintain the subject position that is the genetic subject: “Rather than seeing these practices of genetic subjectification in isolation, we suggest that they intersect with, and become allied to, contemporary norms of selfhood that stress autonomy, self-actualization, prudence, responsibility and choice” (Novas and Rose 2000:502).

In support of this model of genetic responsibility, Novas and Rose draw on data gathered from a Huntington's disease webforum archive (1995-1997) supported by the Massachusetts General Hospital Neurology Webpages (Novas 2003:12)<sup>16</sup>. This webforum provides a milieu where “people who are affected by HD in some way [can] discuss the many facets and ethical dilemmas of living with this genetic disorder” (Novas 2003:12). On this site, then, participants can both discuss issues of disclosure, but also, crucially, have a means by which to *disclose to others* who they consider to be in a similar situation via posts and chat rooms. Novas and Rose argue that this webforum, and sites like it, “exemplify the formation of a new ethics of biomedical subjectivity”: “Like earlier practices of confession and diary writing, the practices of posting, reading and replying to messages in these webforums and chat rooms are techniques of the self, entailing the disclosure of one's experiences and thoughts according to particular rules, norms, values and forms of authority” (Novas and Rose 2000:502).

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<sup>16</sup> The data collection from this webforum was conducted exclusively by Novas but is used by Novas and Rose (2000), Novas (2003), Rose (2007a), Rose (2007b).

Novas, in his more extended work (2003), analyzes “testimonials” or “intimate public disclosure[s]” that were posted to the webforum, demonstrating the kinds of ethical concerns, these individuals express (Novas 2003:172). He concludes through these public disclosures—that expose particular fears, offer advice, keep others up to date on health changes, and generally involve others in similar situations in each other’s own felt obligations and responsibilities regarding the disease—that “this communicative medium [of the webforum] helps to produce and reproduce subjects of particular kinds—the person genetically at risk [the genetic subject]” (Novas 2003:197)<sup>17</sup>. Here, Novas shows us what Novas and Rose argue is a demonstrable locus of subject production. The genetic subject emerges in part from repeated exposure to and engagement with others who are subject to the same governing forces and who are seeking to govern themselves in the same way. Notably, this reproduction is attained through public *disclosure* in an internet forum: disclosure is thus considered to be a technology of the self both that is both *expected of* and *constitutive of* the genetic subject.

### **Case Study: Mary and Roland**

I now present a case study of a patient, Roland, who had, at the time of the study, very recently been diagnosed with Huntington’s disease. I present this case study as one of two that I will use to demonstrate the difference taking a first-person, humanist perspective, versus the poststructural position outlined above makes at the level of data interpretation and analysis<sup>18</sup>.

Siblings Mary and Roland were both in their 50s when we met them at the clinic where they had come to explore treatment options for Roland’s recently diagnosed Huntington’s disease. We learned that Roland had been suffering from movement disorder symptoms for many years, causing him first 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 become

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<sup>17</sup> Elsewhere Novas and Rose (2000) and Rose (2007a, 2007b) have restated this argument.

<sup>18</sup> While there is much to be said about the possibilities for data collection and project design from a first person perspective, I do not focus on these here. See Lahlou (2010, 2011) and Cordelois (2010) for promising first-person methods, particularly Subjective Evidence-Based Ethnography (SEBE).



Roland's devoted caregiver. While the siblings didn't live together (Roland chose to stay at a boarding facility despite Mary's invitation to move in with her and her husband), it was clear that their lives were deeply intertwined.

Roland was one of the more severely symptomatic patients in our study; his memory was extremely poor, he experienced a marked decline in his everyday mental acuity, at times he had difficulty speaking and controlling his movements. While it was necessary for Roland to have a caretaker, Mary and Roland's relationship had become extremely close, far beyond what was needed to simply tend to her brother's day-to-day needs. For instance, at the appointment at the neurology clinic, it became clear that Mary took full responsibility for keeping detailed track of Roland's medical history (they both referred to her, jokingly, as his "secretary"). She had an intimate knowledge of Roland's current state of health, as well as all his past courses of treatment, and participated with Roland in joint interaction with the neurologist.

Like several people in our study, Roland was not the first in the family to show movement disorder symptoms. Both his mother, who had died several years earlier, as well as his brother, Simon, who was still alive and close to Roland's age, showed symptoms similar to Roland's. Mary had cared for their mother the last 17-years of her life, and while their mother had never been tested for HD (the test was much less widely available at the time), Mary was almost certain that her mother had died of the disease. Part of this certainty was brought on by Simon's wife, Laura, a nurse who recognized the symptoms and had pushed for their mother to get tested for HD before she died. Now that Roland had returned to regular participation in family life, Laura had begun to notice and tell Mary that Roland's symptoms were similar to those Simon (her husband) was experiencing. The two women agreed that it was likely the two brothers were both suffering from the same disease their mother had died from years previous.

Due to this growing suspicion based on an extended caregiving relationship with her mother as well as Laura's reports of Simon's behavior, Mary began escorting Roland to a Huntington's support group. This is where Roland and Mary both learned most of what they know about HD, including what potential treatments there are, what clinical trials are going on at the moment, and how to best navigate various

institutions in seeking out treatment for this relatively rare disease<sup>19</sup>. This all occurred before any family member had gotten tested. Eventually, Mary was able to convince Roland's doctor that he ought to get tested<sup>20</sup>. As Roland recounted in an interview, "Mary hooked it up with the test (...) the one test they wouldn't do for some reason was for HD ...[but] I finally tested positive last month." In this same interview, we can see the influence Mary had on Roland's medical decisions at this time in his life:

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

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

Interviewer: Can you tell me how it influenced you?

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

Mary also frequently spoke of herself as having "had him tested." Once Roland tested positive, Mary, Simon, and Roland's twin sister all got tested also. Mary's test came back negative Roland's twin sister, negative too; Simon, positive. Mary and Laura had been right in their suspicions that brothers Roland and Simon's symptoms were indicative of HD.

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

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

Mary: 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 he told us:

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.

Mary and Roland had plans to pursue treatment (all of which remains experimental), and Mary was considering leaving her job to become involved full time in HD patient support and advocacy.

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<sup>19</sup> The prevalence of HD in the United States is estimated to be approximately 12 per 100,000 people, or 0.012%.

<sup>20</sup> 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.

### **Disclosure from a First-Person, Humanist Perspective**

The above case study was drawn from two one-time, semi-structured interviews, one with Roland and one with Mary, as well as an observation of one of Roland's neurological appointments that the pair attended together<sup>21</sup>. It does not in itself represent the kind of analysis that is made possible by taking a first-person, humanist perspective—rather, I hope to show through this case study what can be illuminated by taking this kind of a perspective at the stage of data analysis that is differentiated from the kind of findings we are limited to when taking a third-person, poststructural perspective. In Roland's case, as, I argue, in every case, disclosure is constituted in a particular way that, while perhaps similar to others, is itself singular. Next I examine some constituting aspects of disclosure that are brought to light by a first-person, humanist approach.

Before I begin, I will note that it may seem that I am suggesting to embark on a paradoxical exercise: to make generalized claims about how a first-person, humanist approach brings out the singularity of the constitution of disclosure for each individual. This is a wise critique, and indeed, a difficult one to overcome. Indicating at all “what to look for” when sketching the terrain of a first-person, humanist perspective is in itself privileging *a priori* categories. Nonetheless, we must say *something* about what this kind of approach consists in. I take my role to be similar to that taken by Levy and Hollan in their guide to person-centered interviewing, a method similarly oriented toward individual singularity, and indeed toward the first-person perspective. Person-centered interviewing, they write, is

not made up of standard ‘reliable’ techniques such as those used by ‘scientific’ technicians to assure what they take to be valid and reliable (that is easily replicable) results. The interviewing and observing (...) are rather akin to performing arts, and this manual is something like a musical score (...) This means that none of what follows is to be followed mechanically (...) These methodological prescriptions are no more mechanical and positivistic than is a musical score for skilled performers. (Levy and Hollan in Bernard [1998]:335)

Similarly, I offer the following as a preliminary score.

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<sup>21</sup> For further detail on the methods of this study, see Browner and Preloran (2010).

The central tenet of doing research from a first-person humanist perspective is to pay attention to and try to understand what is “at stake” for individuals from moment to moment in the shifting contexts of their experience through time (Kleinman 1998, 2006)<sup>22</sup>. This approach also takes as fundamental that individuals are always already in the midst of relationships with others, relationships that have particular felt histories and particular asymmetries of all kinds. These relationships will be adumbrated differently in experience from moment to moment, with some aspects revealing themselves frequently and pervasively, in an everyday mode, with others showing through unexpectedly or in particular moments of emotional intensity. This kind of approach takes into account but does not privilege explicit, declarative knowledge, instead looking to apprehend and appreciate the different ways in which individuals “know,” from the varieties of embodied knowledge to implicit knowledge that is never spoken but is nevertheless present in experience. While there are features of the first-person perspective that could be otherwise emphasized, it is these three areas, at-stakeness, relationship, and ways of knowing, all of which are constituted and reconstituted differently in shifting contexts through time that I believe to be most productive for studying the phenomenon of disclosure. Additionally, attention to these aspects of the first-person perspective bolsters the ethnographically-based critiques I have examined above (Featherstone et al. 2006, Konrad 2005) in order to attend to disclosure not merely as the one-time exchange of a certain fixed package of information, but as part of an ever-continuing revealing between individuals in relationship—revelations that have various degrees of intention, consciousness, reflection, and acknowledgement.

With these areas of focus in mind, I turn back to Roland’s case to show the kinds of questions that that are opened up and made salient by taking this kind of approach—questions, I argue, of a kind that are essential to understanding moral experience. Roland’s decision to call Mary and request that he bail her out of jail was an enormous turning point in Roland’s life. Before the phone call, he had not spoken to

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<sup>22</sup> By “experience” here, I refer to what Throop (2003) has termed a “complemental model of experience” (234). Drawing on the insights of Husserl, James and Schutz and others, this model “is grounded in the *organization of attention*” according to the dynamic structuring of what is foregrounded and backgrounded in awareness” (ibid). Importantly, this phenomenologically-grounded model bridges the theoretical gap between “coherent” and “granular” understandings of experience while also incorporating important, seemingly contrary accounts of experience such as those offered by Desjarlais (1994, 1997) and Mattingly (1994, 1998, 2000).

any member of this family in several years, and none of his relatives knew where he was. He had been arrested many times before, each time for vagrancy, and had never chosen to call any of his family for help—until this time. Losing his dream-job as a jazz musician due to problems coordinating his movements and then losing his job as a taxi driver due to his inability to remember street names were both parts of his life that he had not shared with anyone in his family. How aware was Roland that his symptoms were worsening, that his memory and his coordination were in decline? What did he think this might mean? How exposed did he feel by his shaky movements, his muddled speech, and his unreliable ability to walk? Are these the reasons he did not contact his family for years—or was it something else? Roland told us that when he did decide to call Mary, he was following the logic of one of the other inmates who told Roland that if he himself had any family at all to call there was no way he would be sitting in jail. To call his sister, he told us, he had to look her up in the phonebook. What was Roland imagining the consequences of this phone call would be? What doubts, fears, hopes did he have when he decided to call, and how did this all change through the next few hours when he talked to his sister, saw her for the first time in years, and then was brought back to her home?

This disclosure to Mary, of Roland's state of health, of his inability to keep a job, of his long-term homelessness did not happen in a single moment—and yet there is still something about the phone call that signals a readiness, an acceptance of vulnerability and a willingness to trust the person he remembered loved him. Or perhaps not—perhaps it just signaled a fleeting moment of desperation solidified by a concrete action that could not be taken back. Once in Mary's care, Roland's body displayed that he was not in good health. How was this ongoing display understood by Mary and her husband, and how was it experienced by Roland himself? How was Roland's sickness accommodated in the intersubjective milieu of their triadic relationship? Did Roland make excuses? Did Mary ask questions? Did they talk about his behavior at all? How did the disease reveal itself in the experience of everyday interaction?

We learn from Mary's account that she and her sister-in-law, Laura, and been observing the behavior of Roland and his brother Simon, cross-comparing stories and zero-ing in on a shared

explanation. Was Roland aware that he was being watched in this way? Did he have a suspicion of his own about what Mary was up to? Did he, too, have memories of his mother's illness, and wonder if he was following her path? How did these experiences shift from moment to moment as Roland got used to the new contingencies of his life as a participating member of his estranged family?

All of the questions I pose here are directed toward intimating the nature of experiences salient before Roland's actual HD test and positive diagnosis—before he could “disclose” to anyone that he had Huntington's disease. By sketching possibilities for an examination of Roland's experience in this way, we foreground what might have been at stake for Roland and Mary, how their ongoing relationship and its asymmetries (including memories, fantasies, and imagined futures) partially constitutes their everyday experience, and the ways in which different forms of knowledge shape emotional responses, action, and understanding. Attention to these aspects of subjectivity shows disclosure in a very different light than is afforded us by a third-person, poststructural perspective that is concerned with demonstrating how subject positions are produced, enacted, and reproduced. It is different because, by attending to the singularities of experience (even if guided by broad categories), a first-person humanist perspective is sensitive to the diversity of moral experience among individuals who may indeed engage in similar patterns of action and express broadly similar attitudes with regards to a given object (in this case, their genetic illness) but are nonetheless living very different lives in which they are immersed in divergent relationships, projects, and ways of being in the world<sup>23</sup>. To further illustrate this point<sup>24</sup>, I present another case study of a woman who had, when we met her at the neurology clinic, also just been diagnosed with Huntington's disease.

### **Case Study: Ana**

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<sup>23</sup> Once again, this position is very similar to that argued for by Hollan (2012) in his examination and nuanced critique of cultural phenomenological approaches, which, he writes “[have] a tendency to smooth out the differences between people and their experiences by referring to their purportedly common habitus or routines or practices; in some cases to presume that they are thinking and feeling and imagining the same things simply because they are overtly acting in [sic] the same ways” (Hollan 2012:43).

<sup>24</sup> In thinking of the varieties of experience of those suffering from an inherited neurodegenerative disease, it is helpful to remember the case of Catarina, depicted by Biehl (2005). Catarina, who is eventually diagnosed with Machado-Joseph disease, lives much of her adult life in the squalor of Vita, an “asylum” in Brazil's Puerto Alegre—having been abandoned there by her family for her erratic behavior and physical degeneration. It is instructive, in considering the case studies I give here, to keep in mind the many different ways that neurodegenerative genetic illness and diagnosis can be experienced.

When Ana received her positive test for Huntington's, she had been searching for a cause for her symptoms for 14 years. She was at this time 37-years old, and the mother of two children, a 12-year old daughter and a 4-year old son. In 1990, 17 years before the study took place, Ana had watched her father die of what had been clinically diagnosed as HD. This experience had a profound effect on Ana: "Getting the disease [Huntington's] was on my mind from the moment I saw my father in 1990. I had remembered him as a big, handsome man and when I saw him, I couldn't believe it, he was a bag of bones..." (Browner and Preloran 2010:39). When Ana was growing up, her father was an alcoholic who disappeared from family life when Ana was 10 (she never knew the exact reason, although her parents fought often). During her childhood, family members always remarked how much she was "like her father," and Ana remembers never understanding what they meant, but being distressed by it as his father was known for his erratic moods and violent behavior. She and her father were estranged for many years, until she received a call from a hospital that brought her and her then-husband to the bed where he lay dying. A few years after seeing her father die, Ana was convinced that she was developing symptoms of Huntington's disease, and that she was following in her father's footsteps.

During the next decade, motivated by her persistent symptoms and her fear that she had inherited Huntington's from her father, Ana entered under the care of over 10 specialists, including neurologists and psychologists. Ana felt that she was losing her memory and concentration (getting more and more "scatterbrained") and also often experienced what she called "sensations" in her limbs. These "sensations" felt like uncomfortable, internal shaking and gave her the feeling of not being able to fully control her arms and legs. However, Ana's symptoms were continually dismissed by specialists as not being biologically significant and were instead attributed to stress and her rather high-strung personality. She tried for these 10 years to get tested for HD, but no one she consulted with would sign off on the test. Finally, Ana found a neurologist who would order the test; Ana took it, and it came back positive.

At this point, the neurologist who agreed to have Ana tested still maintained that Ana was in the pre-symptomatic stage of HD, implying that the symptoms she was reporting, which were not outwardly visible nor confirmed by any neurological testing, were all in her head. Despite this assessment, the

positive test result was incredibly vindicating for Ana. As she told us in an interview: “ I wanted to have the test because I knew that I had HD like my father, but I couldn’t prove it. Nobody believed me. Now that I have the test nobody can deny it. The test gives you the certainty that you are not crazy... You know that you have a real problem and nobody can say otherwise.”

Throughout the years of her search for a Huntington’s diagnosis, and in the year we followed her after her diagnosis, Ana struggled with depression. She had been prescribed anti-depressants a number of times, but did not like the way they made her feel. She described a back-and-forth battle with medical specialists who would evaluate her, listen to her claims to be depressed by the possibility of having Huntington’s disease, and prescribe her anti-depressants instead of ordering an HD test. While occasionally giving them a try, Ana did not think that “uppers” (as she called them) was what she needed: “those pills can’t change the reality [of having HD] and it is the reality that makes me sad.”

During this period, Robert, Ana’s ex-husband and the father of her two children, was a large part of Ana’s life. Robert had stayed relatively involved in family life after their divorce, which Ana had requested after she caught him cheating on her four years earlier. Ana also remained close close with Robert’s family, especially his sister and his mother. When trying to decide whether or not to go through with the HD test that had finally been offered her, Ana sought advice from Robert, as well as from his mother and sister. And, when the test results came back positive, Robert was the first-person Ana called (the first person she disclosed to), after which time he began to fully step into the role of caregiver and provider of emotional support for Ana. However, while finding herself relying on Robert and calling on him to help her make medical decisions, Ana also thought he was negligent, immature, and unreliable:

He is very irresponsible, you can’t expect him to act as an adult once, you have to prepare him little by little. Now that he knows that have HD—that it’s not my imagination, it’s a HD—now that he knows that he has to be more responsible.

Having Robert more involved in her life also seemed to remind Ana of the sadness of the divorce, and these memories contributed to her depression. While she considered him to be far from an ideal partner, she also had not gotten over the difficult of the divorce:



It was hard and it is hard, very hard for me, with this problem, with HD and all. I can't recuperate from the separation. I am depressed most of the time. I don't want to go outside. I go to work because I need the money, but I am terrified that I will make a mistake.

Ana feared that Robert already had "another family" with some other woman, and that he would not really be around to care for her and their children. This was both depressing because Ana felt rejected romantically, but also because she was so deeply anxious about her future and her children's future.

Robert and Ana had decided together that it would be best not to tell their children about Ana's positive results. Ana was enthusiastic about telling others, especially Robert's family, as they had all been very skeptical of Ana's claims to illness and believed Ana was more or less making the whole thing up. However, when it came to Ana's children, she was very anxious about making sure they were absolutely taken care of, and about what she saw as her immanently declining ability to secure their care. Both Ana and Robert took care of their children to be their utmost priority, and also agreed that it was only by making decisions and acting together that their children would be best taken care of. For the time being, they decided that not telling the children anything about Ana's diagnosis was the best way to take care of them. Knowing that even if their children did have HD that it would be decades before any symptoms set in (each child had a 50% of having it), Ana wanted them to "live a normal life for as long as possible."

### **The Genetic Subject Reconsidered**

How is disclosure constituted in Ana's case? We can think again about the three areas of focus I have proposed as crucial to a first-person humanist study of disclosure: at-stakeness, the complexity of relationships individuals are always already deeply involved in, and variegated forms of knowledge. For brevity, in Ana's case, I'll just focus on sketching some starting points in the area of knowledge. I want to emphasize again that I am artificially constructing these domains as separate entities as a way of being able to actually articulate starting points for an analysis of the kind I am proposing—an articulation which fails to capture the reality at which the analysis aims, but which nonetheless can enable such an analysis.

Tracing Ana's knowledge of her disease, we must begin back when she was a child being told she was just like her moody, drunk, unpredictable father, when it was likely that her father was in fact

already displaying the personality symptoms from his worsening, undiagnosed Huntington's disease (it is worth noting that people with movement disorders who experience uncontrolled movements and trouble walking, both common symptoms, are often mistaken as drunks). We can only begin to piece together the experience of seeing her father on his hospital death bed, a "bag of bones," the few years after, and then the development of Ana's symptoms that she always knew were part of her father's disease that was now in her. Over the course of a decade, Ana attempted to disclose her disease to medical specialists and family members alike, meeting only with skepticism in various forms. During this time, she divorced the man who had been with her at her father's bedside.

From our standpoint in the present, we can only imagine the many ways in which Ana must have attempted to cope with this repeated negation of her felt experience of the world: how throughout this period her attitudes toward herself and toward each other person must have shifted back and forth and somewhere new; how memories faded into forgetting only to emerge years later at new moments, in new contexts, to hold new meaning for her; how she must have doubted, with some doubts becoming familiar and nagging and other fresh uncertainties appearing in new moments. How to understand, from Ana's perspective, her eventual HD diagnosis? And life after the diagnosis, her decision not to disclose to her children, her lingering depression?

Focusing here briefly on the different ways in which Ana "knows" she has HD, I have only adumbrated what I have claimed are the other two reliable points of analysis I have suggested for a first-person humanist study of disclosure: what was at stake for Ana and the particularities of her singular relationships with each other person in her life. However, we can see, even from this brief and necessarily incomplete case study, the complexities of being in the world as a first-person subject. When we attempt to compare Ana and Roland, both individuals who have recently received a diagnosis of the same fatal genetic disease, their respective moral experience is practically, if not totally, incomparable. While in some abstract sense they had the same obstacle to face, a diagnosis of Huntington's disease, and had (again, in some abstract sense), the same decision to make about whom to disclose to, and when, and

how, it is clear that this was not the “same” diagnosis for Roland as it was for Ana, and that their “choice” of how to disclose was in no way constituted by the same parameters.

Returning to the third-person poststructural perspective, both Ana and Roland, in their position as genetic subjects are considered as oriented to the same telos, as having the same ethical obligations and as being engaged with the same ethical striving guided by genetic responsibility, prudence and management of their genomes. I have tried to show, through the above case studies, that while this is true in some sense, it is in this abstract sense alone. Taking a cue from Hollan (1992) and expanding his argument on the cultural models of the self, we might say that while at the level of discourse Ana and Roland are in similar ethical positions (they play the same role at the level of the ethical model), there is no necessary connection between this representation and their actual, living, experiential selves.

However, it is too easy to say that because Roland and Ana’s concerns and experiences are truly unique and largely incommensurable that this in itself demonstrates that subject positions can only give us an abstract account of moral experience. Indeed, according to the third-person, poststructural perspective, the heterogeneity of subject positions creates combinations of overlapping concerns and orientations that individuals each pass through, attaining their own, as we might call it, “subject signature.” Ana and Roland’s divergent experiences, then, might point to the need for a map of subject positions to study the moral worlds inhabited by subjects, rather than a focus on the subjectivity of those “passing through” these positions<sup>25</sup>. This recalls my distinction between the poststructuralist focus on the *where* and the humanist focus on the *who*, and in turn returns us to the ontological debate about the nature of the human self which began this essay: whether subjectivity is inherent in the human being, or whether it is historically created. I have tried with the above case studies to argue for the importance of attending to subjectivity as the fundamental groundwork for studying morality and moral experience and through this voice support for the position that subjectivity is ontologically fundamental to human beings. Unfortunately, however, this is not an argument that can be won merely by pointing to the benefits of

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<sup>25</sup> See Faubion (2011:45-46, 66, 120) for nuanced expansions of this point, which is given very simply here.

“acting as if” and then claiming that it is so. In my conclusion, I will propose a few strategies for approaching this ontological debate, some of which I have relied on here.

### **Conclusion**

In what I have presented here, I have sought to contribute in some small way to an approach to studying human experience that already has many dedicated followers. By orienting my discussion to two divergent understandings of “the subject” I have argued for an approach within the anthropology of moralities that is “concerned with subjectivity that cannot be reduced to a subject position” (Mattingly 2010:40). Following Mattingly (2012a), I have called this a “first-person, humanist” approach. By exploring how the phenomenon of disclosure is constituted in two case studies of individuals recently diagnosed with Huntington’s disease, I have argued that this position allows us to privilege what is at stake for individuals in the shifting flux of their experience, the forms of implicit, embodied knowledge that appear and disappear in the subject’s attention, and with the particularities of a subject’s relationship with others, relationships which have their own particular histories and asymmetries, pulls and tensions, presences and absences. I have thus attempted to demonstrate the “moral particularity” of the life of each individual human being (MacIntyre 1981:220).

I have compared this position to what I have called (again, following Mattingly [2012]) a “third-person, poststructural” approach. This position, which I have represented through the work of Nikolas Rose and Carlos Novas (both of whom take themselves to be working on projects begun by Foucault) is concerned with subjects only inasmuch as they are inhabitants of particular subject positions. Subject positions, which emerge historically through the confluence of diverse forms of governmentality determine the ethical possibilities available to subjects. From this perspective any account of individual human subjectivity is merely an account of the inhabiting of a particular subject position. Within this framework, Rose and Novas have taken on the genealogical project of determining why, in the contemporary moment, the subject positions that exist entail the particular kinds of beliefs that they do about subjectivity. Particularly, that subjects take themselves and others to be particular kinds of selves: selves with interiority which have the capacity for autonomy, choice, responsibility, self-work, and thus a

meaningful biography. This understanding is here only a product of heterogeneous historical processes and does not represent any everlasting “truth” about what it is to be human. To repeat, from this perspective, there is only “a minimal, weak, or thin conception of the human material on which history writes” (Rose 1996:24).

It is guaranteed that no one who ascribes to this third-person poststructural position will have found my presentation of the benefits of taking a first-person humanist approach to studying morality at all convincing—or even plausible. This is because the poststructural approach, by presenting a historical explanation, and thus a meta-psychology of why we take ourselves and others to be whatever kinds of beings we take ourselves to be, at any given time, holds the trump card for dismissing any account of moral experience as merely historically contingent. By describing the conditions of possibility for being the kinds of selves that we take ourselves and others to be, this position disempowers any position that seeks to take those “kinds of selves” as meaningful—and disempowers any advocate of the position that they are meaningful as something of a dupe for buying wholeheartedly into the beliefs that have been instilled in her by the historical powers-that-be. I would like, in closing, to briefly go over what I see as five ways to respond to this trump card.

The first is to dig our heels into the mud. By this, I mean to simply claim that there is something ontologically true about humans, through history, that deserves the kind of attention the first-person humanist account gives to their subjectivity. This would be, in a way, to ignore the genealogical argument.

The second is to get into the details. The capacity for autonomy, choice, responsibility, self-work and the sense of a meaningful biography have been picked out by Rose and Novas (and are commonly recognized by other poststructural thinkers) as characteristics that contemporary subjects attribute to themselves and others. However, these characteristics are not isomorphic with the characteristics of experiential selves; I have been relying on three characteristics of experiential selves, at-stakeness, different forms of knowledge informing attention, and always already being in relationships. Put strongly, it could be argued (and I have already gestured to this above) that the poststructuralist account(s) of the

self speak only to the self of discourse and not to the self of experience (Hollan 1992). While we might have cultural beliefs about ourselves and others that we express in language (in, for example, the Huntington's disease webform) in which we resemble the selves of poststructural subjecthood, that by no means assures a "one to one correspondence" between these declarative beliefs and utterances and our experiential selves (Hollan 1992:286). This supports digging our heels into the mud because it shows that there is something "else" besides what the poststructuralists have identified, that in fact characterizes human selves. However, it doesn't manage to avoid the trump card. I say "characteristic of selves," you say "historically contingent"—for whatever characteristics we might think of.

The third is to pull the trump card back. What are the conditions of possibility for the poststructuralist approach to exist and gain academic traction<sup>26</sup>? We can imagine a world without Foucault (not that any of us would want to). What were the historical contingencies of these ideas coming to fruition and getting published, let alone seeming believable to so many people, having such an influence? This puts both approaches on equal footing. Unfortunately, in doing so, it also grants the poststructural position.

The fourth is to grant the poststructural position. Yes, it is true: everything that is happening at any moment, anywhere in the world, is historically contingent. Everything could have been otherwise, and that includes not just the selves we take ourselves to be, but the selves we actually are. Humans could have been entirely different kinds of beings, and perhaps, at different sociohistorical moments, we were completely different kinds of beings. That does not, however, entail that subject positions are the only meaningful perspective on human subjectivity. It can be that our selves are historically constructed, that subject positions are a useful analytic for thinking about the kinds of selves that exist, *and* that singular subjectivities are meaningful for an account of human morality.

The fifth is to go native. The poststructural account holds that individuals in the contemporary moment in the post-industrial world take themselves and others to be selves of a particular type. When studying these individuals, ought we not to take these beliefs seriously, or, as Caroline Humphrey calls it,

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<sup>26</sup> I owe this third response to Cheryl Mattingly, who pointed it out to me in a moment of cheerful antagonism.

ought we not to take “truthfulness to the people we study” into account (Humphrey 2008:358)? For example, when studying the moral experience patients in the U.S. who have recently been diagnosed with Huntington’s disease, ought we not to take into account the kind of selves they take themselves to be and the kinds of selves who they believe populate the world around them? Of course, this research agenda assumes meaningful subjectivity, and the argument conflates research content with research approach. Indeed, the intuition that these dispositions ought to matter is itself a humanistic one.

These five responses offer several ways of interpreting the material I have presented above. I leave it up to the reader to decide which is the most productive. While likely not convincing anyone who was not already sympathetic to the kind of approach I have offered here, my hope is that the paper as a whole helps strengthen the position that a first-person humanist approach to moralities in anthropology is a worthy endeavor.

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