

Risk, Responsibility, and Relationality:  
Positioning the Subjects of Psychiatric Genetic Testing

by

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DALHOUSIE UNIVERSITY

DEPARTMENT OF SOCIOLOGY AND SOCIAL ANTHROPOLOGY

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## **Abstract**

This thesis explores the subject positions available to users of genetic tests for bipolar disorder in the United States. In advanced liberal societies, tests for genetic susceptibility to complex disorders may be promoted and used as means of performing responsible citizenship through the consumption of health care services. In the context of mental illness, however, key assumptions about the characteristics of consumers may not be met. The research found that because the category of “potential test user” substantially overlaps with the category of “mental health care user,” both the rationality and autonomy of these individuals is subject to question. Test users are framed in relational terms: as family members, as patients, and as consumers – but the last of these relational frames is considered problematic. Therefore, while the tests are framed as tools for proactive health management, responsibilities surrounding their use are largely allocated to family members and doctors.

## **List of Abbreviations Used**

<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>BP</b>	Bipolar Disorder
<b>DBSA</b>	Depression and Bipolar Support Alliance
<b>GWAS</b>	Genome-Wide Association Studies
<b>NAMI</b>	National Alliance on Mental Illness
<b>NIMH</b>	National Institute of Mental Health
<b>SNP</b>	Single-Nucleotide Polymorphism

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# Chapter I: Introduction

Since the appearance, over the past 15-odd years, of genetic tests for susceptibility to complex disorders, many researchers in the social sciences have viewed these tests as “technologies of the self” – tools used to manage one’s health as a part of the process of performing responsible citizenship in the genomic era (Novas & Rose, 2000, p. 492; Rose, 2003, p. 58). In the present context of market capitalism and neoliberal governance, scholars claim, the task of managing health – including monitoring risks and mitigating exposure to them – has been strategically shifted off of the state and onto private individuals and groups, who feel a moral obligation to engage in these processes of self-care, as well as a deep desire to do so in order to perceive themselves as the subjects they are encouraged and assumed to be: responsible, rational, and autonomous (Petersen, 1997; Lemke, 2004). Further, it has been claimed that in using genomic technologies in this way – as a means of both knowing and managing the self – people are finding new ways of engaging with other individuals engaged in the same tasks, and are forming new relationships and networks of responsibility, interdependence, and identification, and that they are increasingly framing and understanding themselves and their relationships in genetic terms (Gibbon, 2008; Heath, Rapp, & Taussig, 2004; Novas, 2008; Schaffer, Kuczynski, & Skinner, 2008).

However, other researchers have identified cases where the formation of new social relations and genetic identities does not appear to be occurring, and where the use of genetic testing for susceptibility is actively discouraged by professionals (Lock, 2008; Lock, Freeman, Sharples, & Lloyd, 2006; Roberts, 2008). In particular, these appear to be cases where the condition concerned is highly stigmatized, or causes the individuals

living with it to experience some degree of social isolation, or where the nature of the disorder is such that it affects the rationality or autonomy of those living with it. In these cases, persons may not be able to take responsibility for managing their own health. This task often falls, instead, to families, who may or may not create social networks and identifications for themselves around the genetic locus of the condition.

Over the past several years, a number of tests have appeared for genetic susceptibility to complex mental illnesses. Most of these tests offer very low predictive power and a number have been introduced onto the market and then promptly removed – whether due to lack of profitability, ethical concerns, or technological issues is uncertain. Very few of these tests are currently available on the North American market. However, because these early offerings appear to foreshadow future developments, which are expected to have greater predictive value and therefore greater clinical utility, there has been a certain amount of public interest (e.g. Nauert, 2010; McKie, 2008; Hsien-Hsien, 2008), which has extended not only to currently offered tests but to research that promises further capabilities in the near future.

Interestingly, this media interest has not yet been mirrored by research from within the social sciences. Of course, this is not to say there has been no speculation about the eventual impacts of psychiatric genetics (see Couzin, 2008; Hoop, 2008; Braff & Freedman, 2008). A number of studies have also examined attitudes of psychiatric patients, family members, doctors, and members of the public to the possibility of genetic tests for mental illnesses, with most of these studies conducted prior to the existence of such tests in reality (Smith, Sapers, Reus, & Freimer, 1996; Trippitelli, Jamison, Folstein, Bartko, & DePaulo, 1998; Jones, Scourfield, McCandles, & Craddock, 2002; Meiser,

Mitchell, McGirr, Van Herten, & Schofield, 2005; Meiser et al., 2008; Laegsgaard, Kristensen, & Mors, 2009). However, to my knowledge there have been no empirical studies by anthropologists or sociologists of the marketing of psychiatric genetic tests in specific, nor of their purchase and use. Therefore, we do not yet know whether these tests are being promoted, or understood, as technologies of responsible selfhood. We do not know if their potential users are being encouraged to view these tests as proactive risk management tools in the manner that has been described for other tests, or to avoid them as clinically premature or “risky” in and of themselves. We do not know, in particular, how the potential users of these tests are understood by key stakeholders in this industry – by the companies selling the tests, by government health agencies, by the popular media, by psychiatric professionals, or by other interested parties – what desires they are expected to possess, and what they are expected to do in order to fulfill those desires. This knowledge is essential to the development of informed legislative and regulatory practices relating to the development, sale, and promotion of these tests. Without an understanding of the purposes for which individuals are expected to use the tests, or how those individuals are understood in terms of their knowledge, abilities, capacities, and characteristics, it is impossible to develop meaningful guidelines for the corporations marketing them, or for the clinicians who might be expected to interpret their results or provide a professional perspective on decisions surrounding their use.

Because mental illnesses raise questions about the autonomy and rationality of those diagnosed with such conditions, it seems wise to take a skeptical approach to the notion that users of genetic tests for psychiatric illnesses will be framed predominantly as ideal-type consumer-citizens. The subject position of consumer may be neither

appropriate to mental health care users (Hazelton & Clinton, 2002), nor effective for marketing purposes (Martin, 2007, p. 157-159). In this context, power dynamics between patients and professionals may more closely resemble the hierarchical arrangements identified by theorists of medicalization in the 1970s and 1980s, at the beginning of the consumer era.

I ask, then: how are the users of genetic tests for bipolar disorder, and for other related mental illnesses, framed by the companies promoting these tests? How are they framed by commentators on these test, including academic researchers, patient advocacy organizations, and journalists?<sup>1</sup> What are the relationships between the subject positions promoted by these different groups of stakeholders? Whose frames appear to dominate? Are test users in fact understood as rational, self-interested consumer-citizens, looking for novel tools with which to understand and manage their genetic health? Or is their capacity to act in this manner held in some doubt? Does the discourse surrounding bipolar disorder genetics show evidence of the development of networks of identification, and if so, around what focal point(s) are they centred? Who is involved? In whose discourses are these networks evident? Are they extant at cross-national, national, or community levels? Or are they largely limited to families?

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<sup>1</sup> The category of “academic researchers” is not a homogeneous one. Among those scholars commenting on psychiatric genetic tests, we find genetic scientists, practicing psychiatrists, genetic counselors, sociologists, anthropologists, and perhaps others, all of whom bring a different perspective, and none of whom are particularly homogeneous groups in and of themselves. Nor are patient advocacy groups all alike in their aims, approaches, and ideologies. The present study faced some limitations in accessing the internal differentiations among these groups, and presents largely the most mainstream and accessible parts of the discourses that circulate among them. These limitations are addressed in greater detail in Chapter 4.



In order to understand the subject positions available to test users, it is necessary to identify how other key elements in the discourse are conceptualized. Subjects are always subjects-in-relation to other subjects, as well as themselves. The responsibilities they are understood to have involve material entities like drugs and abstract concepts like bipolar disorder. Therefore my research examines the portrayal of not only test users, but of bipolar disorder as a (genetic) condition, of genetic information, and of other actors in the discourse (doctors, family members, and so on).

To address these questions, an examination was undertaken of a collection of texts relating to the development of psychiatric genetic tests. Focusing specifically on the introduction of tests for one particular condition – bipolar disorder – my thesis research provides an exploratory look at the discursive trends that are dominant in shaping the subject positions available to psychiatric genetic test users, as well as those areas of tension and contradiction where dominant trends are facing challenges from other discourses, and where subject positions are uncertain and in flux. In addition to examining in some depth the corporate websites of the two companies that have thus far sold genetic tests for alleles associated with bipolar disorder, I also examine texts produced by a number of other groups of stakeholders that comment on the development of such tests. Many of these texts relate directly to the offerings of the companies whose websites I examine (in particular, to the tests offered by Psynomics); others relate to similar tests that are either discussed hypothetically or are expected to be the outcomes of ongoing research in particular labs.

My approach falls into the broad and somewhat porously-bordered field of Foucauldian discourse analysis. In referring to the subject positions available to users of

psychiatric genetic services, I am drawing on Foucault's conception of the subject with regard to the power relations present in everyday social life:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize about him. It is a form of power which makes individuals subjects. There are two meanings of the word subject: subject to someone else by control and dependence, and tied to his own identity by a conscience of self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to. (1983, p. 212)

It is largely through discourse that Foucault, and those who have elaborated upon his theoretical work, have understood subjects to be constituted, and my approach takes no exception to this. However, in other ways my project does differ from what is understood to be "traditional" Foucauldian discourse analysis, if such a thing exists. While most Foucauldian discourse analysts have eschewed a close focus on linguistic details in the texts they examine, being rather more concerned with texts as wholes or ensembles of features, my focus is, to a significant extent, on details within the texts. It is my position that although texts may function as wholes, their components parts also have effects – and sometimes less consciously noticed, or more subtle ones, that contribute to how the text functions as a whole, but may have important functions that are distinguishable from those of the ensemble. A text is not reducible to its components, but nor are its components reducible to their functions in the text. Therefore, in my analysis, I use strategies that are more commonly associated with the critical discourse analysis (CDA) school of thought, including metaphor analysis and conceptual metaphor theory, and some basic statistical measures drawn from corpus linguistics approaches. These strategies are used in combination with a more general thematic analysis of the texts concerned, and are intended to provide additional perspectives on the texts, rather than

the formulation of widely generalizable truth claims. I aim to show how even from an admittedly subjective position, it is possible to identify other subjectivities and potentially point to ways in which these subjective understandings may be dominant or contested, and where the entry points to challenge those understandings we feel to be inadequate or oppressive may be located.

In order to locate these areas of hegemonic discursive dominance, and the areas of resistance and tension, I start with an analysis of key trends in North American, and more generally, Western medicine over the past forty-odd years, from the 1970s to the present, and examine how social scientists have written about these trends.<sup>2</sup> Critical studies of medicalization, responsabilization, the rise of the medical consumer, and the move toward a future-oriented risk paradigm in medicine and public health, in particular, constitute the central areas of focus here. In addition, I examine specific recent developments in genetic research and medicine, including concerns about “geneticization” and the possibility that it will be accompanied by reductionist and/or deterministic understandings of human life (as suggested by, among others, Abby Lippman in 1991), and discussions of the potential for new gene-based identities and identifications to develop out of this research and discourse.

Following this literature review, I ask how these historical and theoretical themes relate to mental illness, and to the case of bipolar disorder specifically. I explore the construction of bipolar disorder as a problematic state of being, and as a genetic disease. I

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<sup>2</sup> In the case of news articles and academic articles, the vast majority of the texts I selected for analysis came from American sources. This was not a conscious decision but reflects the fact that of the texts accessible through the means I employed, the majority were US-based. I discuss this finding, and the limitations it introduced in regards to discussions of the Canadian context, in Chapter 4.

then describe the introduction of genetic tests for bipolar disorder onto the market, and raise some questions about how these tests may be understood in relation to the roles of various actors in the definition and management of bipolar disorder.

I then describe in some detail the methods I use to address these questions, including the choices I have made in regard to the selection of particular texts, their preparation and analysis, and the software tools I have chosen to employ in organizing the texts. This precedes the presentation of my analysis itself, in which I describe the features of the texts, both as a whole, and as (partially) representative of several different categories or genres. I identify patterns, connections, and areas where these patterns and connections are problematized or ruptured, and relate these to the historical and theoretical trends discussed in the literature review. Finally, I close with a discussion of the implication of these patterns and ruptures for the subject positions available to users of psychiatric genetic testing, pointing out probable directions for the future, and areas of uncertainty and contestation. I argue that while the tests are indeed framed by corporate authors as tools for self-management and as such assume a consumer-citizen subject who is capable of this work on the self, other discursive trends found within other genres of texts (and sometimes even within the corporate texts themselves) work to counteract this framing. Psychiatric patients are conceptualized as in need of guidance, and sometimes coercion, and doubts about their abilities to make rational and informed choices are strongly evident. In this context, the “responsibilization” trend identified in the health and welfare systems of neoliberal societies is manifested in an alternative manner. Rather than the patients, or test users themselves, being framed as ultimately responsible, family members are encouraged to take on the task of becoming expert. In addition, because

bipolar disorder is understood to be highly heritable, family members are also charged with informing themselves of their own risks – though it is not clear that genetic testing is yet widely accepted as the means for doing this. The role of doctors in the decision-making process around these tests is also highly salient. While genetic tests offer the ability to provide risk estimates of developing disorder, the act of taking the test itself is held to involve some risk to patients and/or their families; the responsibility for managing this risk and determining whether it is one worth taking falls to medical professionals – psychiatrists genetic counselors, and to some degree academics (i.e. bioethicists).

Finally, it is not always clear what actions individual test users are expected to take in response to the results of genetic tests for bipolar disorder. A tension appears to exist here between the widespread sentiment that the *basis* of bipolar disorder is genetic, and the counterclaim that genes do not fully *determine* illness, and that in fact we are deeply uncertain about the actual mechanisms by which genes function in the development of psychopathology. Both the rationality and agency of genetic test users are therefore attributes subject to question, making the subject position of consumer-citizen an unstable concept in this discourse, subject to contestation by older understandings of health care users as “patients” – perhaps not passive, but neither wholly self-directed or self-aware, and defined more by their relations to experts than defined as experts in their own right.

## **Chapter 2: Medicalization and Markets**

### **2.1 Introduction**

Over the past four decades, many changes have taken place in the health care systems of Western nations. These transformations in medicine reflect shifts in the economic, political, cultural and technological circumstances of Western nations; they also play a part in shaping these wider circumstances. In the 1970s, when welfarism reached its pinnacle in North America (Bauman, 1997, p. 42), the tendency for a widening range of human experiences to become the concern of a pastoral (and sometimes disciplinary) state, through medicine, was identified by social scientists as a major area of concern. The re-definition of problems as medical in nature, and their jurisdictional appropriation by health “experts,” referred to as “medicalization,” became a major focus of study for sociologists and anthropologists, and has remained a topic of much significance. However, as North America has moved from welfarism into the present neoliberal era, and the state has rescinded some of its power, both disciplinary and pastoral, a new set of concerns has arisen (though not replacing the older ones). While the medicalization of life experiences has continued apace, the state no longer wishes to be responsible for providing their solutions. Instead, many scholars have claimed, responsibility has shifted onto individuals, families, communities, and private companies (Bauman, 1997; Rose, 1996). Many social scientists, particularly those working with a governmentality framework, have conceptualized this process of “responsibilization” as a transformation in governmental rationalities, from an era in which governance was sought through direct provision of services and direct enforcement of rules and mores, to an era in which it is seen as more efficient for citizens to govern themselves, in concert with non-state actors,

and where the market sets the rules of engagement (e.g. Rose, 1996). The telos of a neoliberal state is the expansion of capital; the privatization of services, including health care, serves that telos most effectively.

In this chapter, I outline the more prominent critiques that have arisen from within the social sciences to accompany these changes in North American medicine and wider social life from the 1970s onwards. Throughout this discussion, I draw attention to ongoing debates about the impacts of these developments on understandings of mental health and illness, and examine how the subject positions available to health care users, and specifically users of mental health care, have also shifted to reflect the new ways in which care is conceptualized. In chapter 3, I turn to a discussion of the place of genetic technologies within this context. I explore the notions of risk and responsibility as they relate to genetic tests – and specifically as they relate to genetic tests for bipolar disorder.

## **2.2 Defining disorders: The Medicalization Thesis**

### **2.2.1 *The Early Critique of Medicalization***

The political arena post-World War II in the UK, North America, and many other “Western” countries was one of increased state centralization and state involvement in the provision of social services.<sup>3</sup> As bureaucracies grew and experts multiplied, these experts sometimes achieved a level of intra-professional power that was difficult for outsiders to challenge. The ability to define societal problems and articulate their solutions was concentrated in the hands of specialists, and specifically, medical specialists – a group fairly homogeneous in its racial and gendered composition, as well

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<sup>3</sup> Rose (1996) traces this growing sense that the role of government should include some responsibility for “the social” to the early 20<sup>th</sup> century (p. 329).

as predominantly drawn from the middle-upper classes. This group possessed a very particular view of social life and what it ought to entail, which did not encompass many of the experiences and values unique to people who were not born as white, able-bodied, middle-class male subjects; such experiences were often, therefore, defined as problematic, and those experiencing them were defined as disordered.

As these professionals, supported by the welfare states that had endowed them with a central role in governing “the social,” continued to expand their jurisdiction, a backlash started to coalesce. In academic circles, this developed into the critique of what came to be called medicalization. The term was widely used in the 1970s in the writings of Ivan Illich, R.D. Laing, Thomas Szasz, Irving Kenneth Zola and others to describe the process by which medical professionals brought an ever-growing array of life’s experiences under their purview – both discursively, by defining them as medical and often pathological in nature, and materially, by managing them through interventions developed and administered by medical experts. In many cases, this involved a transition from viewing “deviance” as an issue of “badness” to “sickness” (Conrad & Schneider, 1992) – transferring jurisdiction over problems from the legal or moral arena to the medical. The medical model allowed for deviance, while still being a part of the social world, to be conceptualized as a problem concerning (groups of) individuals in society rather than as a “social problem.” Sociologists, whose object of study was “society” and whose *raison d’être* was “social problems,” had, of course, vested interests of their own in decrying the medicalization of what they saw as ultimately social issues – while there was widespread support among social scientists for changes that would take deviance out



of the criminal or moral arena, its immediate importation into the medical-scientific sphere of influence gave short shrift to “social” solutions.

### **2.2.2 Industry Influences**

Although the welfare states of the 1970s and prior decades have receded, and the power and status of doctors have decreased, the number of life experiences that are defined and treated as medical issues continues to grow. As Conrad notes, the process of medicalization continues, but its drivers have changed (2005; Conrad & Leiter, 2004), and along with these changes in society, the focus of medicalization studies has shifted. The emerging “engines of medicalization” identified by Conrad (2005) include the biotechnology industry, managed care, and consumers (p. 5).<sup>4</sup> Efforts by the pharmaceutical industry to increase profits have come under scrutiny, with a number of scholars identifying a shift in industry marketing practices from promoting a new drug as the treatment for a well-known condition to promoting conditions themselves (Conrad & Leiter, 2004, p. 163-4). Much of this scrutiny has focused on the advertising practices of the industry, and particularly on direct-to-consumer advertising, or DTCA.

Direct-to-consumer advertising in the US actually arose out of the joint influences of the patient rights movement in the 1970s and the consumer rights movement in the 1990s, taking off in the early years of this latter decade (Donohue, 2005, p. 661-2, 683). Proponents argued that by making information on available drugs accessible to the

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<sup>4</sup> A discussion of the intricacies of managed care is beyond the scope of this paper, particularly as the specific arrangements and regulatory regimes differ greatly internationally and even at the sub-national level, but it is worthy of note that this industry in some cases works to demedicalize rather than medicalize conditions (Conrad, 2005, p. 10). In mediating the relationships between supply (biotechnology) and demand (consumers), insurance providers may have interests that fall in both courts.

general public, this practice would rebalance power dynamics between patients and physicians – the traditional targets of pharmaceutical advertising – and allow consumers to make informed choices on their own behalves. However, since its inception, direct-to-consumer marketing has faced a great deal of criticism, including claims that it can be misleading, both in regard to the benefits of drugs advertised and their harms, that it plays on people’s emotional needs rather than fulfilling a genuine need for treatment, and that it enables companies to turn normal life experiences into disorders to be marketed (and medicated) (Donohue, 2005; Woodlock, 2005). Psychiatric disorders, in particular, have become a target of well-funded campaigns by pharmaceutical companies, although other conditions are also treated in this manner (Conrad & Leiter, 2004; Conrad, 2005).<sup>5</sup>

A common strategy employed in marketing conditions is the widening of diagnostic thresholds to expand the numbers of individuals falling into existing categories, which changes the quantitative level of particular characteristics needed to be diagnosed as disordered. Studies of this process have included analyses of the expansion of depression as a diagnosis over the past decades in both the West and other countries (e.g. Horwitz, 2002; Horwitz & Wakefield, 2007), as well as the transformation of once-obscure DSM categories like social anxiety disorder (SAD) and generalized anxiety disorder (GAD) into common diagnoses with quite inclusive criteria (Conrad, 2005, p. 6). The symptoms or traits associated with these conditions have often been viewed through a moral lens or as “personality” traits – shyness, for example. Thus the shift from

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<sup>5</sup> Currently, the United States and New Zealand are the only countries that explicitly permit the advertising of prescription drugs directly to consumers (Donohue, 2005). Gardner, Mintzes and Ostry (2003), however, note that Canadian regulatory loopholes in effect allow for this practice to occur here as well.

“badness” to “sickness” identified by Conrad and Schneider (1992) remains relevant even where drivers of medicalization are not doctors but corporate profit margins.

As medical research on the etiologies of both common and rare disorders has increasingly focused on genetics, the genomics industry has become a key player alongside pharmaceutical companies in determining how conditions are defined. I return to this point at some length below, but for the moment, it is essential to note that one of the most economically promising areas of genetic research is in pharmacogenomics – the development of drugs targeted to populations sharing particular genetic characteristics. These genetic characteristics, once linked to a product, may replace to some extent the sets of phenotypic characteristics that to date have been the subject matter of medicalization. Additionally, because corporations desire the widest possible markets for their products, technologies that can be marketed based on (genetic) risk, which can apply to whole populations, may be even more appealing than those that must be marketed to those already experiencing symptoms – usually a much smaller population.

### ***2.2.3 From Coercion to Internalization***

Certainly, biotechnology companies continue to have vested interests in promoting a medical model of mental illnesses, as well as of those other life experiences that cause distress or suffering, and their marketing practices continue to be the objects of intense scrutiny (e.g. Woodlock, 2005). However, analyses of medicalization as a top-down process imposed by state, market and professional interests have in recent years been accompanied by an increasing recognition by social scientists that health care users, both individually and collectively through advocacy groups, have played a substantial role in seeking recognition of their conditions as medical in nature (e.g. Kilshaw, 2006).

Mental health organizations, in particular, have embraced the premise that attributing a medical etiology to a condition leads to a reduction in the stigma surrounding it.

As early as 1972, Reeder suggested that a process of change was in motion whereby patients, formerly cast in a passive role as the recipients of guidance and care delivered by experts, often without explanation or choice in the matter, began to take on a more active and participatory role in their own care (p. 406-7). Since that time, this shift has transformed medicine – economically, politically, professionally, culturally, and technologically – as the coercive power of doctors has retracted and the discourse of patient choice has come to the forefront. In the 1970s and 1980s, the efforts of patients to gain recognition of their conditions as medical were commonly analyzed in terms of social movements (e.g. Reeder, 1972) or in some cases as a part of a move toward a more participatory democracy (Allsop, Baggott & Jones, 2002). However, these perspectives have been joined and to some degree supplanted by a more Foucauldian analysis. As Robert Nye argues, Foucault’s work helped to usher in a more nuanced and complex understanding of medicalization, one which “began to decenter the notion of medical power, locating it in the rules of disciplinary discourses that work on the bodies of individuals” (2003, p. 118). While the agency of patients-*qua*-consumers is not denied, their desires for medicalization are envisioned as largely shaped by societal discourse rather than solely “rational self-interest.” Petersen (1993) notes, in fact, that Foucault did much to destabilize this conceptualization of the fully autonomous subject (p. 120).

#### **2.2.4 Citizenship through Consumption of Care**

The health care consumer, as Henderson and Petersen (2002) note, is only one variant of a wider consumer subject position that has become widespread in advanced

liberal societies. This notion that consumption constitutes the appropriate way to enact one's role as a citizen is one of the primary tenets of a market-based economy where the principles of supply and demand reign supreme. In order for the economy to function, demand for goods and services must continue to rise, as the model is predicated on continuing growth. Once health care is integrated into the market as a commodity, demand for it must continue to rise. This demand is manufactured both through the introduction of new products and services (often for new or expanded diagnostic categories), and the framing of these products or services as necessary not only to one's physical health but to one's ability to fulfill the requirements of citizenship. The *act* of taking care of oneself is itself an essential component of this citizenship. As Petersen (1997) notes, to be a responsible citizen entails that one subject oneself to continuous self-monitoring, self-assessment and self-management; It is not simply the end product (a state of maximized capacity that allows one to adapt flexibly to the changing demands of one's environment) that fulfills this subjectivity, but also demonstrating one's willingness to engage in the project of self-management. Health itself, as well as the services and goods that support it, becomes a commodity to be produced and purchased.

Scholars have also argued that the conceptualization of health care users as consumers opens up certain new possibilities for interactions with experts – particularly in regards to whose knowledge and abilities are regarded as valid and valuable (Novas & Rose, 2000; Heath, Rapp & Taussig, 2004). As consumers, they are discursively endowed with the powers of rational choice and agency (Henderson & Petersen, 2002, p. 2), and thus accorded a more significant role in determining their own care, as well as increased involvement in deciding how care in general should be offered. As Irvine (2002) argues:

The construction of a new subject position, the health consumer, created new possibilities for people to imagine alternative ways of thinking and talking about lay-professional relationships which were fundamentally different from the disciplinary regimen of the past. (2002, p. 34).

### **2.2.5 Limits to Consumerism**

However, many of the same authors who have described the transformative possibilities of this new subject position have also questioned the desirability of the uncritical adoption of the consumer/market model of medical service delivery. Critiques tend to centre on the differing features of medical care delivery as opposed to the ideal-type marketplace situation, both in regard to the services being delivered and the ability of patients to make “unconstrained” choices. In many cases, refusing to purchase a service or product would significantly compromise a patient’s health: they are thus unable to exercise their “consumer choice” and are vulnerable to the choices of companies as to pricing or service quality. In other circumstances, patients may not be in a mental or physical state to make decisions on their own behalf (i.e. they may be unconscious or non-verbal). In addition, Deborah Lupton has argued that the nature of the medical encounter is such that, even when patients are physically, mentally, emotionally, and financially able to make their own decisions about care, they may not always desire to do so. In situations where fear and uncertainty are heightened and patients are made deeply aware of the limitations of their own knowledge, they may prefer for doctors to take a more forceful or directive role (Lupton, 1997a; Lupton, Donaldson, & Lloyd, 1991). In some cases, shaping oneself as a “good patient” may involve manifesting such qualities as obedience, passivity, and a willingness to subject oneself to medical authority; in others, it may involve taking proactive measures, learning about one’s condition, and making careful decisions oneself. Lupton argues that both paths may be

followed by the same patients under different circumstances, or even simultaneously (1997a).

In the context of mental health care, even if patients do pursue a consumer-like subject position, their mental or emotional state may preclude careful consideration or self-interest – or may be expected to do so by those providing care. As Martin (2007) has noted, the rationality of those diagnosed with bipolar disorder is held to be suspect, and those living with this diagnosis are well aware of it. Although most persons with bipolar disorder experience periods of stability or “normality” in between episodes of depression or mania, during which they might be supposed to be entirely as “rational” as anyone else, because manic and depressive episodes may develop slowly, even patients who appear “stable” may be experiencing the beginning symptoms of an episode – thus their decisions always have the potential to be construed as symptoms of mental/emotional changes. In this circumstance, the discourse of patient choice and autonomy is weakened, as patients’ capacity to fulfill this type of subject position is directly at issue.

## **2.3 Health as a Social Good: The Responsibilization Thesis**

### **2.3.1 Foucault and the Governmentality Framework**

As the users of health care are (re-)conceived as active, rational, autonomous subjects, they are increasingly *expected* to act in such a manner, proactively taking responsibility for managing their health in the present and future. Several key concepts drawn from the work of Michel Foucault have found use in analyses of this discourse of “responsibilization” (e.g. Teghtsoonian, 2009). Although Foucault was writing prior to both the full ascendancy of neoliberalism and the genetic paradigm in medicine, his work on the concepts of “governmentality” and on “technologies of the self” has been

instrumental in understanding the ways in which moral responsibility is constructed in the realm of health and illness, and how practices and discourses of what it means to be a healthy citizen are inseparable from the political rationalities of the governing state.

Before continuing my discussion of current trends in Western medicine, it is necessary to outline some of these ideas, which have substantially informed my own work as well as that of many others working within the sociology and anthropology of health and illness.

Foucault's notion of governmentality conveys a "semantic linking of governing ('gouverner') and modes of thought ('mentalité')" (Lemke, 2000, p. 2). As Lemke notes, Foucault used the term "government" in a way that reflected its older sense as "the conduct of conduct" and thus meant not only state apparatuses designed to govern populations, but micro-level practices including the governance of selves and other individuals (Lemke, 2000, p. 2). Governmentality serves as "a contact point between technologies of the self (self-subjection) and technologies of domination (societal regulation)" (Petersen, 1997, p. 202-3).<sup>6</sup>

The concept has provided us with a way to conceptualize the internalization of the "imperative of health" (e.g. Lupton, 1995), and to understand how this internalization benefits the state at the same time as seeming like it originates from within the subject. And of course, a desire for good health is not something that runs counter to the desires or interests of individuals, in most cases: it is not a "false consciousness" forced onto a subordinated population by a dominant class. However, what Foucault aimed to show is

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<sup>6</sup> Foucault defined technologies of the self as those that "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness purity, wisdom, perfection, or immortality" (Foucault, 1988b, p.18).



how so many practices that seem to us universal and inevitable are in fact very much historically constructed and contingent (Martin, 1988, p. 11). This includes not only what we define as illness, and the etiologies we ascribe to it, but also the particular emphasis in Western nations on practices that encourage health, and the constitution of these practices as components of responsible citizenship.

The self-constitution of subjects formed one of the focal points of Foucault's later work. Again, his notion of the subject relies on bringing together two etymological readings: one is both a subject of power, of the state – an object acted upon – and a subject in the sense that one is an agent acting in relation to others. Lupton (1997b) notes that both senses of subjectivity may be at play in medical encounters, and both may take multiple forms, including acceptance and resistance. The choice to resist domination or accept it is fundamentally bound up with practices of self-constitution (1997b, p. 105). However, this “choice” is not always a conscious and “rational” decision. As Petersen points out, for Foucault, the subject does not pre-exist its constitution, nor does it exist outside its structural and discursive conditions: thus the ways in which people govern themselves are profoundly constrained (1993, p. 120).

### ***2.3.2 Neoliberalism and Responsibilization***

Rose & Miller (1992) argue that the transition from welfarism, a system that involved substantial government intervention into the wellbeing, broadly defined, of citizens, to neoliberalism, has ushered in an era in which practices of governance, including those relating to the provision of social goods, are no longer primarily managed by state programs, but instead are shifted onto the individual:

“For neoliberalism the political subject is less a social citizen with powers and obligations deriving from membership of a collective body, than an individual whose citizenship is active. This citizenship is to be manifested not in the receipt of public largesse, but in the energetic pursuit of personal fulfillment and the incessant calculations that are to enable this to be achieved.” (1992, p. 201)<sup>7</sup>

In the field of health care, these processes of self-management rely heavily on the notion of “risk.” Petersen (1997) characterizes health promotion and the new public health as “part of a set of new management techniques of a kind specific to ‘neo-liberal’ societies” (p. 193), and suggests that “the processes of risk management have, in effect, served the objective of privatizing health by distributing responsibility for managing risk throughout the social body while at the same time creating new possibilities for intervention into private lives” (p. 194). This constitutes, in the words of Michael Orsini, the “responsibilization paradigm” (2007, p. 354). The project of improving health is viewed as a matter of grave importance at both individual and societal levels (Callahan, 2000). However, while illness is often framed in as a “burden” or “cost” to *society*, it is usually *individuals* whose behaviour is seen as essential to reducing this burden.

### **2.3.3 Individualization and Social Justice**

Whether driven by doctors or other medical professionals seeking power and status, by pharmaceutical companies seeking profits, or by patients themselves seeking medical recognition and treatment for their experiences, medicalization locates problems at the level of individual biological and biochemical systems. This definitional aspect,

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<sup>7</sup> A neo-liberal society, however, does not imply a total detachment of government from the affairs of individuals; instead, the management of these affairs is overseen by a myriad of non-state actors and institutions enabled by the state to take on this mediating role – a practice referred to by Rose and Miller as “governing at a distance” (1992, p.173).

which Conrad (2005) argues is the “core” of medicalization, is also the core of concerns about medicalization. Rather than addressing the social causes of psychological distress and dysfunction, critics have argued, those working under a medical model of mental illness generally draw attention to, diagnose, and attempt to treat problems in individuals, usually with individual solutions – including, of course, drug therapies. LaFrance, reviewing a range of studies of pharmaceutical marketing campaigns, all of which strongly promote medicalized accounts of depression, locates a common concern among the authors of these studies with what they see as a selective inattention to the social reasons why people, and women in particular, might be experiencing mental distress (2007, p. 128). This disregard for social causes, she suggests, maintains the status quo while working in the economic interests of pharmaceutical companies. Similarly, Lock argues that “with medicalization, attention is deflected away from the social arrangements and political forces that contribute to the incidence of distress and disease and to the experience of life cycle transitions” (2001, p. 481). Thus medicalization, despite its early connection with doctors as power-hungry agents of the state, is now often viewed as one facet of a political order that seeks to shift responsibility for health onto individuals in society and off of those in positions of political power: the state is seen not as doing too much, but too little.

# **Chapter 3: Bipolar Disorder as a Genetic Disease**

## **3.1 Introduction**

Before continuing to a discussion of the genetic tests for bipolar disorder that form the focal points of the discourses I have examined, it is necessary to first describe bipolar disorder itself as it is understood as a genetic condition – and to interrogate what the implications of this genetic understanding might be. In this chapter, I briefly outline social science critiques of what has become known as “geneticization,” focusing on notions of genetic risk and genetic responsibilities. Following this introduction, I discuss current epidemiological and etiological understandings of bipolar disorder, and point out a few particular points of tension within this field of research. I conclude with a discussion of the development of genetic tests for alleles associated with bipolar disorder, both in regard to currently or recently available tests, and likely future directions.

## **3.2 Geneticization: Molecular Destinies?**

### ***3.2.1 Genetic Reductionism and Genetic Determinism***

Since the discovery of the double helix structure of DNA in the 1950s by Watson and Crick, research into both the molecular composition and the functional role of “genes” in the development of organisms has been a heavily funded area of science in Western countries. Much of this funding and interest has been predicated on the idea that if we can describe in minute detail the DNA of an individual, we can follow, step-by-step, the process whereby the “information” contained in this DNA is transcribed into RNA, leading to the production of certain proteins, which in turn lead to the functioning

(or dysfunction) of cells and organs (Herbert, 2005), and thus to the manifestation of physical and behavioural traits and qualities. This simplistic conceptualization of genes as a “code” that can be translated quite directly into human qualities is referred to as the “central dogma,” and has informed a great deal of both professional and popular writing on genetics (Keller, 2000, p. 54).

The widespread interest from public and private funding bodies, popular media, and laypersons in genetic research has been mirrored by interest from the social sciences in the effects this research may have upon society. Abby Lippman, writing in 1991, introduced the term “geneticization” to refer to:

...an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviors and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health (p. 19).

Lippman saw cause for alarm in this trend, as did many others. Lewontin, Rose and Kamin wrote in 1984:

Over the past decade and a half we have watched with concern the rising tide of biological determinist writing, with its increasingly grandiose claims to be able to locate the causes of the inequalities of status, wealth, and power between classes, genders, and races in Western society in a reductionist theory of human nature. (1984, p. ix).

In locating human variation in the genes, they felt, scientists were providing justification for the continuation of discriminatory policies, attitudes and practices. If particular groups could be claimed to be genetically distinct (and further, if it could be claimed that these genetic differences were both unchangeable and more important than other differences), then it could also be claimed that no amount of redistribution of resources would solve existing inequalities. Social justice-oriented campaigns could be

claimed to be misguided and unnecessary – flouting the “natural order.” Writing in the Reagan/Thatcher era of the 1980s, the authors saw a direct link between genetic determinism and the retraction of the welfare state. In the every-man-for-himself (and every woman in the kitchen) ideology of the times, biological differences could be used as handy evidence of the “rightness” of what they called “the New Right” in claiming that the role of the state should not include providing for the entry of women into the workforce, or for the education of disadvantaged ethnic groups.

Paralleling critiques of medicalization, then, the key concern with geneticization as biological determinism is its tendency to individualize problems, locating them at the level of the individual’s genes rather than in their social position (Lippman, 1992).

Although Lewontin, Rose, and Kamin were particularly concerned with the potential for genetic determinism to encourage racism, classism, and sexism, this concern retains a great deal of significance in the context of mental illness, where the relationship between genes and environment has been very much a subject of intense controversy.<sup>8</sup>

### **3.2.2 Genes and Environment: Enlightened Geneticization**

Research into genetics has changed a great deal since the 1980s and early 1990s. Many behavioural geneticists have retreated from bold claims about the power of the genes to determine IQ, criminality, political preferences, and a host of other traits and

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<sup>8</sup> Concerns about geneticization are also particularly relevant in disability studies. In fact, Lippman’s initial coinage of the term came from her study of the discourses surrounding prenatal genetic testing for disabling conditions (Lippman, 1991). Many disability rights activists have argued that locating “disability” in the genes ignores the social conditions that are the true causes of suffering, and reinforces discriminatory attitudes and policies (see Parens & Asch, 1999, for a thorough and balanced discussion of these issues).

behaviours, major and minor.<sup>9</sup> In the realm of medical genetics,<sup>10</sup> while Crick's central dogma may still more or less hold true for (generally rare) Mendelian disorders, which are inherited through a single gene and are usually strongly deleterious, in the case of non-Mendelian disorders (which make up the vast majority of the more common mental illnesses, including bipolar disorder), genetic contributions are much less black and white. Molecular research over the past two or three decades has revealed that multiple genes are involved in most mental illnesses, each on its own having a very small effect, and that those genes interact in complex ways with one another, with epigenetic factors (having to do with whether a gene is expressed or not) and with environmental factors (Frazzetto & Gross, 2007). Herbert (2005) argues that the idea of "genes for" such illnesses is less than useful both in research contexts and in public discourse, and continues to be propagated only because so much research funding and public good will have gone into research programs based on what now seem simplistic models of inheritance.

On the other hand, the new discourse of genetic complexity may continue to accomplish, in a more subtle way, what reductionist language and bold claims did in the past: to focus attention on individual biological mechanisms of illness while ignoring the social sphere in which it develops and is experienced. Adam Hedgecoe has suggested that, while lip service is now paid to environmental factors in the development of mental illness, genetic factors continue to be privileged in medical research. Basing his argument

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<sup>9</sup> See Parens, Chapman, & Press (2006) for a wide-ranging introduction to current research and controversies in this field.

<sup>10</sup> Psychiatric genetics appears to occupy a gray area between the traditional poles of medical and behavioural genetics. This indeterminate categorization reflects the shifting

on the discourse found in several review articles on schizophrenia ranging over the years from 1989 to 1997, he claims that a “narrative of enlightened geneticization” is present, which he characterizes as “the presentation of current genetic thinking as reasonable, non-extremist, and accepting a rôle for non-genetic factors in schizophrenia causation” (2001, p. 875).<sup>11</sup> Through this narrative, scientists justify increases in funding for genetic research by incorporating the arguments of critics into their own discourse, claiming to take into account the influence of the environment (and to some extent, actually doing so), but nonetheless placing genes at the centre of the equation as the target for action.

### **3.2.3 Genetic Risk and Responsibility**

Nonetheless, acknowledging a role, however secondary, for environmental factors and personal action, complicates the picture considerably in regard to determinist tendencies. Instead, many theorists have come to conceptualize genetic tests as one component of the overall trend toward promoting proactive self-management and self-care in medicine. As noted above, this shift is deeply connected to advanced liberal techniques of governance that seek to privatize responsibility for the citizenry’s wellbeing – and that presuppose a subject that is endowed with the capacity and desire to make decisions that alter his or her own future. This conceptualization reflects the fact that popular discourses of genetics heavily emphasize choice and autonomy – as Lippman herself notes (1991). Of course, this freedom to choose quickly becomes a responsibility to choose wisely; however, the assumption that people have the capacity to make these

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definitions of mental illnesses themselves – as organic pathologies, normal variations, personality types, or structurally imposed suffering.

<sup>11</sup> Hedgecoe uses the term “geneticization” in a more limited sense, to refer to what “takes place when a condition is linked to a specific stretch of DNA” (2001, p. 876).



choices, and further, that their choices will have significant impacts on their own future wellbeing, deeply undermines the thesis that determinism is an inevitable outcome of geneticization (Novas & Rose, 2000; Lemke, 2004).

Thus genetic tests for complex illnesses – including bipolar disorder – cannot provide determinative predictions or diagnoses, but only measures of susceptibility. As Lemke (2005) argues, “the identification of individuals with genetic risks does not serve to pinpoint some ineluctably biological fate; nor does it signify something which is beyond control. On the contrary, it refers to a privileged field of interventions” (p. 97). While the “genes” may be fixed, one’s fate can be altered through action upon the environmental factors that determine whether those genes are expressed. Once one’s risk status is ascertained through genetic testing, intervention may take the form of enhanced vigilance to “catch” symptoms at an early stage, adjustments to one’s routines, habits and relationships to decrease “lifestyle” risks, or prophylactic medical treatments to avert the onset of illness.

### **3.2.4 Biosociality and Kinship: Ethics of Care, or Genealogical Ethics?**

Rather than individualizing illness or risk, or even individualizing the means of intervention, a number of scholars have suggested that, in fact, genetic research may actually function to create new means of connecting people. Rabinow (1992) points out the new possibilities genetic knowledge may provide for transforming both identities of, and relationships between, individuals and groups. He claims that “the new genetics [will become] a circulation network of identity terms and restriction loci, around which a truly new type of autoproduction will emerge,” which he labels “biosociality” (1992, p. 241). This concept bears a strong resemblance to the notions of “genetic citizenship” (Heath,

Rapp & Taussig, 2004) and “biological citizenship” (Rose, 2007); in fact, Rose himself makes no real distinction between the terms (p. 23-4). These authors, and a number of others, have conducted empirical research on advocacy groups for genetic diseases, delineating new ways in which the residents of the genomic era relate to one another, the world, and themselves, and use new technological forms of understanding in order to do so (see also Gibbon & Novas, 2008; Schaffer, Kuczyinski, & Skinner, 2008).

In this view, the very nature of DNA as shared (however partially) across populations is posited to be such that interpersonal connections and collective actions may in fact be encouraged (Novas & Rose, 2000; Heath, Rapp, & Taussig, 2004). In an age where communicative technologies allow geographical barriers to be transcended, at least for those with access to the necessary resources, even those diagnosed with extremely rare genetic diseases may be able to connect with others who share their condition (Heath, Rapp, & Taussig, 2004). The commonality of suffering, it has been argued, may induce people to feel a sense of responsibility to others, both those currently living with a condition and those who will be diagnosed with it in the future (Gibbon, 2008; Hallowell, 1999). Heath, Rapp, and Taussig (2004) go so far as to argue that “the networks of association arising from these alliances are transforming the public sphere as a site for an emerging ‘ethics of care’” (p. 155) – and that this new era of collaborative identity-making and action may create “venues for participatory knowledge-making in which the distinction between the subjects and objects of scientific inquiry are regularly called into question” (p. 156).

Many of the responsibilities that attend knowledge about genetic risk, however, may reside at the level of the family rather than in dispersed groups crossing cultural,

national, class, or ethnic boundaries. While information about the health of one person often impacts family members indirectly – changing family dynamics of care, financial circumstances, and expectations for the future – genetic information is fundamentally about the family (or at least close blood relations), and has the capacity to affect them directly. By learning one’s risk status, one receives information about the risk status of other family members.

Polzer (2005), discussing testing for familial melanoma, notes that respondents reported a strong sense of responsibility to (1) become aware of their own risks, (2) take a proactive role in managing those risk, and (3) inform other family members of their genetic risks, and urge them to take preventive medical action. Drawing on Foucault, she views family as “both an object of, and a vehicle for, genetic governance” (p. 88) – individuals are conscripted to govern the health-related behaviours of both themselves and their kin. The discourse that arises is one that centres on the choices made available by predictive genetic testing; however, it “privileges a particular configuration between ‘choice’ and ‘regulation’ such that individuals perform their freedom in ways that cast them as responsible citizens who actively take charge of their health through personal and familial risk testing” (p. 87-88).

It is important to note, as do Cox & McKellin (1999), that this responsibility is deeply gendered: women take on a greater share of the duties around communication of health-related information, and are far more likely to request genetic testing. Hallowell suggests that this gendered division of labour reflects the fact that “women’s sense of self-worth is primarily based upon caring for, and giving to, others” (p. 112). Women’s subjectivities as wives, sisters, mothers, and daughters have long required them to take on

the role of health care “expert” – this now may extend to becoming genetically aware (see also Schaffer, Kuczyński, & Skinner, 2008, p. 156).

The responsibilities that attend genetic information at the level of the family surpass choices about medical care and lifestyle, however, extending to major life choices like reproductive decisions and marriage. Even if IVF offers the ability to ensure that prospective children will not be genetically affected, would-be parents may doubt their own future abilities to provide care or fulfill other responsibilities. In this context, learning, or not learning, one’s risk status becomes an ethically charged decision, as does the choice to pass this knowledge on to others (Konrad, 2003a, 2003b). One’s decisions about which information to pass on, and to whom, form a part of one’s self-constitution as a moral and responsible family member, as well as forming part of a larger discourse about what kinship means in the genetic era.

Genetic risk, then, is by its nature shared – between family members, and between individuals in all sectors of society. But the configurations that arise surrounding the taking of responsibility for these risks may differ greatly in regard to different conditions, depending on their unique characteristics and their pre-existing definitions – as medical conditions, as genetic disorders – and who they are seen to affect. Lock has argued that for some complex disorders (her example is Alzheimer’s), taking part in “biosocial” networks and identity practices may not be practical or desirable (Lock, 2008). In this case, she claims, a combination of factors, including a sense of stigma or shame surrounding the disorder, the absence of treatment options, the high cost of tests, and a public recommendation against testing by the Alzheimer Disease Association “effectively

blocks any form of biosociality beyond the immediate family for the majority of people dealing with Alzheimer's disease" (p. 59).

These configurations may also change over time and in different locations, as they are highly dependent on their wider political-economic contexts. As Rose and Miller argue, "governing at a distance" – through the construction of subjects who take governance upon themselves – has become the preferred strategy for neoliberal states (1992). Yet this distance may be achieved in a variety of ways – through shifting responsibility onto professional groups (e.g. doctors and genetic counselors), onto families, onto "communities" (whether defined spatio-temporally or by the shared possession of common attributes – including diseases) or onto individuals. "Biosocial" groups have the ability to connect with the market and with expert knowledges in new and innovative ways (Heath, Rapp & Taussig, 2004; Novas, 2008); while in some cases, these connections may take pressure off the state, in others they may enhance the capacity of the population to make demands on the state for more care, more information, or more regulation (Schaffer, Kuczynski & Skinner, 2008; Rose & Novas, 2005).<sup>12</sup> In this case, locating responsibility for attending to genetic risk at the level of the family rather than potentially politically powerful "biosocial" groups might serve the interests of a neoliberal state rather more effectively.

### **3.3 Bipolar Disorder as a Genetic Disease**

Although much popular discussion of bipolar disorder (BP) treats it as a single illness, psychiatrists recognize a number of related conditions forming a bipolar spectrum

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<sup>12</sup> Elizabeth Roberts notes that the formulation of biosociality as a type of citizenship "entail[s] a state (no matter how privatized) that is assumed to be a stable entity that can distribute desirable social welfare benefits" (2008, p. 83)

(Barnett & Smoller, 2009). As outlined in the DSM-IV, patients diagnosed with a condition on the bipolar spectrum may be categorized as having BP I, BP II, cyclothymia, or BP-NOS (not otherwise specified) (NIMH, 2009). All of these conditions are characterized by marked and impairing variations in mood over time, ranging from mania to depression (Barnett & Smoller, 2009, p. 331). A diagnosis of BP I is dependent on the patient experiencing “manic” episodes, while patients who experience depression along with hypomanic episodes but no manic or mixed episodes may be diagnosed with BP II. Cyclothymia is characterized by a similar pattern but with hypomania and mild depression rather than major depressive and manic episodes. BP-NOS is a diagnostic category used when a patient exhibits symptoms but does not fit the criteria for any of the other specified conditions (NIMH, 2009). Researchers have estimated prevalence in the Canadian and American populations to be between roughly 2 and 4.5%, depending on the criteria used for inclusion (Schaffer et al., 2006; Merikangas et al., 2007).

Hinshaw and Cicchetti note that biological models (if not genetic) for mood disorders are traceable to Hippocrates, and it was his theory of unbalanced “humours” that resurfaced in the Renaissance as scientific reasoning came to the forefront and overtook the theological models of demonic possession that had held sway in the Middle Ages (2000, p. 562-565). The humouric model was succeeded in North American society by the early 20<sup>th</sup> century largely by psychodynamic models that gave little weight to organic causes and attached a great deal of significance to early childhood environment and parenting. As Hinshaw and Cicchetti argue, however, theories seem to have shifted

cyclically, and the mid-20<sup>th</sup> century saw a rise once again in biological models, this time with the emphasis on the genes.

Kaufman notes that as early as 1838, familial transmission of “mania” was posited as a likely mechanism by Esquirol (Kaufman, 2003, p. 81). However, it was not until the 1960s and 1970s that twin and family studies provided the heritability estimates that are still relied upon today.<sup>13</sup> These studies calculated the heritability of bipolar disorder to be in the 80 to 85 percent range – much higher than for many single-gene disorders (Barnett & Smoller, 2009; Serretti & Mandelli, 2008).

Molecular genetic research on bipolar disorder has linked a number of different genetic mutations to both increased risk of developing the condition and to lowered risk. Few studies have consistently implicated mutations at the same genes, but the recent move away from linkage studies toward association studies, particularly genome-wide association studies (GWAS), has shown some promise (Barnett & Smoller, 2009; Psychiatric GWAS Consortium, 2009). Serretti & Mandelli (2008) discuss recent findings and state that “a number of genes seem to be definitively involved in bipolar disorder” (p. 742). Barnett & Smoller (2009) also suggest a number of other genes that have been associated with bipolar disorder in independent studies, but caution that none have been established. Thus while bipolar disorder is certainly understood as a genetic condition, the state of current knowledge about which genes cause it, and the means by which they do so, is very limited.

A particularly interesting trend to emerge from recent psychiatric genetic research

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<sup>13</sup> Heritability, in this context, refers to a statistical concept: the amount of variation in a population in regard to diagnoses of bipolar disorder that can be explained by genetics, as opposed to the amount of variation that is thought to be due to non-heritable factors.

is that traditional diagnostic categories and divisions between mental illnesses, which have long been a highly contested terrain, are facing new challenges. The fact that some of the same genes are consistently implicated in patients with different diagnoses has led to a growing sense within the field that viewing these diagnoses as discrete disorders is untenable. A large and growing number of studies have suggested common genetic factors for bipolar disorder and major depression (e.g. Akula et al., 2010); a similar trend prevails with schizophrenia. Porteous (2008), referring to the latter disorder, argues:

Although the dominant tradition in psychiatry has been to treat these conditions as distinct psychopathologies, there are no uniquely defining features. Differential diagnosis is based upon a subset of overlapping, self-reported indications. This conventional dichotomy is under challenge from the genetic evidence” (p. 229).

Other researchers have taken genetic research as evidence not merely of the indistinctness of boundaries between previously categorical disorders, but of the incoherence of bipolar disorder itself as a “syndrome.” Bowden (2008) argues that the DSM criteria for diagnosing bipolar disorder may actually hinder genetic research as they tend to lump together many quite different phenotypic expressions of bipolarity, relying on combinations of traits that may originate through different biological pathways. Hence he emphasizes the potential offered by studies of both biological and behavioural endophenotypes (see also Gottesman & Gould, 2003).<sup>14</sup> Similarly, a number of researchers have argued that genetic research into bipolar disorder should focus on populations defined by drug response. Alda et al. (2005) suggest that individuals who respond well to lithium treatment could form a genetically coherent group for further

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<sup>14</sup> Endophenotypes are “measurable components unseen by the unaided eye along the pathway between disease and distal genotype [...] Endophenotypes represent simpler clues to genetic underpinnings than the disease syndrome itself, promoting the view that psychiatric diagnoses can be decomposed or deconstructed, which can result in more straightforward—and successful—genetic analysis” (Gottesman &



study. This kind of genetic research has major implications for the pharmaceutical industry (in relation to pharmacogenomics), but is also of deep importance to diagnostic practice, as it may substantially redefine what we consider to be the “core” components of bipolar disorder.

It should now be clear, then, that the search for a genetic explanation for how “bipolar disorder” develops has not been straightforward, and “successes” have been partial and often led to more questions than answers. While research continues, some scientists involved in psychiatric genetics express increasing skepticism about the ability of their research to lead to curative treatments (Frazzetto & Gross, 2007). Even the development of reliable diagnostic and predictive technologies seems far out of reach for some (Holtzman & Marteau, 2000). The discovery that so many genes contribute to risk for mood disorders, and that those genes are often shared between disorders, has complicated matters considerably. Whether this knowledge leads to a more spectrum-based diagnostic system where bipolar disorder and other mental illnesses are considered less discrete entities than variations on a theme, or to a further fragmentation of diagnostic categories into subtypes, remains to be seen. However, it is clear that genetic research has a considerable capacity to affect how we understand bipolar disorder as a condition, and even how much of a “disorder” it is.<sup>15</sup>

In addition to acknowledging genetic complexity, most recent research in psychiatric genetics does, as noted by Hedgecoe (2001), recognize a role for the

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Gould, 2003, p. 636).

<sup>15</sup> Frazzetto and Gross go so far as to state that “behavioural genetic studies should not regard (...) mental disorders as things in themselves, but instead should view them as restricting factors operating on the complex mix of direct and indirect effects at different points in a causal chain” (2007, p. S5). It is interesting to note that among geneticists, diagnostic boundaries and borders may be fluid; however, in the popular media and other genres of discourse, including corporate-authored texts, the notion of “bipolar disorder” as a defined entity is alive and well, as we shall see in the analysis section (p. ##).

environment (defined as any non-genetic factors) in the development of disorders. In particular, environmental stressors are central to the “common-disease common variant hypothesis” currently in vogue in psychiatric genetic research, and hence to genome-wide association studies. As the authors of the Psychiatric GWAS Consortium explain:

SNPs<sup>16</sup> become common because they are neutral or favorable with respect to survival (...) However, some have mildly harmful effects, perhaps depending on environmental conditions (e.g., preserving fat during an ice age but leading to obesity in the fast food era). The common-disease common-variant GWAS strategy assumed that many different common SNPs have small effects on each disease and that some could be found by testing enough SNPs in enough people. (Psychiatric GWAS Consortium Coordinating Committee, 2009, p. 542).

In addition, because it is on the potential of environmental interventions to avert or ameliorate a disorder that the utility of (and assignment of responsibility for) early diagnosis and/or prediction is predicated, discussions of environment-gene interaction take on a moral weight as well.

Of course, ascribing a moral dimension to particular factors in the development of mental illness is nothing new. Older models of etiology that predate the current genetic emphasis sometimes lay all, or most, of the responsibility at the feet of “the environment” – in some cases, specifically attributing mental illness to poor parenting. The psychodynamic models that prevailed in the first half of the twentieth century apportioned a fair share of blame to parents for having “warped” their children with incorrect child rearing techniques; they also lay the responsibility for change upon the patient, who was charged with gaining understanding of his or her self in order to master it. In contrast to this, it has been argued, genetic models of mood disorder remove control from the patient and their family, and also remove blame – and therefore, should function to remove or lessen stigma (this is referred to

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<sup>16</sup> Single-nucleotide polymorphisms.

as “attribution theory” (Hinshaw & Cicchetti, 2000). However, we should recall that theories of demonic possession and humoral balance, while also attributing causation for mood disorders to forces outside the individual’s control, did not always, or even often, serve to reduce stigma (Hinshaw & Cicchetti, 2000). Likewise, a number of scholars have argued that the “geneticization” of mental illness does not universally ameliorate stigma (Goldstein & Rosselli, 2003). Attitudes about the moral culpability of those suffering from mental illness may in fact be lessened (Goldstein & Rosselli, 2003). However, other components of stigma, such as a desire for social distance or beliefs about the dangerousness of mentally ill individuals, may actually be increased by employing a genetic model, due to a perception of a lack of personal control over behaviour (Dietrich, Matschinger, & Angermeyer, 2006). Hinshaw and Cicchetti (2000) argue that the model most likely to truly contribute to less stigmatizing attitudes is one that acknowledges a multiplicity of complex factors, some within individuals’ control and some without – a model which is theoretically quite close to what current research in genetics would suggest is also the “correct” model, but has been less than thoroughly translated into popular discourses.

### **3.4 Genetic Testing for Bipolar Disorder**

#### **3.4.1 Demand and Regulation**

Despite continued difficulties surrounding the replication of studies linking particular alleles to bipolar disorder, and the very small proposed contributions of those linkages that have been replicated, both geneticists and social scientist have been anticipating the development of genetic tests for bipolar disorder genes for over a decade. Prior to the marketing of any such tests, a number of studies were carried out to investigate demand among patients and their families for tests for “mental illness genes,”

and to examine attitudes of psychiatrists, genetic counselors, and general practitioners to the availability of tests. These studies found a significant demand existed for tests that would inform people about their own genetic risk status, and for the risk status of their existing children. Hoop (2008) reviews the results of studies stretching back to 1996. Based on a meta-analysis of these findings, Hoop claims that even where tests are not expected to have 100 percent predictive power, most patients and families felt that the tests would be helpful in enhancing their ability to make life decisions and in aiding early diagnosis (2008, p. 326-7). Hoop suggests that this high level of demand is driven in part by an overestimation on many respondents' part of their own risk –and that patients' and families' levels of interest in fact exceeded the levels of confidence expressed by genetic researchers that such tests would prove to be useful tools at all (2008, p. 327).

Perhaps responding to this demand, two companies recently began offering genetic testing services for candidate genes linked to increased or decreased risk of bipolar disorder. Both companies are based in California, and advertise the tests for private purchase over the Internet, via mail order. Both fall under the mantle of “direct-to-consumer” genetic tests (although one is both sold and marketed directly, while the other is marketed to consumers but purchases must be approved by a doctor), and as such fall into a regulatory gap at the federal level in the US. While laboratories conducting the actual testing are monitored under the Clinical Laboratory Improvement Amendments (CLIA) (Magnus, Cho & Cook-Deegan, 2009), the FDA does not place any special regulations on genetic testing laboratories and does not require such tests to have clinical applications (Kaye, 2008).

At a state level, the California Department of Public Health has taken a position on the sale of genetic tests to consumers. In June 2008, ‘cease-and-desist’ letters were sent to 13 companies offering these tests, demanding that they “comply with state law that requires a license to perform clinical laboratory tests and prohibits offering genetic tests directly to consumers without a physician's order” (Magnus, Cho & Cook-Deegan, 2009). While this was heralded as a proactive move to address some of the ethical dilemmas raised by these tests, within three months, two of the largest companies sent the letters, Navigenics and 23andme, swiftly received licenses allowing them to continue to sell tests directly to consumers in California (Pollack, 2008). Thus the state laws appear to allow considerable room for maneuver, while federal agencies have thus far remained out of the fray. Commentators have continued to call for more comprehensive regulation and harmonization between state and federal agencies, as well as on an international level (e.g. Magnus, Cho & Cook-Deegan, 2009; Hogarth, Javitt & Melzer, 2008).

#### **3.4.2 Marketed Tests: *Psynomics* and 23andme**

Although the basic regulatory context is the same, there are clear differences between the two tests that have been offered in relation to bipolar disorder. One, offered by 23andme, tests for two alleles associated with a reduced risk of bipolar disorder. This test is offered as a component of 23andme’s “Health Edition” and “Complete” products, which are sold for \$429 and \$499, respectively. Both of these products offer risk estimates based on genotyping for a wide range of conditions (23andme, 2010). While this particular test does not appear to have attracted much media attention, 23andme’s product line as a whole, and their business model in general, has raised eyebrows (e.g. Fujimura, Duster & Rajagopalan, 2008).

Psynomics, Inc., is a small company based in La Jolla, California. Founded in part by a psychiatric geneticist involved in research on bipolar disorder, the company offered, beginning in 2008, a test (Psynome1) for two SNPs on the GRK3 gene associated with an increased risk of bipolar disorder. They also offered a separate genetic test to assess patients' likely responses to SSRI antidepressants. While sold directly to customers via the website, Psynomics' policy was to send results to customers' psychiatrists (Psynomics, n.d.), as the test was intended only to provide an additional diagnostic tool for patients already exhibiting psychiatric symptoms, and offered weak predictive power. Neither test is currently being offered, and the company has no plans to resume sales of these products. They do, however, intend to introduce further psychiatric genetic tests at a future date, which may include risk factors for disorders other than bipolar disorder (K. May, personal communication, March 3, 2010).

### **3.4.3 Future Directions: The Discourse of Possibilities**

As should be clear, developing a “genetic test for bipolar disorder” is not a matter of checking one location on one gene and providing definitive information from the results. One can, indeed, test only one or two locations on one or two genes, as is the case for both of the tests discussed above, but the information such a test can provide is very limited, representing only a slightly increased or decreased risk of developing the disorder. It is thus an open question whether such tests are clinically useful at this stage – and many commentators have answered to the negative (Hoop, 2008; Burke, Kuszler, Starks, Holland, & Press, 2008). Nonetheless, the tests have become a part of the landscape of bipolar disorder diagnosis and management – discursively if not in clinical practice. The assumption that more tests are expected in the near future has been a factor

in both the volume and the tenor of commentary on tests. There appear to be several potential directions for future bipolar-related tests to take: more precise tests of susceptibility (i.e. lowered or raised risk), prenatal tests, and pharmacogenomic tests for drug response. Although the use and regulation surrounding these categories of tests may differ, there is substantial technological overlap.

The aim for future susceptibility tests is to assess the presence or absence of multiple alleles associated with bipolar disorder to provide more accurate risk estimations. Due to the less-than-complete heritability of the disorder, even if such tests could account for every risk allele involved (an assumption that does not reflect current reality) the information provided would still be probabilistic (Hoop, 2008). Susceptibility testing may be used for symptomatic persons to assess the probability that their existing symptoms are caused by a particular genetic disorder, or for non-symptomatic individuals to assess the likelihood that they will, at some future date, develop the genetic disorder.

The justification for predictive genetic technologies, in the context of complex illnesses, is that this knowledge may assist persons in mitigating other risk factors that are more amenable to such efforts. If one knows, for example, that one has a higher-than-average chance of developing diabetes, one can be more careful with dietary choices and undertake regular exercise. If one knows that one's risk of developing major depression or bipolar disorder is high, likewise, one can try to avoid stressful situations and, again, make healthful choices in regards to diet and exercise. This type of proactive risk mitigation fits well with the current discourse of public health and surveillance medicine, in which one is expected to be constantly acquiring information about oneself, and acting on it before one finds oneself in a problematic situation where one is no longer a

“productive” member of society (Teghtsoonian, 2009, p. 32) This aim is held out as one of the primary aims of genetic research on complex disorders in general and psychiatric genetics in particular: that people will be able to find out what disorders they are at high genetic risk for and make adjustments to their environment (including their self-surveillance behaviours and potentially their medication regimes) so that their overall risk is lowered (see, for example, Roche Diagnostics, 2004, p. 10). Thus while there are no tests currently being sold that purport to inform people of increased risk of developing bipolar disorder in the future, much of the discussion taking place in popular media, patient advocacy websites, and academic articles focuses on this possibility.

Prenatal testing is not yet available for bipolar disorder. Theoretically, the science underlying it would be the same as for adult testing, although a somewhat different set of ethical issues would come into play. Prenatal testing offers the choice to terminate a pregnancy if the fetus is determined likely to be carrying a deleterious mutation. This, of course, raises a vast number of ethical issues relating to what exactly constitutes a deleterious condition, whose prerogative it is to make such a decision, and what impacts this may have on people already living with disabilities (see Parens & Asch, 1999, for an overview of these concerns). Studies have indicated that there is some demand for prenatal testing for bipolar disorder (Smith et al., 1996; Laegsgaard, Kristensen, & Mors, 2008; Jones et al., 2002), both among those with a family history or personal diagnosis of bipolar disorder and among the general public, as well as among clinicians, although this did not always accompany an intent to terminate the pregnancy. This demand is not as strong as for adult testing; however, should the technology become available, it is likely to find a market. In fact, while their test was being actively sold, Psynomics received a



number of requests from persons who were interested in using the test to assess their risk of passing bipolar disorder on to their children – a purpose for which the test was not marketed nor sold (K. May, personal communication, March 3, 2010).

Pharmacogenomic testing was not the focus of the present research, and I have, for the most part, steered clear of discussing this technology and the issues that accompany it in any great depth, in order not to dilute my focus in what is already a large and complex area of research. However, the foregoing discussion should indicate that susceptibility testing and pharmacogenomics testing are not really separate areas of research. Research into endophenotypes may involve drug response studies (e.g. Alda et al., 2005), and this work may inform how the diagnostic boundaries of disorders are defined, both in regard to genotypes and phenotypes. Despite this substantial overlap, however, and the potential for even greater overlap in the future, pharmacogenomic testing appears to have attracted less concern among commentators over ethical issues than susceptibility testing – most of the critical responses to Psynomics focused on Psynome1 rather than on Psynome 2 (e.g. Couzin, 2008; Hoop, 2008; Burke, Kuszler, Starks, Holland, & Press, 2008).

# Chapter 4: Methodology

## 4.1 Introduction

My research, as noted above, examines how the subject positions available to the users of psychiatric genetic testing services are being constructed and transformed as this controversial industry emerges. In referring to the subject positions available to users of psychiatric genetic services, I am drawing on Foucault's conception of the subject with regard to the power relations present in everyday social life:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize about him. It is a form of power which makes individuals subjects. There are two meanings of the word subject: subject to someone else by control and dependence, and tied to his own identity by a conscience of self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to. (Foucault, 1983, p. 212)

It is the discursive power (Foucault's power/knowledge) that is exercised in semiotic interactions between persons or groups that I envision as working to constitute these subjects. My aim, then, was to explore how discursive practices associated with psychiatric medicine, neoliberal state politics, and free-market economics are interpolated with the emerging technology of psychiatric genetic testing. Through an analysis of a selection of texts produced by influential interest groups – including academic researchers in psychiatric genetics, corporations offering psychiatric genetic tests, patient advocacy groups for bipolar disorder, and the news media – I examine how particular ways of framing subjects are preferred (consciously or unconsciously) over others in texts, and how these frames both reflect and contribute to the continual (re-)construction of habits of thought, of practice, and of social organization around this industry.

In order to do so, I drew upon a number of methodological strategies. The most basic was an analysis of prevalent themes within the texts – both those that spanned all categories of texts, and those that appeared to be more concentrated in one or two of the categories analyzed. I also identified instances of metaphorical language in the texts, and examined how (or if) these metaphorical expressions formed coherent conceptual clusters that might tell us something about the subconscious assumptions embodied by the texts in regard to particular elements under discussion. I supported these thematic and metaphorical analyses with some limited use of quantitative tools borrowed from corpus linguistics methodology. Specifically, I examined collocations and keywords in the texts in order to provide a different angle from which to look at some of the themes and metaphors identified through qualitative analysis.

It should be noted that although my project falls broadly within the genre of “Foucauldian” discourse analysis (a category with porous boundaries if ever there was one!), some of the techniques I employ – specifically, the quantitative measures and to some extent the metaphor analysis – tend to be more associated with discourse analysis that falls under the rubric of critical discourse analysis (CDA). CDA is an approach to language that, like Foucauldian discourse analysis, is concerned primarily with its role in social life.<sup>17</sup> As Wodak and Meyer define it, CDA is “fundamentally interested in analyzing opaque as well as transparent structural relationships of dominance, discrimination, power and control as manifested in language” (2009, p. 10). However, unlike Foucauldian discourse analysis,

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<sup>17</sup> To muddy the waters a little further, it should be noted that one of the main figures in CDA, Norman Fairclough, draws very heavily on the work of Foucault, although sometimes in ways that seem quite at odds with Foucault’s original intentions. As O’Regan notes, “Where Foucault’s main objective was ‘to create a history of the different modes by which, in our culture, human beings are made subjects’ (Foucault, 1982, p. 208), Fairclough’s interest, and the long-term concern of a great deal of work in critical discourse studies, has been how subjects might be emancipated from those same

CDA tends to follow Habermas in their normative desire for “communicative rationality” and the notion of a “universal pragmatics” (Haig, 2004, p. 135).

Because a number of discourse analysts have directed some fairly trenchant criticisms at CDA (e.g. Widdowson, 2004), including researchers who proclaim themselves to be broadly sympathetic to this programme of research: (e.g. Haig, 2004), I would like to note that, while there may exist a number of unresolved epistemological issues and inconsistencies within what might be termed the “mainstream” of CDA (namely, the work of Norman Fairclough, Teun van Dijk, and Ruth Wodak, and their collaborators), this does not detract from what I see as the essential strength of the approach: namely, conducting detailed and “retroductable”<sup>18</sup> analyses of the linguistic features of texts (and drawing on linguistic theory and methods to do so), while treating the texts as both reflective and constitutive of social practice and ideology. In attempting to do so, CDA treads a dangerous middle ground: discourse analysts who identify to a greater extent with linguistics have faulted CDA for weighting analyses too heavily toward social context and “interpretation” – or particularly, of subjective *over*interpretation (e.g. Widdowson, 2004; Haig, 2004, p. 136), while social theorists have concerns that CDA researchers are too eager to make positivist judgments and truth claims – which do not sit well with those steeped in standpoint theory (Pennycook, 2001; Graham, 2008). Both critiques centre on CDA’s normative orientation to research and practice: as Teun van Dijk notes, research within this paradigm

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modalities (2006, p.231).

<sup>18</sup> Ruth Wodak coins the term “retroductable” as a translation of the German word *nachvollziehbar*: literally, “comprehensible,” but in this context also referring to reproducibility, transparency, and avoidance of alienating jargon (in Kendall, 2007, p. 8).

is conducted within a normative perspective, defined in terms of international human rights, that allows a critical assessment of abusive, discursive practices as well as guidelines for practical intervention and resistance against illegitimate domination. (2009, p. 64).

My approach differs from CDA primarily on this point: I am not really concerned with “uncovering” the discursive means of oppression in my texts, implying as that does both an agent deliberately or at least consciously employing those means and an object of oppression who exists blissfully (or miserably?) unaware of his or her poverty of existence, in addition to assuming a fundamental difference between the two. Nor do I start from a position where “oppression” or “discrimination,” the two bugbears of CDA, are assumed *a priori* to reside in the texts selected for analysis. Instead, I am interested in examining the discursive conditions under which subjects come to exist – under which they define themselves and are defined by others – and the relationships imagined between those subjects and other subjects and elements of the landscape. However, I take the position that employing (some of) the methodological tools that have been used in CDA does not automatically require the analyst using them to take on the normative and positivist positions associated with CDA (positions which are sometimes less than wholeheartedly embraced by those working explicitly within CDA – e.g. Haig, 2004).

In the interests of the principle of retroductability, I have taken some care to outline (below) the methods I have used to analyze the texts, as well as the various technological tools I employed in the process. I also describe the texts I have chosen for analysis, briefly delineating my reasons for selecting these particular texts, my means of doing so, and the lines I have drawn in order to place the texts in categories. Following this, I note some important relationships between particular texts and others, and between particular categories of texts and others. I close the chapter with a brief discussion of

some of the limitations of the current project, and suggestions for how these might be overcome in future research.

## **4.2 Thematic Analysis**

The thematic analysis worked bidirectionally: first, themes identified as important in the literature review were related to the texts – for example, because both “determinism” and “risk” were prominent notions in the literature surrounding genetic testing, and because these ideas suggested very different sorts of understandings of both disorders and subjects as genetic entities, I looked at the texts with an eye to how determinism and risk featured in the discourse. Second, upon close analysis of the texts themselves, themes emerged that I had not initially expected to be so prominent. These themes then informed further reading in order to understand their connections to other elements of the discourse.

In order to apply codes reflecting these themes to the texts, I used a qualitative analysis program called HyperRESEARCH (ResearchWare, 2009). This program allows researchers to organize texts and code sections of these texts according to themes chosen by the researcher, and following this, to retrieve for easier analysis those sections of the texts to which a particular code has been applied. After importing all chosen texts into HyperRESEARCH, I marked, in each text, sections that referred to (1) bipolar disorder, (2) genetic tests for bipolar disorder or other psychiatric disorders, or (3) the users of such tests. These often comprised large sections of the texts under question. I then went through the texts a second time and, focusing on these sections, applied additional, more specific, thematic codes that I felt to be relevant to the analysis. These included, for example, “doctor-patient relationships,” “consumerism,” “stigma,” “preventive care and

self care,” “benefits of testing” and so forth. I then retrieved the sections of texts associated with each code and examined them in more detail to locate patterns within the texts. Both general patterns and specific examples from the text were selected to support my analysis of the themes identified in the literature review, and the themes identified through analysis itself were re-integrated into the literature review – all in all, a recursive process of re-reading, re-coding, and re-analysis.

### **4.3 Metaphor Analysis**

Metaphorical language functions to blend concepts with one another, both in the mental spaces of the mind and the textual spaces of the page (Johnson, 2007). In creating such conceptual blends, metaphor has the potential to both highlight and hide particular features and components of its referents (Lakoff & Johnson, 1980; Johnson, 2007). Therefore, this type of analysis is particularly appropriate to questions about the types of subject positions that are being promoted in texts, and how novel positions might be constituted from elements of existing subject positions, while other elements that do not fit with current rationalities of medicine, of governance, and of the economics of the biotechnology industry may be hidden.

After applying the thematic codes, I went through each text again, marking instances of metaphorical language. The process of identifying metaphorical language is not a universally agreed-upon one. Lakoff and Johnson claim that “the essence of metaphor is understanding and experiencing one thing in terms of another” (1980, p. 5), and studies based on their approach to metaphor have used this as the essential criterion. However, this broad conceptual approach, while providing the guiding precept for my own study, is less useful when it comes to identifying each metaphor in a text than it is

when talking about metaphor in the abstract. Therefore, I referred also to the work of the Pragglejaz group (2007) and their principles for metaphor identification. While their procedure calls for identifying *all* metaphors in the text, and for focusing on lexical units rather than phrasal units, which were not always appropriate strategies for my research, they do provide a very clear and concise set of criteria upon which to base decisions about whether to count a given item as metaphorical (see Appendix F).

However, working by the principles these authors propose, a very large proportion of language could be considered metaphorical. I did not wish to limit my analysis of metaphor to only those phrases or words used in reference to specific elements of the texts (i.e. to genes, or to test users), because this would preclude the possibility of finding extended metaphorical concepts that employ different elements of a metaphorical source domain to refer to different elements in the target domain. Nor did I want to limit my analysis to looking only at novel metaphors that were “obviously” metaphorical, because this would exclude conventional metaphors that have become so deeply embedded in the discourses of health and genetics that the ways in which they are not literal are sometimes overlooked. These highly conventionalized conceptual metaphors are an important part of how we understand the world around us (Lakoff & Johnson, 1980), and are as important to consider as those that stand out as novel analogical devices. Therefore, when commencing the project, I initially employed the Pragglejaz Group’s fairly inclusive criteria to mark metaphors in texts. Once I had coded several texts in this manner, I reviewed my coding and decided that there were a number of common conventional metaphors that did not relate in any sense to the themes of my project, and that I could therefore safely ignore for the remainder of the study. For



example, most prepositions in a text could be considered metaphorical according to the criteria of the Pragglejaz Group, and of Lakoff and Johnson (1980), but were not relevant to the issues at hand. Thus after my initial thorough coding and review, these types of metaphors were not coded in the remaining texts.

As I marked each instance of relevant metaphorical language, I began to recognize clusters of metaphors around themes. On the next pass through the texts, I coded those metaphors which appeared to fit within one of these identified clusters or themes. I discuss some of these themes, and their associated metaphorical realizations, in depth in the analysis section.

#### **4.4 Corpus Tools**

In order to supplement the thematic and metaphorical analyses, I also used some additional strategies developed initially by corpus linguists. These tools allowed me to make some very basic quantitative characterizations of particular features within the sample of texts – for example, determining the relative frequencies of particular words, and the associative relationships between one word or set of words and another word or set of words. To facilitate this analysis, I utilized a piece of software called AntConc (Anthony, 2007).

Three of the features of this program were particularly useful for my purposes. First, the program allows the researcher to search in one or more text files for specific words and/or phrases in order to obtain a list of all the places in the texts where the word or phrase is used, and its immediate context. These lists are known as keyword-in-context (KWIC) lines, or concordances. The lists allow the researcher to quickly gain a sense of the variety of ways in which a particular word that they have identified as significant is

used in their texts, both in terms of whether it carries a negative or positive connotation, and in terms of what other words it is frequently used in close connection with.

AntConc also offers another feature for exploring the associations between words, called collocations. By performing a statistical operation on the same KWIC lines, the program can generate a list of words that appear in close proximity to other words more frequently than would be expected by chance. Researchers must make certain choices about how much context to include (I limited the KWIC lines to encompass three words on each side of the node word), and what statistical test of significance to use. I chose to use t-scores as they tend to be less likely than other measures to provide inflated scores for words that occur very infrequently (Barnbrook, 1996, p. 97-98).

Finally, AntConc also allows researchers to generate a list of words that appear significantly more frequently in a given text or texts than in another collection of texts that might be expected to be comparable in other respects. This collection of comparable texts is called the reference corpus and is used in the generation of statistics that can show whether the relative frequency of a word in the text being analyzed is greater than chance. This list, calculated using the log likelihood statistic, shows the relative “keyness” of certain words in the analyzed text(s).

While I could have chosen to compare my collection of texts to an external reference corpus of texts from a particular genre of English,<sup>19</sup> I felt that this would not be very informative, leading to over-obvious findings like the fact that the words “bipolar,” “genetic,” “gene” and so forth are used at a much higher frequency than in a reference corpus (which, indeed, is what I found when I experimented with this method). What

turned out to be more useful was using my own collection of texts as a reference corpus, then determining whether particular words were more key in particular categories of texts within that sample than overall.

## **4.5 Text Selection**

### **4.5.1 Introduction**

I chose for analysis a selection of texts from four different categories: (1) the websites of those corporations offering genetic tests for alleles associated with bipolar disorder, (2) academic articles discussing the use of such tests, (3) news articles discussing the development and use of such tests and related ones, and (4) the components of the websites for patient advocacy organizations that dealt with genetic issues related to bipolar disorder. Many of the texts in the latter three categories discussed, either centrally or in passing, the tests offered by Psynomics: thus these tests, and those offered by 23andme, constitute a central focus of the analysis.

I chose texts relating to the North American context broadly, rather than focusing only on Canada. The tests are sold by companies based in the United States and thus are inherently enmeshed in the American social, political, and economic context, which would have made limiting my analysis to Canadian commentaries rather difficult. Canadian texts addressing these tests and their use and sale were few in number, at least where publicly accessible texts are considered, which would have made for a very small sample size. Additionally (most specifically in relation to my collection of news articles) I wished to gain a sense of the discourses that would be accessible to potential test users

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<sup>19</sup> For example, the American National Corpus has a freely available subsection of data that researchers can download for comparative purposes (ANC, 2010).

conducting an internet-based search, and I did not expect that this group would really distinguish between “Canadian” and “American” sources. Finally, many of the general trends in medicine that I have discussed above are shared broadly by “Western” countries; therefore, much of the analysis was applicable to both countries. However, this choice introduced some limitations in regard to the coherence of discourses, especially as regards the role of the state and the market. Future research would gain from focusing analysis more closely on one particular region. In order to accomplish this effectively, it is likely that in-depth interviews and a longer research time-frame for locating relevant texts would be needed to supplement the type of publicly available materials on which I based the present analysis.

#### **4.5.2 Corporate Websites**

As noted above, only two companies – Psynomics and 23andme – have offered genetic tests for alleles associated with bipolar disorder. Although a number of other tests – for depression, schizophrenia, and suicidality – have been temporarily offered or are likely to be introduced soon, to the best of my knowledge no other examples currently exist of genetic tests for psychiatric disorders. Thus the discursive constitution of genetic test users adopted by Psynomics and 23andme – the way in which these companies frame their customers – is the best means of obtaining some insight into the subject positions that will come to be available to future genetic test users.

Although I have for the purposes of categorization lumped the websites of Psynomics and 23andme together as “corporate,” the tests offered by Psynomics differ substantially both in terms of their intended utility and the ways in which they are

marketed and sold from those tests offered by 23andme. Therefore, I have chosen to treat the company websites separately in some sections of the analysis.

Because Psynomics' sole focus is psychiatric genetics, their entire website was of relevance to my analysis. I therefore collected the full text of each page, excluding only pages that were left empty of content, which left me with 18 web pages. Psynomics also provides four additional files in PDF format through a link at the bottom of each page: their privacy policy, consent form for testing, mailer instructions, and a "model report." I downloaded and saved these files as well, for a total of 22 texts (see Appendix A).<sup>20</sup>

In the case of 23andme, because the company provides information to clients about a wide range of alleles associated with many different disorders, as well as traits categorized as non-pathological, and on ancestry, I collected only pages from their website that bore direct relevance to bipolar disorder, as well as the website's home page. This comprised three pages that presented different components of a "sample report" on the results of bipolar testing, and one pop-up page that elaborated upon the nature of the information presented there, as well as three pages from the Spittoon (a research and news blog maintained by 23andme staff) that featured news about genetic discoveries relevant to bipolar disorder. With the home page, this gave me a total of eight texts from 23andme (see Appendix B).

#### **4.5.3 Academic Articles**

The development of genetic tests for bipolar disorder, of course, depends greatly on academic research in psychiatric genetics. Their endorsement by medical

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<sup>20</sup> Some of the content on these web pages is borrowed from the NIMH. I address this in more detail below (p. 63-66).

professionals, including general practitioners, psychiatrists, and genetic counselors, also depends greatly on academic research, and particularly on assessments of their validity and utility, as well as of potential problems. In addition, popular media rely on academic research (often filtered through press releases drafted by university communications offices) to present scientific discoveries and developments as news. How genetic tests for bipolar disorder and their users are framed by academics, then, may have a profound influence on how these tests are framed by popular media, and on their incorporation into clinical practice.

There are a great many academic articles that could be considered relevant to this project: those dealing with bipolar disorder as a genetic condition, those concerned with the risks and benefits of genetic testing, and those examining the demand for tests among particular populations, in addition to more theoretical articles on genomics in society. In selecting texts for analysis, however, I needed to limit my sample to a small number of texts that could be examined in detail. I therefore decided to select only those that dealt with questions of the clinical validity and/or utility (for psychiatrists or for genetic counselors) of genetic tests specifically for bipolar disorder and related psychiatric conditions, even if this discussion only comprised a small part of the articles. In addition, I was particularly interested in review articles, as I expected that these would be reflective of mainstream discourse, and potentially would be the articles most accessible to those unfamiliar with this area of research – for example, clinicians who were curious about the tests but had had little exposure to discussions of their use.

To find articles that fit these criteria, I searched the PubMed/Medline, PsycInfo, and Web of Science databases, using a variety of keyword search strings. I limited my

search results to articles published in 2005 onwards, in English. After skimming titles and abstracts, and identifying a set of articles that came up in multiple searches, I selected five that both fit my search criteria and appeared to most directly focus on the topic of genetic tests for bipolar disorder. The five articles are listed in Appendix C. Of these articles, two (Braff & Freedman, 2008; Mitchell et al., 2010) are critical commentaries on the introduction of genetic testing into clinical psychiatric practice in the North American market. Two others focus on issues in genetic counseling and psychiatry and discuss the potential role of genetic tests in some detail (Austin & Honer, 2007; Finn & Smoller, 2006). The remaining article (Escamilla & Zavala, 2008) reviews current research on the genetics of bipolar disorder from a more general perspective; genetic tests feature only briefly in this piece, but the focus on bipolar disorder is more concentrated than in the other articles. By choosing these articles, I aimed to get a fairly broad view of current perspectives from within the psychiatric community on this technology. This category of texts was particularly illuminating in regard to the roles test users were expected to adopt with respect to doctors (and vice versa) – and what that indicated about the characteristics test users were expected to embody.

#### **4.5.4 News Articles**

I examined popular media discourses on genetic testing for bipolar disorder because I felt that these articles would be more likely to be read by potential test users than the academic articles. Academic articles might potentially be very influential on the attitudes and decisions of physicians, and hence the subject positions made available in a clinical encounter, as well as potentially shaping regulatory policies. However, they are not generally accessible to the lay public. They are therefore unlikely to be perused by an

individual seeking information on mental health who does not have a technical background in it. Journalists, however, often rely on academic or corporate press releases to translate scientific or medical research into popular discourse. These articles act as a crucial link in determining how new technologies are framed, and how the discourses of researchers and corporations are recontextualized and re-presented to a lay audience.

A major concern in finding news articles was to locate those that might be read by potential test users. In most cases, these would be individuals with a pre-existing interest in their own mental health or in genetics, or individuals whose friends or family have such an interest. Numerous studies have found that the Internet is becoming a primary source for those seeking health-related information (Segal, 2009; Schaffer, Kuczynski, & Skinner, 2008; Rice, 2006). Rice (2006), reviewing a range of studies by the Pew Internet and American Life Project, notes that in 2002, 62% of Internet users had utilized the web for health-related searches, with this number increasing to 79% in 2004 (p. 9). It seems plausible that that number has increased further in the years since. Describing the typical Internet health seeker, Rice claims that she<sup>21</sup>:

starts at a search site, not a medical site, and visits two to five sites during an average visit. She spends at least 30 min on a search. She feels reassured by advice that matches what she already knew about a condition and by statements that are repeated at more than one site. She is likely to turn away from sites that seem to be selling something or do not clearly identify the sources of the information. (2006, p. 9).

In my own searches, I also began at a search site (Google.com). I started with quite general searches and then became gradually more specific in order to find relevant articles. The search strings I used in the end were probably considerably more complex

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<sup>21</sup> Internet health seekers are more likely to be female, as the results of multiple studies have indicated (Rice, 2006; Schaffer, Kuczynski, & Skinner, 2008).



than those used by the average health-information seeker; however, the pages I selected for further review were intended to conform to the general principles identified by Rice. I chose articles that identified their information sources (often doctors), and that tended to overlap in content with other websites (many of the articles I chose were reproduced elsewhere on the web, or were close reproductions of content that did). Rice also suggests that information-seekers are likely to turn away from sites they were unsure had been recently updated (2006, p. 17); I therefore selected only articles that were both recent (2005 and onwards) and showed a date. I also limited my searches to sites whose main business was producing information (i.e. news-oriented websites) rather than other product lines or services (with the exception of one site, the APA's *Psychiatry News* website, all websites were centred around for-profit journalism).

I expected that those seeking health-related information would be more likely to end up on websites that specialized in health or science-related news; therefore, the majority of texts I selected came from such websites (e.g. *Medical News Today*), or from the health-related sections of larger websites with a more general focus (e.g. *AOL Health*).<sup>22</sup> I limited results to articles published in English, after 2005, and eliminated all results that which discussed pharmacogenomics or blogs.<sup>23</sup> Despite the quite strict limitations I had placed, which undoubtedly did exclude numerous relevant articles, I still

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<sup>22</sup> Of course, many health information-seekers are looking for fact-sheet-style information on conditions or treatment, and not specifically for news. However, in the context of a very new technology, news articles were both the most ubiquitous and the most authoritative sources of information that appeared to be widely accessible.

<sup>23</sup> This may have artificially removed articles that referred to pharmacogenomics or blogs only in passing, but the trade-off in eliminating pages and pages of search results that bore only a tangential connection to my interest was, I believe, worth that risk. Although, as I have noted above, pharmacogenomics is very much connected with susceptibility testing, I wished to avoid diluting my focus too greatly.

obtained 106,000 search results. I examined each article from the first four pages of results (40 articles in total) and selected nine that appeared to be relevant and to cover a variety of different types of news sources. All were published by organizations based in the US or Canada. See Appendix D for a list of the articles chosen for analysis.

#### **4.5.5 Patient Advocacy Organization Websites**

In examining the websites of patient advocacy organizations, my intent was not to gain insight into the frames used by “actual psychiatric patients” discussing genetic testing for bipolar disorder. These websites are oriented toward presenting a public face for users of psychiatric health care and those dealing with mental illness, either as patients or as the family members or friends of patients, and to influencing public attitudes and policies in ways that will be beneficial to these constituents. Therefore, the discourse they present is intended to reflect positively upon psychiatric health care users, rather than to provide a venue for the views of patients to be directly voiced. It is also representative of organizational interests (and sometimes of the interests of funding bodies). I view these groups, therefore, as influential corporate entities with agendas that may differ from those of the patients they claim to speak for. These organizations may in many cases successfully promote their frames, influencing medical practices, cultural attitudes, and legislative and policy development (Allsop, Baggott, & Jones, 2002, p. 53-6).

A number of organizations in the US and Canada engage in advocacy on behalf of individuals living with bipolar disorder. I chose to investigate two of the most prominent groups, each of which has a substantial presence on the web, and each of which provides access through their website to texts directly relevant to psychiatric genetic testing. These

organizations are the Depression and Bipolar Support Alliance (DBSA), which has branches in both the US and Canada, and the National Alliance on Mental Illness (NAMI), located in the US. In both cases, I examined the home pages of the organizations' websites, and then conducted a search for web pages internal to the websites relevant to genetics. The final list encompassed three pages from DBSA and four from NAMI, including both organizations' home pages, two news stories, a transcript of an online discussion forum with a geneticist, a large report intended for public release entitled "The State of Depression in America", of which I extracted only the relevant sections, and a handout guide for individuals working as "family-to-family teachers," of which I again extracted a portion (see Appendix E for a list of the texts).

#### **4.6 Intertextuality**

It is incumbent upon me to note a few areas of overlap, or "intertextuality," between the texts I selected – with each other, and with other texts not selected for analysis. Reisigl and Wodak state:

*Intertextuality* means that texts are linked to other texts, both in the past and in the present. Such connections are established in different ways: through explicit reference to a topic or main actor; through references to the same events; by allusions or evocations; by the transfer of main arguments from one text to the next, and so on. The process of transferring given elements to new contexts is labeled *recontextualization* (...). The element (partly) acquires a new meaning, since meanings are formed in use. (2009, p. 90).

Clearly, the texts I selected do refer to common elements; both broad concepts like bipolar disorder and genetic tests, and specific elements like particular researchers, specific genes, particular research labs, and so on. But what is more striking is the

transfer of main arguments or plot lines, and sometimes even the wholesale importing of large chunks of verbatim text from one text into another.

This is exemplified in the news articles, where the plots of academic research articles are sometimes translated into a more accessible and shorter news format. For example, AOL Health presents a shortened summary, written in 2008, of Finn and Smoller's (2006) article, "Genetic Counseling in Psychiatry." Many of the main arguments made by Finn and Smoller are reproduced here in plain language and re-presented as news-worthy (although this is still one of the more technical of the news texts). The article states that "Content [is] provided by the Faculty of the Harvard Medical School" (AOL Health, 2008).

Similarly, a number of articles refer to a study from the journal *Nature Genetics*, published in August 2008, by Ferreira et al. The Intellihealth website article "Update from the Medical Journals: August 2008," written by Mary Pickett (also of the Harvard Medical School) references this study; searching for it also leads to a very similar article on MSNBC that was not included in the study, but was also written by Mary Pickett (Pickett, 2009). This article is also referenced on the 23andme website. Content of this type also appears to be plagiarized frequently by other health-related blogs and websites. This type of borrowing may actually contribute to the authority of such pieces of writing: if, as Rice (2006) suggests, people grant more credence to information that turns up in multiple locations, those articles that spread across the web will tend to be the most authoritative.

The discourse that appears to have spread most widely across the web comes, in fact, from a category of text I did not include in my study. I chose not to analyze

government discourses on genetic testing for mental illnesses, primarily because this appeared to be a limited resource where publicly available documents were concerned, particularly in the Canadian context. I felt that government viewpoints, though deeply relevant to the questions at hand, would be better accessed through interviews with policy makers or others involved in the regulatory or funding processes for genetic research. At the very least, an adequate representation of government discourses would have required a broader analysis of texts not directly related to psychiatric genetic tests, which in the course of the present study did not appear feasible, due to the constrained time frame

However, as I began to examine the texts from the selected categories, it became clear that many of these organizations made heavy use of texts produced by the National Institute of Mental Health in the US, either through linking to the NIMH website or its publications, both past and recent, citing individuals associated with the NIMH, or reproducing (parts of) NIMH publications on their own websites. In particular, the Psynomics website drew upon NIMH content in describing both bipolar disorder and major depression and outlining widely accepted standards of treatment (Psynomics, n.d.). I am unsure why Psynomics chose to present NIMH discourse rather than writing their own information content, which they would undoubtedly be able to gear toward the sale of their products. Whether the choice was made out of a lack of concern for commercial promotion and a taking of the easy route in terms of web development, or out of a sense that citing an authoritative source like the NIMH might assuage criticism from other psychiatric professionals or journalists, I do not know. In either case, it is clear that the NIMH is a deeply influential institution in the ongoing development of this discourse.

## 4.7 Limitations

In addition to the difficulties posed by intertextuality, there are a number of other limitations associated with the present study that I wish to highlight. First of all, the size of the corpus itself limited both the quantitative and qualitative components of the analysis. It was sufficient for exploratory purposes, but smaller than ideal for the purposes of statistical comparison, as well as for the teasing out of more elaborate patterns. It was not always possible to make comparisons between one category and another when the size of each was so small, and internal differentiation within categories could not be fully assessed. Future research could address this issue by collecting a small selection of texts from a wider number of more precisely defined categories of sources that could be hierarchically grouped together for analyses, and to attempt some type of random sampling procedure. This would allow for a wider number of comparisons to be made, and for the results to be interpreted with greater confidence.

I have noted above the lack of analysis of government discourses. Although this choice was a pragmatic one based on the difficulty of accessing such discourses in a short time period, it placed a significant limitation on what I was able to say about how test users are framed in relation to the state, as well as in regards to regulatory responses to the psychiatric genetic testing industry.

Also noted above is the decision that was made to conduct a broad overview of “North American” discourse rather than focusing on either American or Canadian discourses. This made sense as a category in relation to accessibility by potential test users, but placed serious limitations on what could be said about the overall political context in which the tests, and the texts that relate to them, exist, and the influences that

different approaches to the delivery of health care may have on their reception. Future research should address this lacuna, potentially through a comparative study that is able to trace the influences of what is predominantly an American phenomenon – the direct-to-consumer marketing and sale of genetic tests - north of the border.

Such research should ideally also combine textual analysis with ethnographic research. Neither personal experience of and involvement with the various stakeholder communities that produced the texts examined, nor interviews with key members of these groups, were possible in the time span available to conduct this research. For that reason, many viewpoints were missed altogether, and others were represented in less depth than they deserved. For example, patient advocacy groups are not a homogeneous category of organizations. Many of these groups may take far more radical approaches to the experience of mental illness than the mainstream groups I considered in my analysis. Academic researchers also fall into many theoretical camps, and often disagree with each other on major as well as minor points. They bring different priorities to their research and writing, and thus the small sample considered here should not be considered representative of “academia” as a whole, or even of any small part of it, but merely as an example of some of the more mainstream discourses that currently circulate on these topics. Because the articles I chose were largely review pieces, they do not present some of the more challenging debates that occur surrounding the role of genetic research in the constitution of disorders or of persons – debates that may be deeply influential in determining the course of future practice and policy.

Finally, and perhaps most importantly, I was unable to access the discourses of actual or potential test users. Thus while I can propose some findings in relation to the

subject positions being made available to test users through the discourses of influential stakeholder groups (if at a very broad level), I am not able to say anything about how the people intended (or intending) to use the tests react to these subject positions. Do they embrace them? Resist them? In what ways do they attempt to blend them together to create subjectivities that feel comfortable and appropriate, and how does this process vary according to the situations and characteristics of individuals? These are questions that have consistently proven difficult to answer through discourse analysis alone (Condit, 2004; Haig, 2004). It is essential to acknowledge that the ways in which analysts interpret texts may differ from lay interpretations of the same texts, and that traditional discourse studies that examine only the texts, rather than observing or asking questions about either the production or interpretation of texts, miss out on one of the central qualities of discourse: that it is always an interactive process. “Meaning can no longer be held to reside pristinely in texts, nor in the minds of authors, as Haig, notes (2004, p. 144): it is always in interpretation that texts take on power, and the power that they do take on differs depending on the person who is doing the interpreting. This limitation can and should be addressed through in-depth ethnographic research.



# Chapter 5: Test Users as Individual Subjects

## 5.1 Introduction

I have divided my analysis into two sections. The present chapter examines test users as individual subjects, focusing on the qualities and characteristics that are attributed to them (either directly, or in most cases, indirectly), the terms used to make reference to them, and the ways in which they are represented (or not represented) in images. As test users are substantially defined, in this context, by their status as persons-at-risk of bipolar disorder, I begin this chapter with an analysis of the construction of BP as a serious mental illness, and as a genetic disorder. While it is clear that BP is defined both as problematic and as genetically rooted, it is less clear that genetic research has functioned to clarify its status as a bounded entity – a finding that has particular implications for how we understand genetic risk. I follow this with a discussion of the benefits and risks that are seen to accrue to individuals from the use of genetic tests for bipolar disorder, focusing on what these suggested consequences entail in the way of framing test users. I conclude the chapter with an analysis of the terminology and images used to represent test users – both of which make clear that test users are to a large degree defined by their relationships with other figures.

Taking this observation as a starting point, Chapter 6 approaches the positioning of test users through an examination of the webs of relationships in which they are seen to be engaged. Test users can be understood as consumers, purchasers of a product, with the central relationship (however problematic) being that between them and the test provider. They can also be understood as mental health patients, with the doctor-patient relationship in sharp focus. In many cases, they are framed as family members: a

positioning that implies a relationship of interdependency and shared risk, as well as potentially shared responsibility. Finally, they can be viewed as citizens of a state – in this case, a neoliberal one, where the welfare of citizens is understood to be largely a matter of private responsibility – but just which private entity is here responsabilized is a sticky question.

Those identified as “at risk” of bipolar disorder make up a large proportion of potential test users (Jones, Scourfield, McCandles, & Craddock, 2002; Meiser et al., 2008; Laegsgaard, Kristensen, & Mors, 2009). In some cases, these are individuals who are experiencing mental health problems and are searching for a diagnosis. In others, they may be family members of those already diagnosed with bipolar disorder or another mental illness that shares genetic components with bipolar disorder, and wish to assess their likelihood of developing this disorder, whether or not they are currently experiencing symptoms. Individuals may also seek testing for their children or to assess the risk that they will “pass on” a disorder to potential offspring. Although neither prenatal testing nor testing for children is available at the present time, Jones, Scourfield, McCandles, and Craddock (2002) have noted that demand does exist for this service, if at a lower level than for adult testing services – both among those diagnosed with bipolar disorder, and members of the general public. The position of test user is therefore substantially defined by the characteristics attributed to those at risk of, or diagnosed with, bipolar disorder, which makes it essential to understand how bipolar disorder itself is conceptualized in these texts. What effects is it seen to have on individuals? How does it affect their abilities to take up particular subject positions? I divide my analysis of the construction of bipolar disorder into two main strands: (1) the representation of bipolar

disorder as a serious problem, and (2) its depiction as a genetic disease. That bipolar disorder is defined as having a genetic “basis” is key to understanding how subjects are defined as “at risk” in a genetic sense, and how family members may be interpellated into the subject position of test user.

## **5.2 Bipolar Disorder as a Serious Problem**

The problems that bipolar disorder poses can be located at three overlapping levels: that of the individual (revolving around the personal experience of symptoms and the impacts of those symptoms – and of the label of bipolar – on individual lives); the interpersonal (involving difficulties in relationships with family members, friends, and employers, and particularly involving stigma, discrimination, guilt and blame); and finally the societal level, where costs to the community, or even the state, are calculated.

### **5.2.1 Bipolar Disorder as an Individual Problem**

The personal experience of bipolar disorder is usually described in the texts in terms of “mood swings” or “ups and downs,” and often in terms of its effects on their ability to function “normally” and lead “stable” lives.

“Bipolar disorder (also called bipolar affective disorder or manic depression) is a type of depression that causes extreme mood swings.” (Pickett, 2008)

“A serious illness, people who suffer from it can experience mild or dramatic mood swings, shifts in energy and a diminished capacity to function.” (Medical News Today, 2008)

It is interesting that these fluctuations and changes are portrayed as so deeply problematic. As Zygmunt Bauman (and many others) point out, constant change and instability are the hallmarks of life in the present era, and in fact an ability to change oneself in relation to one’s changing circumstances is the ultimate requirement to

function successfully in such an era (Bauman, 1997, p. 14). I suggest, therefore, that it is most likely not the changes in mood and motivation themselves that are truly considered problematic, but the perceived inability of the individual to control these changes and to ensure their appropriateness to the circumstances.

Emily Martin, in her ethnographic account of bipolar disorder in the US (2007), argues that in fact, the behaviours associated with bipolar disorder are sometimes consciously *performed* by those with the diagnosis in the context of support group meetings, acting as a sort of meta-commentary on the experience of inhabiting a mentally ill subjectivity. Further, while such “insider” performances might appear inappropriate to those external to the group, she notes that there are in fact circumstances under which manic behaviour is even encouraged – including theatrical performances like stand-up comedy, but also the world of financial management. The cultural associations between mania and productivity, as well as creativity, may have led to a partial re-valuation of what Martin terms a “manic style”; where considered appropriate to the circumstances, it is sometimes prized. However, it is clear from the texts that *bipolar disorder as a diagnosis* is still viewed negatively. When patients are unable to alter their behaviour to fit the circumstances – or alter the circumstances to fit their style of behaviour (as indeed is more possible for famous actors and wealthy financiers than it is for most mental health care users) – the connotation remains profoundly negative. As Martin notes, the differing social positions of those exhibiting manic behaviours substantially contribute to how these behaviours are evaluated by others – as examples of a disorder in need of treatment, or as the (mostly) normal responses of highly intelligent people to stressful situations (2007, p. 118-126).

Very few references to positive aspects of bipolar disorder were to be found in any of the texts, and when these were mentioned, they were framed as warning signs that should be considered problematic in and of themselves, even if they deceived the patient into enjoying them:

“A mild to moderate level of mania is called hypomania. Hypomania may feel good to the person who experiences it and may even be associated with good functioning and enhanced productivity. Thus even when family and friends learn to recognize the mood swings as possible bipolar disorder, the person may deny that anything is wrong. Without proper treatment, however, hypomania can become severe mania in some people or can switch into depression.”  
(Psynomics, n.d.<sup>24</sup>)

The personal experience of bipolar disorder, its symptoms and signs, was emphasized heavily on corporate websites, with several pages of textual space devoted to listing these, presumably so that potential test users could identify convergences between their experiences and these symptom lists. In the case of Psynomics, this data was largely drawn from information sheets produced by the National Institute for Mental Health (NIMH); 23andme appears to have written its own copy. This difference probably reflects the greater corporate marketing resources possessed by a large company like 23andme as opposed to a small startup like Psynomics.

It was also notably emphasized in the news articles, where it may be assumed that the purpose was not to encourage individuals to purchase products, but to play up the “human interest” angle. As Suleski and Ibaraki note, “journalists seek the human interest angle on research stories” (2010, p. 122), which makes press releases that relate research to individual experiences more compelling and more likely to be taken up as news items.

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<sup>24</sup> This is an example of text borrowed by Psynomics from the NIMH. Although the precise citation of the source is not provided, a web search found several sites with text that matches that of this section word for word, and those sites sometimes link to various NIMH booklets.

Bipolar disorder was also discussed metaphorically as an enemy. Although this metaphor was employed throughout the discourse, it was particularly common in academic articles, and in fact, where it surfaced in news articles, it was usually in contexts where the content of these articles had been drawn from academic work or press releases from a research institute. The texts made frequent references to the “struggle” or “fight” against bipolar disorder, and a number of militaristic metaphors were employed to expand this concept. For example, the genes were sometimes conceptualized as “targets” for research or for drugs, and were often depicted as enemy forces, which is consistent with the metaphor of bipolar as enemy, assuming, of course, that one views the genes as the cause of bipolar disorder. The disease is also known to “strike” individuals – implying, first, that it originates outside of them, and second, that the effects are concentrated at the individual level.

“Even small increments in predictive power could help in effectively targeting preventive efforts.” (Mitchell et al., 2010, p. 229)

“Such approaches may yield clear pharmacologic targets which can intervene in disease processes that have their origin in genetic risk variants.” (Escamilla & Zavala, 2008, p. 149)

“Asked about the potential benefits of testing, the majority of patients and spouses (67.5%) felt that the most important benefit was “to obtain treatment to prevent attacks.” (Finn & Smoller, 2006, p. 111)

“As with many other common diseases, researchers have been using genomewide association studies in an effort to find SNPs associated with bipolar disorder in order to begin to understand how and why this disease strikes and how best to treat it.” (Zandme, 2008)

### **5.2.2 Bipolar Disorder as an Interpersonal Problem**

Academic articles, on the other hand, did not devote much attention to characterizing the personal experience of bipolar disorder. Instead, they focused on the

family problems associated with bipolar disorder, including guilt, stigma, and blame. This was particularly a feature of those articles that dealt with genetic counseling.

The websites of DBSA and NAMI also emphasized the interpersonal dimensions of the problematic nature of bipolar disorder. References to stigma or guilt were prevalent, but usually cursory. Often, discussions of misdiagnosis and personal struggles to find correct treatment were highlighted as well – tying the individual experience of distressing symptoms to difficult relationships with doctors and professionals. It is probable that a different and larger sample of texts from these websites would be more enlightening and possibly present a different picture of how patient advocacy organizations conceptualize bipolar disorder as a problem; because I only examined texts that discussed genetics, which in this case was a very limited sample, I am hesitant to make many claims on the basis of this data.

### ***5.2.3 Bipolar Disorder as a Societal Problem***

A number of the texts made reference to the widespread nature of bipolar disorder in either the United States or the world. Although these types of statements were found in news articles and academic articles, they were particularly prominent on the corporate websites:

“More than 2.3 million Americans are known to have bipolar disorder. Some studies say the number is closer to 8.2 million. Are you one of them?”  
(Psynomics, n.d.)

These statements reflect the findings of Einseidel and Garansar (2010), who note that it is a common practice on DTC genetic testing websites to emphasize the widespread nature of a particular disorder, in order to convince a wider section of the

population to purchase tests for it. Thus, in the case of these corporate websites, statements about the prevalence of bipolar appear to be intended to encourage purchases.

However, in only two instances were the costs to society mentioned (Escamilla & Zavala, 2008; McIlroy, 2009). While this might be interpreted in a positive sense, as implying that monetary costs of mental illness are not allotted the most importance in this discourse, it may instead imply that the costs of dealing with bipolar disorder are substantially located in the private sphere. This interpretation is supported by the limited role granted to the state in the discourse overall, and by the widespread emphasis on the roles of families, individual care providers, and corporations.

## **5.3 Bipolar Disorder as a Genetic Disease**

### ***5.3.1 Bipolar Disorder Originates Organically***

Many, if not all, of the texts represented biological evidence as essential to advances in diagnosis and treatment. This certainly implies that the basis of the disorder is viewed as being rooted in organic causes. There is, of course, a certain selection bias at play in the texts I examined: through searching for texts that discussed genetic research and tests for bipolar disorder, I guaranteed that these themes would be present in all texts. Nonetheless, their presence alone does not determine their treatment. By looking more closely at how genetic information is conceptualized in these texts, and how bipolar disorder is talked about in relation to that information, it is possible to get a more detailed and nuanced picture of the role of the genes in constituting subjects who are diagnosed with, or suspected of having, this condition. Here, I focus on the subtle strategies used to highlight genetic factors in the development, diagnosis, and management of bipolar disorder. In particular, the use of conceptual metaphors where the genes are seen to be



more *basic* or fundamental to a person or illness than other elements was one of the most important textual strategies identified.

From a close reading of the texts, I noticed that the words “underlie(s),” “fundamental,” and “basic/based/base(s)” tended to appear in phrases that emphasized genetic influences on bipolar disorder or other illnesses, while words like “factor(s),” “component,” and “contribution(s),” tended to show in phrases that discussed environmental influences, either alone or in combination with genetics. To me, this appeared to represent a fairly extensive conceptual metaphor whereby the genes, or the biological factors in general, were identified as the basic or “deepest” level of the person, or of their condition, “underlying” symptoms and behaviours.

“Normal human gene function is expressed in the brain as an elegant symphony of neurons firing across widespread neural circuits that underlie the motor, cognitive, and emotional expression that forms the basis of the CNS's ability to maintain the singular and rich experience of being a person.” (Braff & Freedman, 2008, p. 952)

“‘If some of the same genetic risks underlie schizophrenia and bipolar disorder, perhaps these disorders originate from some common vulnerability in brain development,’ said Dr. Thomas Insel, director of the National Institute of Mental Health, in a statement.” (23andme, 2009b)

In addition to the “genes” themselves appearing in this foundational position, the results of genetic tests were also framed as the best “basis” for actions or diagnosis.

“Though genes may explain only half of psychiatric etiology and interact with environment, genetics promises a new biology-based approach to diagnosis.” (Psynomics, n.d.)

The results of collocation analysis supported this observation. Looking at the collection of texts as a whole, I found that of the top ten words that co-occurred with the words “base,” “basic,” “bases,” “basis,” and “based” (considered in combination as one word), the only ones that carried substantive meaning other than a grammatical function (e.g. “the,” “and,” “of”) were “genetic” and “disorder.” The statistical measure used was

the t-score, which for “genetic” was 5.5 and for “disorder” was 3.4. Barnbrook (1996, p. 97-8) suggests that in this context, a t-score over 2 should be considered significant – thus both “genetic” and “disorder” appear significantly more frequently in the immediate context of the wordforms examined (within 3 words on either side of the node) than one would expect from chance.

Of course, as Barnbrook notes, the assumption that words are ever distributed “randomly” in a text or collection of texts is a gross mischaracterization of the nature of language; thus these statistical measures should be interpreted with considerable caution. However, combined with the observation that the words “environment” and “environmental” appeared nowhere in the list of words significantly associated with the “basic” wordforms, the numbers seem supportive of my qualitative findings. In addition, when examining the words “factor(s),” I found that “environmental” was the word most significantly collocated with it. The word “genetic” was also strongly associated with “factor(s),” which might be expected in light of the observation that many of the occurrences of “factor(s)” were in the context of claims that both genes and environment play a role in the development of illness, as opposed to “basic,” which was usually used to refer solely to genes or biology. Likewise, the words “underlie,” “underlies,” and “underlying” (again, considered as one word), were significantly collocated with the word “genetic.” In fact, “genetic” was the only word, other than “the” and “and” to be found in close association with the “underlying” wordforms significantly more frequently than chance would dictate. Table 1 shows the relative positions of “genetic” and “environmental” as collocates of the words in question, and their t-scores:

Table I								
<i>Significant Collocates of “Base,” “Underlying,” and “Factor”</i>								
base, bases, basic, based, basis			underlie, underlies, underlying			factor, factors		
Rank	Word	T-Score	Rank	Word	T-Score	Rank	Word	T-Score
1	the	8.81	1	the	3.95	1	<b>environmental</b>	5.09
2	of	8.47	2	of	2.94	2	and	5.09
3	on	7.55	3	<b>genetic</b>	2.63	3	the	4.79
4	and	6.06				4	risk	4.73
5	<b>genetic</b>	5.28				5	<b>genetic</b>	4.64
6	to	5.08				6	of	4.44
7	a	4.98				7	to	3.97
8	for	4.57				8	that	3.93
9	is	4.11				9	in	3.76
10	in	3.85				10	may	3.75

Note: The wordforms “base,” “bases,” “basic,” “based,” and “basis were considered as one word; similarly, “underlie,” “underlies,” and “underlying were considered as one word, and “factor” and “factors” were considered as one word.

Table I: Significant Collocates of “Base,” “Underlying,” and “Factor.”

Thus, while environmental contributions to illness are indeed acknowledged in most of the texts, there appears to be a subtle privileging of genetic factors, similar to the “narrative of enlightened geneticization” identified by Adam Hedgecoe in scientific review articles pertaining to schizophrenia (2001). The authors of most of these texts take some pains to ensure that they do not appear to weight the genes too heavily (leaving themselves open to charges of determinism, reductionism, and the other aspects of geneticization that have concerned so many social scientists), and thus the environment is often brought into play textually. However, its role is limited to being “another factor” – something that should be considered and may impact outcomes, but is not “fundamental” to the illness. In contrast, the genes are conceptualized as the base layer underlying human functioning – and dysfunction – and information about them is therefore also

conceived as the most “basic” sort of knowledge – something that can be relied upon to guide treatment without the worry that it is mutable and open to outside influence. Non-genetic information, usually observation-based methods that focus on symptoms, is seen as a problematic basis for diagnosis or treatment:

“Currently, bipolar disorder and other conditions such as depression are diagnosed based on the patient's description of their symptoms and the physician's judgment, sometimes making it difficult to get an accurate diagnosis or determine the severity of a patient's condition.” (Mitchell, 2010)

It is interesting to compare this “base/foundation” conceptual metaphor with the “blueprint” metaphor, which Lippman (1992) argues carries strongly deterministic implications (see also Nelkin & Lindee, 1995). Lippman suggests that viewing genes as a blueprint for future development of the individual leads to a view that both that individual's qualities (including any disorders they might develop) and the outcomes they experience in life are largely predetermined by genes and cannot be altered. She also suggests that this provides grounds for discriminatory policies and attitudes, where persons with genetic disorders are viewed as fundamentally flawed. When genes are conceived of as the “foundation” of disease, disorder, and life itself, it is tempting to also say that this metaphor is deterministic and ultimately discriminatory.

Celeste Condit, however, in an investigation of how American audiences interpret metaphors relating to genetics (1999), has suggested that the blueprint metaphor itself is not always interpreted in a deterministic manner, and even when it is, is not always discriminatory. Instead, a blueprint is sometimes envisioned as a design that can be changed, and does not determine in precise detail every feature of the edifice for which it is intended to provide the plan (p. 172-3). Some of the changes that were envisioned by Condit's respondents had to do with technological progress and actually altering the

genes (which suggests to me that they did in fact view the genes as deterministic of fate); others, however, referred to adaptations that people could make to genetic “flaws,” and to other interventions that could be chosen, including drugs and lifestyle changes (p. 173).

A similar case could be made for the “base/foundation” metaphor of genes.

Although my research did not include any audience studies or interviews with respondents about how they might interpret such a metaphor, it is plausible that, like a blueprint, a foundation could be interpreted as merely providing some limitations (shape, location, stability) for the edifice which is eventually to be constructed upon it. It does not determine what the overlying layers will be made of, or how they will be put together. Choices can be made that alter the final structure.

### **5.3.2 Bipolar Disorder Requires Organic Treatment**

One of these choices that can be made is in relation to treatment - although this is not always a choice made by patients themselves. There was broad agreement across all categories of texts that bipolar disorder required treatment with medications. Although references can be found throughout the texts to the use of particular drugs (and the difficulties of finding the “right” ones), one particularly striking example is the following instance, from a chat transcript hosted by the DBSA, in which a member of the public asks the “expert” about his opinion on non-medication-based treatments for bipolar disorder. In fact, this is the only place in the collection of texts where the received wisdom – that BP does require pharmaceutical treatment – was even placed in question, and the response, in addition to indicating fairly clearly that medication *was* in fact necessary, also reinforced the role of the doctor in making decisions about this treatment.

HariKari (May 28, 2008 3:21:05 PM): Do you believe BP can be treated without medications? Say therapy, good diet, exercise & supplements?

Dr McInnis (May 28, 2008 3:22:46 PM): all good things are good and to be encouraged. These interventions do not generally keep someone with BPI well, I encourage all good things, including wise use of medicines in collaboration with your doctor. (DBSA, 2008)

The subject of pharmaceutical treatment raises difficult questions about what impacts – discursive and otherwise – the regular ingestion of mood and mind-altering substances has on the subjectivities of mental patients. Emily Martin notes that when one’s rationality is seen to be substantially affected by a chemical, it is not implausible that the chemical itself might be seen as the “manager” of mood, and hence of behaviour, rather than the person taking the chemical – especially if that person is doing so under the guidance or even coercion of a doctor or family member (2007, p. 168). This drug-mediated, other-mediated management regime exists uneasily alongside notions of the ideal-type process of self-monitoring and self-maintaining that forms the central means of performing subjecthood within the neoliberal imaginary.

### **5.3.3 Overlapping Genotypes and Phenotypes: Definitional Tensions**

Despite the broad consensus on the genetic foundations of bipolar disorder, a tension exists in many of the texts between a recognition that bipolar disorder substantially overlaps both in symptomatology and genetic risk factors with other conditions, including major (unipolar) depression and schizophrenia, and the need to maintain bipolar disorder as a valid category with a unique genetic “basis” for diagnosis, research and treatment. While all genres of text appeared to note problems with the boundaries of bipolar disorder, both the characterization of this problem, and its solutions, differed. Some texts appeared to be more invested in a spectrum-based

classification system of diagnosis, while others favoured the breaking apart of bipolar disorder into smaller and more discrete categories, based either on phenotype, genotype or both. The major point of agreement within the texts seemed to be the acknowledgement that bipolar disorder (however narrowly or broadly defined) was difficult to diagnose with any certainty, and that this was a major source of trouble for both patients and clinicians.

In this discourse, it appeared that even the “gold standard” of psychiatric diagnosis, the DSM, was viewed with some skepticism. Very few of the texts referred to the DSM criteria for defining mood disorders as a strategy for constructing bipolar disorder as a defined category. In one of the only examples of this type of reference, the use of DSM criteria in diagnosis was actually framed as problematic in that it relied too heavily on patients’ experiences of illness and not enough on “objective” evidence:

“Although research in genetics and the neurosciences is giving us new information about the possible causes of mental illnesses, there is still no valid technology available to diagnose them. In other medical illnesses, we can depend on objective biological measures; but there are no lab tests (blood, urine, x-rays) that will conclusively determine the diagnosis of any mental illness. Consequently, for decades psychiatrists have used a detailed diagnostic manual (called DSM) to identify mental illnesses according to their “clinical signs,” based on the self report of symptoms from the patient. Diagnosis is made solely on the basis of how a person feels, acts, behaves and thinks—that is, clinically. As families well know, this means that doctors can sometimes miss the mental illness entirely, or patients can be tethered to a misdiagnosis for years.” (NAMI, 2008).

Two of the five academic texts mentioned the potential of genetic research to redefine the boundaries of bipolar disorder as a category (or set of categories). However, whether genetic research on bipolar disorder will function to reframe it as a particular manifestation of an integrated spectrum of mood disorders, recognizing the ways in which both phenotypes and genotypes overlap with schizophrenia, unipolar depression

and ADHD, or will actually work to reinforce the fragmentation of the existing “bipolar spectrum” diagnosis into smaller and more discrete categories (bipolar I, II and other subtypes), is uncertain. In some texts, the complexity of bipolar disorder was given as a reason to more tightly define phenotype-based diagnosis (e.g. Escamilla & Zavala, 2008). Although in this case, this diagnostic specificity was promoted for the purposes of genetic research rather than therapeutic outcomes, it seems likely that the corporate desire to “target” drugs to specific biochemical factors might also encourage this trend. Finn and Smoller, however, take the opposite tack, arguing that knowledge of overlapping recurrence risks should be taken into account in counseling situations:

“An additional complexity is the likelihood that psychiatric symptoms exist on a continuum. Should relatives with broader spectrum symptoms (e.g., schizotypal personality disorder) be counted as affected for the purposes of risk assessment? Family studies have often presented recurrence rates for narrowly and broadly diagnosed disorders, and reviewing these findings may help clarify diagnostic boundaries for recurrence risk counseling in a given family. Furthermore, for some psychiatric conditions, risks for family members may also exist for related disorders— for example, increased risks of all mood disorders among family members of bipolar patients.” (Finn & Smoller, 2006, p. 115)

Discussions of symptomatic and/or genetic overlaps in news articles and on patient websites are usually linked with discussions of the problematic effects of misdiagnosis leading to improper treatment. In these texts, diagnosis is seen to be *difficult*, but nonetheless accomplishable if one can sort through the confusing and deceptive symptomatic manifestations and identify the “objective” evidence for it – usually conceived of as genetic. Thus overlaps between symptoms are not identified as important in their own right, but as sort of red herrings that belie the underlying differences between conditions. Genetic overlap is not emphasized in these texts, particularly in the news articles.



Both the websites for 23andme and for Psynomics made reference to the way bipolar disorder “shares genes” with other disorders:

“The International Schizophrenia Consortium analysis also found that many of the variations associated with schizophrenia are also associated with bipolar disorder, a finding at odds with the traditional view of psychiatrists that the two are distinct diseases.” (23andme, 2009b)

“(…) some of the same regions and genes involved in bipolar disorder may also be involved in schizophrenia. This suggests a more complex relationship between these disorders than had been thought. This is also consistent with the idea raised earlier that biochemical pathologies involved in illness may cut across our current behaviorally defined diagnostic system.” (Psynomics, n.d.).

However, somewhat contradictorily, Psynomics also appears to be heavily invested in the idea that phenotypic overlaps are smokescreens hiding the true (genetic) nature of the condition. Perhaps this should not be surprising, as the product they offered is intended to uncover this evidence:

“Historically, diagnosis of psychiatric illness has centered on subjective evaluation of the patient's reported behaviors and feelings. No objective bases for evaluation has been available. As such, accurate diagnosis has been extremely challenging, particularly in illnesses such as this with many variations that may appear to be a different illness altogether (...) Psynomics' DNA-based test is the only objective test available for bipolar disorder.” (Psynomics, n.d.).

While elaborating upon the problems inherent in symptom-based diagnoses for mood disorders, however, Psynomics seemed to contradict their own position that genetic evidence is more “objective” and hence useful by making frequent reference to the DSM as an authoritative source of “truth” about conditions (in fact, this was the only text I examined that did so). I interpret this as a proactive framing strategy aimed at addressing expected criticism about the premature nature of genetic testing for bipolar disorder: by referencing the importance of the DSM in diagnosis, they are attempting to present an image of themselves as balanced. This impression is supported by their frequent references to the need for psychiatrists to be involved in the diagnosis process – and

indeed by their business model itself, which requires a psychiatrist to act as intermediary in ordering tests. While Psynomics is heavily invested in bipolar disorder as a valid diagnostic entity, they acknowledge the difficulties in determining its boundaries. Their test is framed as an additional “tool” that can be used to do so only by persons with a specialized skill set – a point to which I return below.

The definition of bipolar disorder as a condition discrete from other conditions appears to be a contested terrain. It will be interesting to follow, over the next few years, whether the DSM in fact remains the gold standard for diagnosis, or becomes supplemented or supplanted by gene-based procedures. It is clear that genetic research has the potential to lead to changes in diagnostic boundaries: whether a spectrum-based or more fragmented classification system is advanced, however, might depend as much upon which approach leads to more commercial opportunities as on actual results of research. I return to this shift in classificatory approaches in Chapter 7, where its implications for policy are discussed.

#### **5.4 Benefits of Genetic Testing for Bipolar Disorder**

Two main discourses were distinguishable in the texts in regards to the benefits of psychiatric genetic testing. The first, evident in the academic articles, and some of the news articles, took the position that the tests are not currently useful at all, and in fact may do more harm than good. The current state of genetic knowledge on bipolar disorder was claimed to be as yet so partial that no benefit can be derived from employing that incomplete knowledge for either predictive or diagnostic purposes. However, genetic research was viewed positively, and the discovery of genetic influences on bipolar disorder was also held to be desirable. Generally, it was not the concept of genetic testing

that was seen to be at fault, but its premature application. In these texts, discussions of benefits tended to focus more on genetic research in general, and genetic attributions, than on tests. These benefits were usually tied to the interpersonal troubles that surround mental illness in general: stigma, guilt, and blame:

“Most [respondents] felt that a genetic explanation was likely to decrease the stigma associated with bipolar disorder, as it shifted the locus of control and responsibility away from the individual toward the role of heredity.” (Mitchell et al., 2010, p. 234)

As with the academic articles, patient advocacy websites emphasized the contributions of genetic research not solely to treatment outcomes and diagnosis, but for its capacity to contribute to understanding of bipolar disorder, both for patients and their families and on the part of society. However, these texts seemed in general more representative of the second discourse. This second discourse, found also (and most explicitly) on the corporate websites, also acknowledged the incomplete nature of genetic knowledge of bipolar disorder. Both Psynomics and 23andme explicitly acknowledged that their tests did not provide definitive information and could not be used on their own for diagnosis; nonetheless, they presented the tests as bestowing some benefits regardless.

23andme’s test assesses customers, as noted, for reduced risk of bipolar disorder rather than heightened susceptibility. It is not explicitly marketed as a medical product; however, other parts of the site imply that by using 23andme’s genetic tests, one can in fact have a positive impact on one’s health - the home page of the website exhorts customers to “Take Charge of Your Health” (23andme, 2010). Thus the disclaimers that accompany the “Sample Report” on bipolar disorder to the effect that “the information on this page is intended for research and educational purposes only” seem somewhat disingenuous. If customers are purchasing these tests in response to advertising that

suggests they can improve their health, it seems reasonable that they ought to be able to expect some utility from the tests. However, the 23andme website sells these benefits in a rather general way, largely through the homepage, and does not focus its marketing around psychiatric conditions or target those seeking psychiatric diagnosis or treatment.

Theoretically, the test could be used in much the same manner as Psynomics' test – to provide “objective” evidence that makes a diagnosis of bipolar disorder *less* likely rather than more so. However, the way it is currently marketed makes it clear that the test is not to be used as a diagnostic aid. 23andme's position seems to be that simply the action of obtaining information (whether that information is currently actionable or not) is the hallmark of a responsible genetic citizen.

The Psynomics website, on the other hand, suggests that its tests can and should be used for this purpose, but only by a practicing psychiatrist and only in combination with traditional observation-based methods of diagnosis. Thus while genes are the focus for both sites, and the basis of their products, both take some pains to ensure that their audience does not view the genetic information these products provide as completely authoritative. This effort likely has a great deal to do with the potential for litigation (a risk also faced by doctors, as discussed in more detail below). In the case of Psynomics, however, where the company's co-founder is in fact a psychiatric geneticist, and where substantive limitations are in fact placed on test purchases that are not commercially advantageous, it seems that this cautious approach to authority may also actually reflect real concern for patients' wellbeing.

Psynome1, so Psynomics claims, strengthens the grounds on which a diagnosis can be made, allowing doctors not to rely solely on observations or patients' self-reported

symptoms but “objective” evidence (Psynomics, n.d.). This type of test use appears to be less about proactive risk management and more about reacting to an existing health problem by obtaining more information. The notions of risk and responsibility are still deeply relevant. Here, however, the “risk” involved is that of misdiagnosis and/or improper/inadequate treatment, and the responsibility involved is becoming an expert on oneself (or allowing others to become an expert on one) so as to avert this problem.

Psynome2, the test for SSRI response, was also marketed as a tool to assist doctors – this time in the determination of appropriate drug regimes for their patients. In this case, explicit links were made between the use of Psynome1 and Psynome2 – the suggestion is that the former can clarify diagnosis, while the latter is then used to clarify treatment options. Although my own focus was on susceptibility testing, it is important to note that Psynomics’ advertising copy was developed in many cases to be applicable to both tests. Additionally, Couzin (2008) claims that Psynomics at that time was planning to add several genes to their testing panel – three of which were concerned with response to lithium treatment (Couzin, 2008, p. 275). Couzin’s article is unclear as to whether this information was intended to guide treatment or diagnosis decisions – which again highlights the substantial areas of overlap between susceptibility tests and pharmacogenomics.

For the corporate websites, the benefits of testing are seen to accrue largely to individual test users, who gain a “correct” diagnosis, and to doctors, who gain another tools for making “objective” assessments. The only interpersonal relationship emphasized here is that between the doctor and the patient. For patient advocacy groups, the same

benefits are seen to arise from testing; however, these are accompanied by more general benefits of genetic research: namely, decreases in stigma, guilt, and blame.

It should be noted that in many of the news articles, both of these views were presented, usually as a back-and-forth between quotes and viewpoints of principal researchers and other academics, particularly bioethicists, who took a more critical stance.<sup>25</sup> This type of “balanced reporting” makes it difficult to say whose discourse is being promoted – both risks and benefits, however, tend to be played up in the news articles. For example, RedOrbit cites Dr. John Kelsoe, the co-founder and Executive Vice President of Psynomics, commenting on the value of his test:

“But he said his test is a critical starting point in the departure from the notoriously tricky practice of diagnosing bipolar disorder based solely on a person’s behavior. ‘The goal of this is to try and help doctors make an accurate diagnosis more quickly so the patient can be treated appropriately,’ Kelsoe told the AP.” (RedOrbit, 2008)<sup>26</sup>

The author then followed this quote with a series of counterbalancing quotes from bioethicists and other psychiatric professionals, most urging caution in using these tests and one expressing limited endorsement of Psynomics. Overall, however, the prevailing sentiment within this subset of the articles is that, in addition to aiding understanding of bipolar disorder generally, these tests can now, or will be able imminently, to aid in

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<sup>25</sup> Of the 38 quotes incorporated in the news items, including those published on the websites of Psynomics, 23andme, DBSA and NAMI, 18 were from researchers or psychiatrists reporting on their own research or corporate ventures, 19 from psychiatrists, bioethicists, and administrative figures providing external commentary on these projects, and one from a US Senator. None of the sources quoted were potential or actual test users, persons diagnosed with bipolar disorder or their family members.

<sup>26</sup> Another example of the type of intertextuality found within the study: this article is a paraphrasing of an article found on the Huffington Post website, “Bipolar Disorder At-Home Test Causes Stir.” While the Huffington Post credits Marcus Wohlsen of the Associate Press as the author, RedOrbit does not cite an author, implying that the content is their own. However, they use the same quotes from the same sources, and follow the

diagnosis and treatment and that, although ethical concerns remain, the clinical value of the tests will only continue to improve.

Overall, benefits of genetic testing for bipolar disorder are largely located at the level of the individual – an individual who is seen to be concerned largely with receiving a correct diagnosis and therefore correct treatment. The “targeting” of appropriate pharmaceutical substances to an “objectively” diagnosed biochemical entity is, in this case, the ultimate aim of genetic research. These benefits are emphasized by the companies marketing these tests, as would be expected. Academic scholars were disinclined to tout the present benefits of tests for patients, but instead focused on the interpersonal benefits of genetic research in a more general sense – viewing the relationships between persons and their families as areas of key concern. Patient advocacy organizations tended to promote both discourses of benefit (personal and interpersonal), viewing both testing and research in quite a rosy light. Benefits to society were rarely mentioned – the sole exception appears to be an article in the *Globe and Mail* (McIlroy, 2009), where the claim was made that new technologies “could save the health care system money.” As noted below (p. #), it is of interest that this reference to the health care system came from one of the few Canadian articles in my collection.

## **5.5 Risks of Genetic Testing for Bipolar Disorder**

Two chief risks of DTC psychiatric genetic tests were prominently discussed in the academic articles: ineffectiveness and misinterpretation. Whether tests are effective or not is a major question that may affect whether the tests are treated as consumer goods, or

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format of the AP article very closely, altering the language only slightly – assumedly in a not-altogether-successful attempt to avoid outright plagiarism.

as medical necessities, as noted above. However, concerns that the tests are inaccurate are most informative in relation to the characterization of the expected responses of users to this misinformation:

“A false negative bipolar test may reinforce an ambivalent patient's failure to take medication. Likewise, a false positive "suicide gene" test may have terrible consequences for already depressed and frightened patients by increasing their fear of harming themselves.” (Braff & Freedman, 2008, p. 954)

Pretty obviously, test users (here glossed as patients) are expected to make poor choices in response to poor information. However, what is problematic here is that the tests are generally not sold as definitive at all – the advertising copy on both Psynomics and 23andme’s websites makes it quite clear that their tests show very slightly increased or lowered *risk*, not the presence or absence of bipolar disorder. Thus it is the test users who *misinterpret* the information – as they are suggested to be likely to do regardless of the test’s result, when they are not provided with expert guidance:

“In addition to inappropriate use of genetic tests—both scientifically and ethically—there is enormous potential for misinterpretation of information, with potentially very damaging consequences; in addition, often there is little provision of follow-up care by the testing organizations.” (Austin & Honer, 2007, p. 259)

“Hogarth and colleagues focused on the lack of appropriate counseling and advice on the suitability of such DTC tests and the consequent potential implications, such as a lack of expert interpretation of test results, and a lack of guidance on actions to take as a consequence of such testing. Furthermore, these investigators argue that such adverse implications apply particularly to complex diseases (the mechanism of inheritance pertinent to most psychiatric illnesses) in which the relationship between specific gene variants and disease is less clear.” (Mitchell et al., 2010, p. 230)

Thus we see that it is not only the quality of test information but the inherent complexity of genetic information that makes it unlikely that consumers will be able to interpret results and respond appropriately. Even clinicians are expected to have difficulties with this type of information (a point I discuss in some detail below):



“If the tests are marketed directly to consumers, the results may be sent to clinicians who do not understand the test’s meaning, or do understand it and think that it is not worthwhile.” (Braff & Freedman, 2008, p. 954)

Nonetheless, physicians and counselors are seen as the most appropriate persons to interpret test results – not patients. As Bunton and Petersen argue, “the premise that more information provides more choice and thus enhances autonomy is widely held as an unproblematic given by many professionals within public health and medicine” (2005, p.12). In this context, however, we see a countervailing claim – information is in fact sometimes found to be harmful, particularly when provided to a vulnerable population:

“Responsible genetic testing in modern medicine has to take into account not only the promise but also the consequences of offering information to patients. (Braff & Freedman, 2008, p. 954)

While those at risk of mental illness provide one of the clearest examples of populations perceived as vulnerable to the effects of knowledge, this discourse may, of course, also be found in relation to other groups in the medical setting, as in other contexts – for example, those with lower levels of education and economically or ethnically disadvantaged groups – and indeed, the general population – may be deemed vulnerable in this manner and their “exploitation” by commercial interests broadly condemned, with “expert” mediators claiming a role for themselves in knowledge translation. However, the suspect rationality of the mentally ill (in combination with the genetic “foundation” of their illness) means that there may not be an expectation that the locus of control will ever shift to them – they are not “immature” consumers but “fundamentally” flawed ones.

## 5.6 Terminological Choices

The following table shows the log likelihood scores for the frequency of particular words used to refer to the potential subjects of genetic testing. A score of 3.84 or more indicates that that the result (the observed frequency of a given word in the sample) has less than a 5% chance of being due to random variation; a score of more than 6.63 indicates a less than 1% probability of the outcome if the distribution were random (p-values of 0.05 and 0.01, respectively) (Lancaster University, n.d.). For the purposes of this study, I consider the less stringent threshold of 0.05 to be acceptable, as we are dealing with a small sample and therefore unlikely to see particularly large log likelihood scores for many words. Because of these limitations, I have also chosen to provide the numbers even where statistical significance is not reached, as the alpha-level was somewhat arbitrarily set and I am employing these statistical techniques more to gain a sense of general trends than of precise proportions.

Term	Academic	News	23andme	Psynomics	Patient Orgs
“consumer”	1.11	--	--	-6.68*	8.05*
“consumers”	-0.12	--	--	--	12.40*
“customer”	--	--	--	1.47	--
“customers”	--	--	3.96 <sup>a</sup>	0.95	--
“patient”	-3.17	7.873*	--	2.64	-2.76
“patients”	--	11.329*	--	-0.03	-6.03*
“individual”	0.94	0.23	0.06	-0.87	-0.60
“individuals”	7.36*	-2.32	-6.62*	-7.07*	--

Note: Log likelihood scores are given for categories of texts considered in comparison with corpus of texts as a whole.

\*p < 0.05

<sup>a</sup> This figure was based on fewer than 4 observations in the texts under consideration and is therefore not reliable.

Table 2: Log Likelihood Scores for Terms Used to Refer to Test Users

In comparison to the overall collection of texts, the patient organizations were significantly more likely than other categories of texts to use the term “consumer” or “consumers.” They are significantly *less* likely to use the word “patients.” The 23andme website also appeared to prefer the word “customers,” but this was based on a very small total number of observations, and is unreliable. 23andme, by and large, avoided using all of the terms in question – where there is a blank space in the table, this indicates that the word was not used at all in that category of texts.<sup>27</sup> Psynomics, on the other hand, was significantly less likely to use the term “consumer,” and somewhat more likely (though again, not significantly so at the set alpha-level) to use the term “patient.” News articles were much more likely to use the terms “patient” or “patients,” and did not, in fact, use any of the other terms at all (except in the context of the phrase “direct-to-consumer,” which was not considered here). Academic articles were weighted heavily toward use of the somewhat formal and specifically non-relational term “individuals.”

These figures seem to match up with the qualitative observation that Psynomics is quite heavily invested in a traditional doctor-patient model of service delivery, rather than fully embracing the consumer model that 23andme has adopted. It also provides support for the (somewhat obvious) finding that patient organization websites also tend to frame mental health care users as consumers rather than patients, providing a more active and choice-oriented subject position for them than the traditional role as recipients of care. It is interesting that news organizations tend to take the opposite tack, framing test users as

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<sup>27</sup> One limitation of AntConc is that, while it generates a list of negative keywords (of which I have made use), only words that appear at least once in the texts under consideration are scored for keyness. Thus words that appear in the corpus but not in a particular category remain un-scored; however, these words, by virtue of their total lack

“patients” even where directly discussing direct-to-consumer test purchases. I suggest that this is because many journalists are re-contextualizing the discourse of psychiatric researchers, who in academic articles might use the term “individuals” (especially when talking in the aggregate about study respondents or participants in trials), but when speaking informally with a journalist or in the context of a press release might be more likely to use a term such as “patients” – something that emphasizes the vulnerability of the population whom their research is intended to benefit, while playing up their own role and that of their colleagues as care providers in relation to members of that population.

## **5.7 Imagery**

Only occasionally are test users represented or described in the texts: the corporate websites for 23andme and Psynomics depict customers visually through photographs, assumedly intended to resonate with their target markets. Figure 1 shows the top section of 23andme’s home page. The individuals depicted here are healthy-looking, contemplative but not distressed. The “Health Edition” test is clearly linked to the theme of family through the choice to depict what appears to be a father and child, implying that a responsible parent “takes charge” of his or her own health in order to be able to take care of his or her family members.

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of appearance, are of course likely to be significantly negatively associated with the category in question!

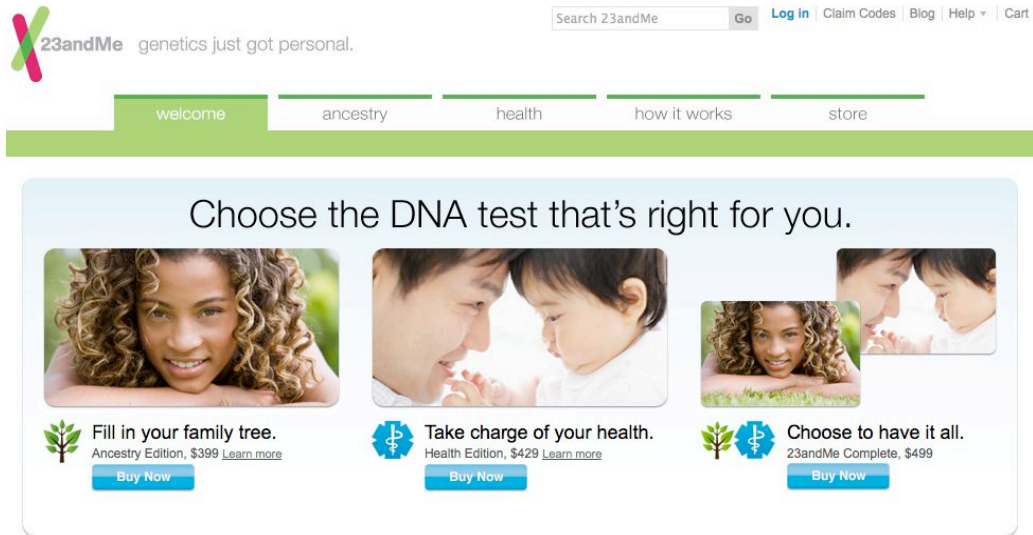


Figure 1: 23andme Home Page (23andme, 2010)

Psynomics also depicts a potential test user on the home page of their website. Here, the mood is ambiguous. We might imagine her as contemplative, or perhaps concerned. Confused? Perhaps she is having trouble getting an accurate diagnosis.



Figure 2: Psynomics Home Page (Psynomics, n.d.)

It is not generally the policy of companies to show potential customers in the state of anxious need, but to show the satisfaction of that need through the consumption of their product. Here Psynomics seems torn between a recognition that their customers *are* likely to be in distress, confusion, perhaps uncertainty as to what is going on in their heads, and the desire to promote their product as a consumer good. What is particularly notable in this illustration (in addition to its fundamental ambiguity) is the isolation of the

person from any other element. The woman wears no makeup, no jewelry – even, it seems – no clothes (although interestingly, she has chosen to apply nail polish). No other persons are present, and the background is a serene nothingness incorporating only the Psynomics logo. This absence of other figures points to the more individualizing approach to marketing that Psynomics has chosen; family is not a central feature of the discourse, nor is the patient’s social positioning. It is only the genetic/biological “basis” of the mental disorder that is at stake, and Psynomics (and the “new psychiatry” it promises to deliver) is positioned to address that issue.

The patient organization websites also provide depictions of individuals. These are not, however, meant to represent (necessarily) potential test users, but rather people already living with a diagnosis of mental illness. Of course, there is a substantial overlap between the subjectivity of “mentally ill” person and “genetic test user” as with other subject positions. As noted above, the family members of those diagnosed with or at risk for a genetic condition are genetically at risk themselves; thus they may simultaneously inhabit both the subject position of family member (imbued with particular responsibilities and burdens) and test user, or person-at-risk. In many cases, then, a single person might inhabit all of these roles: at once, they are a patient (in relation to a doctor), a consumer (in relation to a company), and a family member (in relation to others at-risk or diagnosed, or unaffected). They may also be a peer, a friend, a teacher, or a professional, and it is this overlap that the patient organizations are keen to emphasize. In the selection of images below, interpersonal dimensions are key, and the potential of individuals to support one another is highlighted through both text and image.



Figure 3: DBSA home page (DBSA, 2010). Here the supportive potential in family relationships is highlighted



Figure 4: DBSA Home Page (DBSA, 2010). Again, intergenerational connection is highlighted.



Figure 5: NAMI Home Page (NAMI, 2010). Hands are a recurrent theme in the imagery on these websites, symbolizing interconnection (often between to person who appear to be family members), but perhaps also a certain active capacity.



Figure 6: NAMI Home Page (NAMI, 2010).

The pictures published on the home pages of DBSA and NAMI are reflective of an orientation toward highlighting interconnection, interdependency, and the diversity of people whom mental illness is seen to strike. While they are intended to depict the faces of mental illness, these are also the faces of potential test users. They are the faces of patients, of family members, and of “consumers” as well. It is never really possible to disentangle these many and varied positions from one another: while particular texts emphasize one or the other, and may be able to promote their particular relational subject position as the most important, most appropriate, or most desirable one in a given situation, people will always be enveloped in networks of association with many other people and entities, and these relationships will require them to take on (sometimes reluctantly, sometimes eagerly, sometimes without really considering the alternatives) different roles. Nonetheless, it is precisely this matter of emphasis, of degree, with which we are concerned.

While the patient organizations I examined promote familial and peer relationships as essential, they clearly recognize that the people on whose behalf they advocate are enmeshed in relationships with a state (if somewhat distant at times), with various doctors and medical professionals (if flawed and inadequate), with private companies like insurance providers, and with themselves. Likewise, corporate groups recognize that the purchaser-provider relationship is not the only one in which their customers are engaged, and academic researchers are aware that the doctor-patient dyad is not the only arena in which mental health care users exist. However, many of these groups of stakeholders betray a tendency to exhibit particular relational configurations as



the most important or vital, while others are portrayed as problematic. I discuss this issue at length in chapter 6.

## **Chapter 6: Test Users as Relational Subjects**

### **6.1 Introduction**

As noted above, the construction of psychiatric genetic test users as subjects in the discourse took place largely through indirect means, with these figures most visible in the light of their relationships with other figures and institutions. I now turn, therefore, to a more detailed discussion of these relational frames, and of the qualities and characteristics of test users that they imply.

Throughout the texts, test users were primarily framed as subjects in relation to three key (groups of) figures. In the academic texts, and to some extent in other categories of texts, the doctor-patient (or professional-patient) relationship was emphasized. In this discourse, test users were viewed primarily as patients, reliant upon doctors' guidance and judgment, as well as their expertise. In other texts (and in some of the same texts), the family relationship was a central focus. This frame implied a relationship characterized more by interdependence. Finally, test users were also seen as consumers of products, with the relationship in focus being that between the test purchaser and the company providing it. This relationship was identified as the most problematic in many of the texts, as the ideal-type consumer-provider relationship requires a consumer that embodies a number of characteristics that those at risk of, or diagnosed with, a mental illness are not always assumed to possess: rationality, autonomy, and the capacity to make decisions in their own interest. In very few texts was a relationship between test users and the state, or with a community (however defined), brought into focus – an absence which is informative in and of itself.

Table 3, below, provides measures of keyness for a selection of terms used to refer to figures other than test users in the various categories of texts under consideration, considered in relation to the body of texts as a whole. From these calculations, it is possible to see that family-related terms are used very frequently in the academic articles. The other categories of texts are less likely to emphasize familial relationships, although the patient organization websites tend to use the word “family” with a high frequency, and 23andme prefers the term “related.” Psynomics, on the other hand, exhibited very heavy use of the terms “doctor” and “psychiatrist,” suggesting an orientation toward a patient-professional relationship (as we saw earlier in Table 2, Psynomics also preferred the term “patient” over “consumer,” “customer,” or “individual”). News articles also tended to focus discourse around professional figures, including “doctors” and “clinicians,” but particularly around “researchers” and “experts.” These “researchers” also featured prominently in the discourse of 23andme (although this is likely to originate from the “Spittoon” blog texts, which do closely resemble news articles, rather than the sales parts of their website). While the patient advocacy websites do mention professional figures, these are framed as “providers,” with the “consumer” relationship highlighted (recall that Table 2 showed a high preference for the term “consumer” in patient organization texts). Clearly each category of text shows particular preferences in regard to the relationships they wish to highlight, and these preferences have major implications for the framing of test users as relational subjects.

Table 3					
<i>Log Likelihood Scores for References to Relational Figures</i>					
	<b>Academic</b>	<b>News</b>	<b>23andme</b>	<b>Psynomics</b>	<b>Patient Orgs</b>
family	4.10*	-5.89*	-17.24*	-0.89	1.22
families	8.75*	-0.96	--	-5.47*	-4.57*
relative	3.08	-0.04	-0.01	--	--
relatives	4.94*	-1.46	-0.68	-6.67*	-1.38
related	--	-0.64	3.91*	-1.06	-0.32
doctor	-28.20*	--	-2.45	22.26*	-0.08
doctors	--	18.14*	--	-0.22	--
clinician	-0.10	--	--	--	--
clinicians	--	8.10*	--	-10.14*	-0.04
psychiatrist	-13.46*	-0.51	--	23.41*	--
psychiatrists	2.55	--	-1.57	-2.17	-2.7
experts	-1.18	6.05*	--	-0.28	--
researchers	-9.49*	24.13*	18.67*	-6.48*	--
provider	-1.439	--	3.658*	0.882	--
providers	-4.0*	--	--	-1.05	26.12*

Note: Log likelihood scores are given for categories of texts considered in comparison with corpus of texts as a whole. Blue indicates positive keywords, while red indicates negative keywords.

\*p < 0.05

Table 3: Log Likelihood Scores for Relational Figures

In this chapter, I discuss how these entities are framed in the texts under consideration: doctors and genetic counselors, families, the market, and the (largely absent) state. Looking through this somewhat indirect lens helps to define the conditions of possibility that surround test users: the spaces that are created in relational situations for them to exist in, and the roles they are expected to assume.

## 6.2 Doctors and Other Professionals

As discussed above, in many areas of medicine, the capacity for physicians to dictate treatment and even diagnosis may be waning. With the rise in prominence since the 1970s of consumer rights discourses, deference to the authority of medical professionals in general has declined, and in many cases doctors are seen as partnering with patients in care, or even as playing more of a consultant role to “client-consumers” (Reeder, 1972). However, Lupton, Donaldson & Lloyd (1991) have questioned whether

this is an adequate characterization of doctor-patient relationships in general, and others (Hazelton & Clinton, 2002; Petersen, Kohanovic, & Hansen, 2002) have suggested that in the context of mental illness, professionals may be less willing (or able) to relinquish their authority, and may not be required to do so by patients or by policy.

Throughout many of the texts, the roles of doctors and other professionals (e.g. genetic counselors) were emphasized in relation to diagnosis and management of bipolar disorder and the associated genetic risks. In almost all cases, the assumption was implicit that the judgment of the doctor should be deferred to where questions about diagnosis, treatment or other choices about illness management were concerned. Interestingly, this included the corporate sites offering tests associated with bipolar disorder, who in fact were more likely to outline this relationship explicitly:

“You should always seek the advice of your physician or other appropriate healthcare professional with any questions you may have regarding diagnosis, cure, treatment or prevention of any disease or other medical condition.”  
(23andme, 2009b)

Medical professionals, although placed in this position of *authority*, also seem to bear a fair share of the weight of *responsibility* for making choices about treatments, and their authority does not appear to extend to a “the doctor is always right” mindset. This is especially clear in the academic articles, where the knowledge of psychiatrists about genetics, and of genetic counselors about psychiatric conditions, is placed directly in question. The fallibility of current systems of symptom-based diagnosis are also held to be an ongoing problem.

“Treating mental illness is often a trial-and-error process, and side effects can make patients unwilling to stick with a treatment regime. If a drug doesn't work, or causes serious side effects, patients can lose faith in their doctor.” (McIlroy, 2009)

The risk paradigm in medicine engages not only patients in webs of self-surveillance and endless anxieties over future possible outcomes, but orients professionals toward the future and uncertainty as well (Rose, 2005). One of the primary reasons that many psychiatrists have come out in opposition to genetic testing may have to do with their own personal risk calculations. These tests in most cases do not seem to provide much in the way of clinical assurance, Psynomics' advertising copy notwithstanding; they are, however, seen by academics as risky in and of themselves. As Reuter (2007) has noted, doctors who have *not* helped patients to engage in genetic risk management – doctors who have, inadvertently or consciously, denied their patients the right to fulfill their own desired subjectivities as responsible and proactive consumers of care (in this case reproductive genetic testing), can be held liable. The riskiness of genetic tests for doctors is particularly emphasized in the academic articles, and is sometimes made mention of in the news articles.

“Quite a conundrum (and possible liability) is foisted on a physician who may well never have wanted the direct-to-consumer test ordered in the first place. Thus, this direct-to-consumer platform seems especially risky. This risk is increased when leading academic institutions add their imprimatur to this endeavor.” (Braff & Freedman, 2008, p. 954)

The corporate websites, of course, emphasized the benefits of genetic tests over their risks. In particular, Psynomics was keen to show precisely what benefits accrued *to doctors* from their products. However, they also appeared cautious not to oversell the authority of their tests, leaving the doctor's judgment as the decisive factor in any diagnostic or treatment decision. The dominant framing of genetic tests here was as a “tool” to expand the repertoire of a doctor in making what are acknowledged to be difficult and subjective decisions that have deep impacts upon patients' lives.

“[Benefits to physicians include] ...Unique, progressive and branded tools with which to increase their effectiveness and patient satisfaction (...) The opportunity to be one of the first to use a dramatic and superior new tool that is on the leading edge of the merger of two exciting fields: psychiatry and human genomics.” (Psynomics, n.d.)

This framing was echoed in many of the news texts and academic articles – however, in these texts, the “tools” were often positioned as premature:

“...the current premature marketing of insensitive and confusing genetic tests is misleading to consumers and may cause human suffering and societal mistrust of what will ultimately be a valuable tool for psychiatric practice and science.” (Braff & Freedman, 2008, p. 955)

A substantial difference was observed between the approach to the doctor-patient relationship promoted by Psynomics and that of 23andme. 23andme appears to pay lip service to the need to consult doctors, perhaps more out of concern for liability than belief that a doctor’s input is needed. This is reflected in their business model: they both market and sell their tests directly to purchasers without requiring a doctor’s signature. Their advertising copy also reflects the ideal of tests being used as “tools” by *consumers*, rather than by doctors:

“23andMe is a genetic testing service that provides information and tools to understand your DNA.” (23andme, 2010)

Psynomics, on the other hand, emphasizes the role of doctors in the diagnosis and treatment process to an even greater degree than other categories of text.

In contrast to the corporate sites, which emphasized the involvement of doctors in the testing process, news and academic articles tended to highlight the “direct-to-consumer” nature of genetic testing. The requirement placed by Psynomics upon the use of their tests only in collaboration with a physician was seen as a mitigating factor that made this company less “risky” than others. However, other hypothetical and “coming-

soon” genetic tests for bipolar disorder and other mental conditions were seen as problematic largely because they did not require a doctor’s guidance or approval:

“(…) genetic tests for a wide range of conditions, including bipolar disorder and Alzheimer's, are now being marketed directly to individuals and offered for sale on the Internet. ‘If you Google ‘genetic test,’ you will find tests for 20 or 25 disorders that companies are marketing right now,’ Appelbaum said. ‘So we as psychiatrists and our residents may not get to make the decisions about [whether to use these tests].’” (Moran, 2008)

Doctors are thus in a double bind. If they choose to use genetic tests, or to help patients interpret their results, they may be taking on additional responsibilities for little reward – the tests, at this point, will generally not help them make diagnoses<sup>28</sup> or predictions of individual, familial, or reproductive risk. They also may be exposing their patients to risks of discrimination, family discord, or psychological harm, by choosing to employ the tests (and setting themselves up as liable for having done so). If they do not use the tests, however – or sign off on a patient’s request to access testing, in the case of Psynomics – patients or their families may feel that they are denying them the “right” to access their own genetic information, and hence the right to both understand and manage themselves as responsible citizens (cf. Reuter, 2007). They may also be criticized for driving patients into the ruthless private market. Although currently the risks of using these tests appear to outweigh the risks of not using them for professionals, this situation may change if corporations are successful in the ongoing process of defining genetic knowledge as both a right and a responsibility.

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<sup>28</sup> Although pharmacegenomic tests could potentially be useful in treatment decisions, susceptibility tests generally have such low predictive power that their clinical utility is presently agreed to be limited to non-existent. Pharmacogenomic tests may suffer from the same or similar limitations but as this was not the focus of my research, I cannot speak authoritatively on this subject.



A subset of the academic articles – those that pertained to genetic counseling – focused on the role of the genetic counselor, who was seen to play a less directive but still central role in making choices and defining the scope of those choices. In contrast to doctors, genetic counselors were depicted as “supporting” the decision-making processes of families and individuals; their role involved providing information, attempting to mitigate harms associated with that information, and facilitating access to follow-up care. In this model, the autonomy of patients is enabled through the provision of information:

“In some scenarios, patients may have decisions to make—for example, about treatment and medication in preparation for or during pregnancy. In this situation, the counselor’s role is to facilitate and support decision making, not to direct decisions, and to help the patient to adjust to his or her decisions.”  
(Austin & Honer, 2007, p. 256)

### **6.3 Families**

Substantial portions of the texts in several categories were devoted to outlining the (also substantial) role of family in the diagnosis, treatment and management processes surrounding bipolar disorder and other mental illnesses. In the context of genetic testing, family members were seen to be involved both indirectly, as support providers and decision-makers for afflicted or potentially afflicted kin, and directly, as potentially at risk themselves.

Because genetic information is not just “about” the individual, but pertains very directly to their blood relatives, particularly close kin like siblings, parents, and children, when one family member makes a decision to take a genetic test, the results may provide information on the risk status of other family members. Decisions must then be made about whether or not to inform those family members of their increased or lowered risk, which may lead to these individuals undergoing testing themselves. As van Riper notes:

“The decision to be tested is rarely an autonomous decision based solely on the needs and preferences of the individual being tested. Rather, it is a socially situated decision, one that is often based on feelings of responsibility and commitment to other family members.” (2005, p. 227)

Clearly, when results indicate increased risk of a particular condition, the potential is highest for this information to cause distress, as some individuals may regard this knowledge as a burden, casting a shadow over their lives and decisions (Polzer, 2005, p. 87-88). However, even where the results of testing indicate lowered risk, the testing process can place strain on family relationships (van Riper, 2005).

In the texts I examined, several made very clear links between individual risk and family members' risks. In particular, the academic articles that focused on genetic counseling (Finn & Smoller, 2006; Austin & Honer, 2007; Mitchell et al., 2010), and the news items that drew heavily on these studies (e.g. AOL Health) emphasized the familial nature of genetic risk. The claim was made in several cases that assessments of genetic risk for a given individual should involve taking a thorough family history – and the general superiority of this method to the current state of the art of genetic testing was asserted.

As a corollary to this, of course, if the person in question – in this case, the genetic test user - is diagnosed with bipolar disorder, the genetic risk status of other family members is raised. This means that they too are potential test users. Thus the subject position of “family member” is partially defined in the same way as the subject position of “test user” and vice versa. Although these texts suggested that many family members believed that genetic attributions would relieve some of the stigma associated with mental illness, it is clear that the shared nature of genetic risk was partially responsible for their

feeling stigmatized in the first place, which supports the claim (Phelan, 2005) that the relationship between genetic attributions and stigma is not a simple one.

In addition to being the locus of genetic risk, genetic stigma, and sometimes genetic guilt, the family was also perceived in these texts to be the one of the central units or scales at which decisions should be made and interventions initiated (i.e., it was also the locus of some genetic responsibility). This observation brings to mind Polzer's claim that families may be viewed, in the context of genetic testing, as "the 'natural link' between the personal ethic of maintaining good health and more general political objectives (...). The family is constructed as both an object of, and a vehicle for, genetic governance" (2005, p. 88). This is evidenced also through the ubiquitous phrases "patients and their families" and "individuals and their families," which were used to refer to the recipients of genetic counseling throughout the texts, as well as through the thorough reviews of many studies that have examined attitudes toward genetic test use from the perspective of various family members.

The patient advocacy websites also placed families at the centre of the equation. However, here the emphasis appeared to be less on the genetic relationships between kin than on the practical responsibilities they take for one another. Genetic tests were not a major focus of discourse on the advocacy websites, although they were generally looked upon favorably. Nor was risk emphasized. Instead, the websites were focused around the practical provision of support (within families, but also between families, through group settings, in online formats, and other private means).

The notion of "support" played a large role in this discourse. Both the patient advocacy websites and the articles focused on genetic counseling were concerned with

the provision of support to those undergoing diagnosis, treatment, or living with bipolar disorder. The centrality of this concept is important, because it implies that those on the receiving end of this support are incapable of managing on their own – i.e. *not autonomous*. So who is seen to provide this support? What does it consist of? And what does it indicate about its recipients?

In the patient advocacy texts, it often appears that patients and families are constructed as interdependent – providing support to one another because no one is able to get through it on their own. One can be both a provider of support and a receiver – both dependent and depended upon. The support referred to is usually in the form of an online group, consisting of peers (either other patients or other family members). For example, on the NAMI home page, there is a link to “Support and Programs,” followed immediately by another link that describes “How You Can Help” (NAMI, 2010). Similarly, the DBSA home page contains a link on the left hand side entitled “Find Support”; when highlighted, one of the options it provides is “Start a Support Group.”<sup>29</sup>

In the articles focused on genetic counseling, on the other hand, the support provided by the professional was usually the centre of focus. While there was a great deal of talk of “empowerment” and “facilitating,” it was clear that the genetic counselors were the ones with the ability to “empower” people and “facilitate” their decisions; the relationship was not reciprocal.

“Because a causal explanation is important in developing coping strategies, facilitating adaptation to illness, and making behavioral decisions, genetic

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<sup>29</sup> Martin (2007), discussing two other, more regionally-based, patient support organizations, notes that one of the major divisions between the two organizations is over who is actually at the helm of providing support: whether the management of the organization is in the hands of patients, or of “experts.” This suggests that even in the context of these groups, there is some uncertainty over who exactly is capable of providing support, and at what level.

counseling may provide some balance and perspective for the affected individual. Supportive counseling strategies and complex-disorder models can be used to empower the patient and increase his or her perceived personal control over the illness, which can help to promote health-enhancing behaviors.” (Austin & Honer, 2007, p. 257)

Support was far less central a concept in the other texts – including the corporate websites, news items, and those academic articles not focused on genetic counseling – perhaps indicating that the word “support” itself carries connotations of “empowerment” or enabling rather than guiding and directing, thereby suggesting that those diagnosed with, or at risk of, mental illness should take a more active role. Those sections of the Psynomics website that were drawn from the NIMH did make reference to support groups and the support provided by family and friends; however, this appears to be a feature only of this recontextualized discourse and not of the text authored by Psynomics staff or management. The overall message of the site was centred around care (provided by a doctor who retains an authoritative role) rather than support (provided by peers, family members and sometimes professionals who relinquish decision-making power).

The corporate website for 23andme was very much oriented to familial relationships and familial risk predictions. Their whole corporate strategy, in fact, is very much geared toward the promotion of open sharing of genetic information amongst families, and of discovering ties of ancestry and kinship, as well as health risks. The “Ancestry Edition” of their product line provides the opportunity – in addition to uncovering your genetic similarities to populations of particular geographic locations – to “find all the other 23andMe members who match your DNA” (23andme, 2010) Members are actually able to contact those who appear to be “related” to them. The “Health Edition” product line (where the test for relative risk of bipolar disorder) appeared to share with the “Ancestry Edition” a focus on openness and relational data: members are

encouraged to examine their family members' data (which of course is to a certain extent the same as their own data). Figure 7 shows the way in which genetic data was presented as inherently familial:

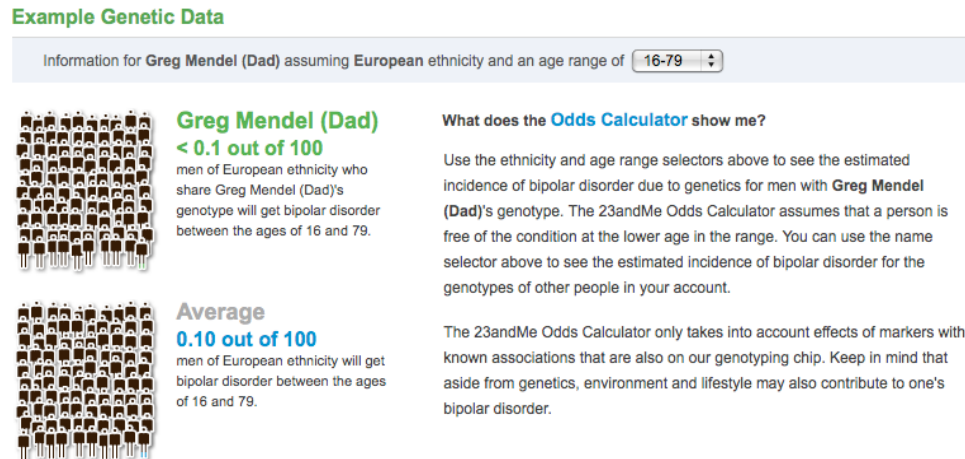


Figure 7: 23andme Example Genetic Data (23andme, 2010). This appears on a “sample report” that provides an example of the type of data 23andme provides.

In this case, the genetic relationship was central rather than relationships of social responsibility. The connections that 23andme imagines among its members are numerous, but primarily technological, biological, and based on a vision of genetic test users that has little to do with dependence. The notion of support is not central here because 23andme’s customers are not seen to need support: they resemble, much more closely than do the imagined customers of Psynomics, the ideal consumer of neoliberal governance: rational, self-interested, and autonomous. Although the shared nature of genetic risk information is central to the discourse, the emphasis here is on *information* rather than *risk*. Although information about risk may impact other family members, it is not expected to cause distress, but rather to increase autonomy.

## 6.4 The Market and the (Disappearing) State

Clearly, the market is now playing a role in the discourse surrounding psychiatric genetics. However, that role is not an unproblematic one. In many of the academic and news articles, the market is not seen as being the appropriate venue for delivering (or providing information about) psychiatric genetic testing services.

“In addition to inappropriate use of genetic tests—both scientifically and ethically—there is enormous potential for misinterpretation of information, with potentially very damaging consequences; in addition, often there is little provision of follow-up care by the testing organizations.” (Austin & Honer, 2007, p. 259)

Companies offering these testing services are frequently characterized as irresponsible. But why might this be so? The nature of a company in a capitalist society is that it is oriented toward making a profit: generally, while a product may be widely considered useless, tasteless, or frivolous, or in some cases even harmful, it is seen to be an individual's choice whether or not to purchase the product, and if the company can turn a profit off selling Tickle-Me-Elmo dolls, horoscopes, fast food hamburgers or cigarettes, then that is within their right. The consumers are to blame for their poor choices in purchasing the product. Of course, this conceptualization is not without its detractors – the cigarette companies and fast food joints of the world have some dedicated enemies, and many ordinary citizens do feel that it is, to some greater or lesser degree, the responsibility of a company to ensure that their product at least does not cause harm – and particularly, that it does not cause *health-related* harm. For the field of health care as a whole is still not wholly within the consumer realm. Products like pharmaceuticals and medical devices that malfunction, or are ineffectual, are taken very seriously, partially because in many cases the user does not have a choice about whether

to use them or not; the principle of “buyer beware” cannot apply when the buyer is coerced into making the purchase.<sup>30</sup>

Genetic tests occupy a grey area in the discourse between medical devices and luxury items. On the one hand, they must be marketed as necessities: people must be convinced that they have a need for them in order to buy them. But this can be accomplished in one of two ways: they can be marketed as filling a direct medical need (diagnosis), as in the case of Psynomics, or they can be marketed as lifestyle goods, as tools to work on the self – needed to fulfill one’s subject position as a proactive and self-managing, autonomous individual, but not a matter of life or death (as is the case with 23andme’s products). In both cases the product is information, and very similar information at that, but the meaning attached to it by purchasers may be very different.

Neither marketing strategy is trouble-free. Psynomics runs into problems because their product is not seen by commentators as particularly useful. As they are clearly marketing their tests as medical devices, aimed at addressing a medical necessity, they are held to the standard of their product being both effective and unlikely to cause harm. However, they are seen as “more responsible than others that promise a glimpse into the future” (RedOrbit, 2008), because of the requirement they impose that a psychiatrist be involved with the purchase and interpretation of the test. This standard – expert involvement – is one that applies to some degree to most medical products where information is seen to be potentially confusing. However, it is particularly important in cases where not only the technical knowledge but the rational capacity of purchasers is in

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<sup>30</sup> The ultimate “buyer” may be either the individual paying for his or her own health care needs, or the insurer, public or private – in either case, the choice to purchase the item is not freely made.



doubt. We might draw a parallel between marketing fast food to children (often treated with excoriation) and marketing fast food to adults (not strictly approved, but accepted).

The consumerist model adopted by 23andme removes physicians from the equation altogether, and does not seem to have received much real criticism for it – at least not in specific regard to the test for bipolar disorder. It seems to me that this is only possible because 23andme does not *focus* on mental illness susceptibility, but merely offers the test for alleles associated with reduced risk of bipolar disorder as one part of a much larger panel of tests for risks associated with everything from earwax type to height to various cancers. However, should their product line grow to include more testing for susceptibility to mental illnesses, it seems likely to me that they will face sharper criticism. This is because, although they may have skirted the need for their products to be effective and harm-free by marketing them not as necessities but as luxury items, should they start to market to those at risk of mental illness, they will be open to the charge of preying on the vulnerable. Ironically, it is probably only when their actual products reach a higher level of clinical utility that this charge is likely to start gaining ground; in the meantime, disclaimers that their information is to be used “for research and educational purposes only” (23andme, 2010) may suffice.

In sum, the users of Psynomics’ tests are assumed by commentators (academics and journalists, for the most part) to be unable to act fully as consumers because they are under the treatment of a psychiatrist, i.e. they are mentally ill and of questionable rationality. An unregulated market is not seen as the appropriate means of addressing their needs (and indeed there appears to be a certain reluctance by the company itself to adopt this position). The users of 23andme’s tests are assumed (at least by 23andme’s

website developers) to be fully rational consumers purchasing products for their own self-development, and the market is ideally placed to facilitate these transactions. Because most of the academic and news articles I examined did not refer to 23andme, it is difficult to tell whether they accept this stance.

The texts obtained from patient advocacy websites fully embraced, like 23andme, the consumerist subject position. Here, however, it was less clear whom these consumers were acting consumer-like in relation to. The market was not a focus of discourse. Genetic testing companies were rarely mentioned, and when they were, it was usually neutrally but with reservations as to their effectiveness.

Instead, demands were made against the state: for improved regulation, more funding for research, and better provision of care. Although the word “consumer” was employed, what was really evident in these texts was a discourse of active citizenship – framed particularly in terms of the rights of citizens rather than their duties.

“We must work together to deliver health care reform to millions of Americans who are either uninsured or underinsured. Let your legislators know how you feel. Tell them they need to do what is right for you, your family and your country.” (DBSA, 2010)

In very few places other than on the patient advocacy websites were the positions of individuals as residents of a nation-state, possessed of particular duties and rights in line with that position, evidenced. Discussions of the provision of care generally referred only to “your health provider” as an individual doctor or counselor. This may reflect the fact that almost all of the texts I examined originated from within the United States; it is certainly possible that a primarily Canadian discourse might have had more to say about the role of government in providing diagnostic, treatment and management services, or information about such services. This suspicion appears to find some support in the fact

that, of the newspaper articles, only the one from the *Globe & Mail* refers explicitly to government's obligations to provide care. Even here, however, cost-saving on the part of the government is emphasized to as great a degree as quality of care:

“The new research initiative, known as neuroIMAGENE, is being funded by a \$2.8-million grant from the Canada Foundation for Innovation. That grant is expected to be matched by one from the province of Ontario. The program could save the health-care system money, Dr. Kennedy says.” (McIlroy, 2009)

The government was not exactly absent from the equation in the other texts, but its responsibilities were usually not explicitly addressed in detail. Government funding for research was acknowledged, and the development of legislation referenced (particularly in regards to the Genetic Information Non-Discrimination Act of 2008 in the US). The academic articles in some cases called for greater regulation of the genetic testing industry (e.g. Mitchell et al., 2010). These duties of government – regulating the marketplace, funding industry – are framed as being “for the good of citizens.” However, when it comes to the actual provision of care (including genetic tests) there is a resounding silence on the role of the state. Instead, it seems to be accepted, by and large, that these tests will be offered privately (whether direct-to-consumer or by prescription, but paid for out of pocket in either case) and that the role of government is not to step in and absorb the costs, but to provide an environment where citizen-consumers are possessed of the information to make choices between high-quality products. Whether this will change if and when the products become *too* high-quality to be defined as consumer goods and instead are being actively used as diagnostic tools for members of society who are unable to act fully as consumers (i.e. are mentally ill) remains to be seen. In Canada, the point at which a consensus is reached in the psychiatric community that these tests have real clinical value might be the point at which they join the items in the

Medicare basket, and become something government is responsible for providing as they are “medically necessary.” In the US, this may be a cue for private insurers to expand coverage to include such tests. We can expect the discourse on each side of the border to proceed differently, but to have some substantial areas of overlap.

# **Chapter 7: Conclusion**

## **7.1 Introduction**

When I first set out to conduct this research, I expected to be focusing more or less directly on the representation of genetic test users, examining how these figures, whom I considered central to the discourse surrounding psychiatric genetic testing, were framed by influential interest groups. It turned out that the idea of framing was exactly right to describe what I was in fact examining – but instead of the metaphor of a picture frame, where the central image is complemented by the surrounding material, I found the metaphor of a window frame to be more appropriate. I found that potential test users were barely present in these texts in explicit ways. Like a window, they were defined almost wholly by the frame surrounding them, its shape, placement and constitution determining what view a reader would have – what aspect they would look upon. Thus in order to describe the subject positions being made available to the users of psychiatric genetic tests, I needed also to describe the structures, relationships, and contexts in which they were seen to operate, and the materials of which those structures appeared to be built.

## **7.2 Defining Test Users: Genetic Risks**

I examined, therefore, how bipolar disorder was conceptualized, in order to understand how people who have, or are at risk of having, this condition are conceptualized. As a whole, the texts I examined indicated that a medical model of bipolar disorder is heavily dominant in this discourse. As Petersen, Kohanovic, & Hansen state, “Despite the development of diverse critical perspectives on mental illness (...) in the ‘practical’ realm of mental health services alternatives to the disease or deficit model

are seldom evident in practice” (2002, p. 121). My research uncovered no exception. It is clear that bipolar disorder is conceptualized as a serious problem both at the individual and interpersonal levels. Mentions of bipolar disorder as either reflective or constitutive of problematic conditions in society, however, were extremely rare. The American texts (which constituted the majority of my selection) were disinclined to consider bipolar disorder as a societal issue, with the exception of patient advocacy groups, who tended to employ a rights-based discourse of citizenship. In the other texts, the problematic aspects of bipolar disorder were envisioned as residing at the more encapsulated levels of the individual and his or her family and close interpersonal relationships.

Bipolar disorder was also understood largely as a genetic disorder. While most of the texts’ authors acknowledged environmental contributions, the genes were looked upon as the most basic level – underlying other biological structures, as well as traits and behaviours, and ideally acting as the basis for therapeutic and diagnostic efforts. However, the genes were not conceived as totally determining the person – as the foundation of a house determines its placement, size, shape, and some of its features, but does not dictate what colour the walls are painted, nor indeed who lives within.

Despite being so basic, it was clear across most categories of texts that the genes underlying bipolar disorder were poorly understood. Genetic scientists depicted their own knowledge as partial and uncertain – while this is in part a general feature of academic writing (motivated both by stylistic convention and by the “scientific” principle that no theory is ever proven, simply supported), but it also appears to be a feature of genetic research in particular. This may be due to a fear of replicating some of the abuses perpetrated by eugenicists, who took strong stances on the basis of what we now consider

to be not only flawed but morally unconscionable conclusions, or perhaps due to a fear of being accused of such. This discourse of uncertainty was taken up by journalists and patient advocacy groups, and even by Psynomics and 23andme.

In part, the partial nature of genetic knowledge was constructed as a feature of the present state of understanding, with expectations evident that further research would fill in some of the details. Complexity and contingency were also constructed, however, through the imputation of environmental contributions as influential (though not “fundamental”) in the development of bipolar disorder. Many of the texts’ authors, therefore, were careful to state that genetic information, no matter how well understood in and of itself, can never provide complete knowledge of a person. Thus the discourse appears to be more representative of Adam Hedgecoe’s (2001) notion of “enlightened geneticization” than of the more deterministic models of genetic influence that caused such concern to Lippman (1991, 1992) Nelkin & Lindee (1995) and Lewontin, Rose, & Kamin (1984). Rather than inevitability, the notion of genetic risk was omnipresent: the very idea of a susceptibility test relies upon it.

However, what precisely one is at risk for is a sticky subject. One of the greatest tensions observed in the texts had to do with the difficulty in defining the boundaries of bipolar disorder. The substantial genotypic and phenotypic overlaps between BP and other disorders, including very commonly diagnosed conditions like ADHD and unipolar depression, raise questions about who is defined as “at-risk” populations, and thus about who is exhorted to purchase genetic tests, seek genetic counseling, or encourage family members to do so. If genetic risk is shared across phenotypes, and if we regard the current high prevalence rates for mood disorders as accurate, then almost all members of

the Canadian and American populations could be defined as “at-risk” for bipolar disorder, by virtue of being related to someone diagnosed with one (or many) of these disorders. Whether or not this illustrates a “need” for genetic testing to be broadly applied, however, or whether it instead indicates that our attentions might be better directed toward those less equitably distributed but theoretically more mutable risk factors such as poverty and discrimination, is a matter of perspective. I would suggest that the latter approach is more appropriate – in addition to a concerted effort at questioning what those high prevalence rates really indicate about our society, and about the nature of the category of “mental illness.” Unfortunately, it appears more likely that the continued construction of populations as “at risk” will continue to be driven by commercial interests looking to sell not only treatments but diagnoses.

Similarly, there are significant differences between a view of bipolar disorder itself as an internally blurry section of a spectrum that may extend into the territory of other disorders, or as a category hierarchically differentiated into other discrete subcategories. The implications may be greatest in the area of commercial medicine (the pharmaceutical and genomics industry, and particularly pharmacogenomics), where the era of “personalized medicine” may be ready to embrace the idea that we are all different and as such suffer from different ailments – but only if that difference can be translated into profit. While individually tailored prescription might be most effective, some system of categorization will likely be more appealing to marketers, who rely on a disease construct with particular features to promote a product for it. I suspect that only if each endophenotype can be framed as its own disease entity will we see the advance of this spectrum-based understanding into corporate discourse – otherwise we are more likely to



see the fragmentation of bipolar disorder into more and more “sub-types” – some of which overlap more or less with other disorders, and many of which are likely to be applied to increasing numbers of people.

The reasons behind the growth in prevalence rates of bipolar disorder (NIMH, 2007) over the past few decades are unclear. If it is truly a “genetic disease,” we should be surprised to see such increases – unless we are prepared to grant a much greater role to the environment than has been the case. What seems more likely, however, than an absolute increase in people exhibiting symptoms of bipolar disorder, is an increasing tendency to label such symptoms as bipolar disorder – precisely what theorists of medicalization have observed for psychiatric disorders in general as new treatments hit the market. However, with the line between “at-risk” and “disordered” becoming increasingly blurry due to genetic research, should genetic testing reach a certain level of clinical utility in cases where symptom-based diagnosis is already ascertained, it seems possible that we will see these tests used to apply a diagnosis of bipolar disorder even in cases where symptoms are not clear, or perhaps not even present. Thus there is a sense in which everyone could be considered “at risk” and therefore a potential test user.

### **7.3 Defining Test Users: Relationality**

As noted above, individual test users can be seen in the texts primarily through the lens of relationships with others. This is an observation that appears to span all the categories of texts – perhaps suggesting a fundamental uncertainty, or ambiguity, over just who the users of genetic tests are and will be in terms of their own qualities and characteristics. There is, however, a central tension in the texts between two views of what the primary relationality of the patient consists of.

The first view, promoted largely in (some of) the academic articles, the news items, and on the pages of the Psynomics website, but also found on the patient advocacy websites and the 23andme website in less concentrated doses, takes the doctor-patient relationship to be central. Here, the test user is seen as an individual. His or her own needs are the ones that are presented as central. However, s/he is not really an *autonomous* individual – instead, s/he is a patient reliant upon a doctor’s judgement. The patient in this context may be active in his or her own care and decisions, but this activity and self-management is seen to be limited in the context of psychiatric genetics. In fact, patients taking too much initiative is viewed as risky for them, because they are (1) not qualified experts and therefore bound to misinterpret information; and (2) vulnerable, because they are potentially mentally ill, and therefore not necessarily rational. Thus while the individualist ethos of neoliberal governance is upheld here, the patient is not seen as being able to enter into the ideal consumer-citizen subject position – in the words of Bauman (1997, 1998), they are “flawed consumers.”

Thus patients were not always the subject of address, even in marketing discourse. At the start of my research, I had expected these tests to be marketed primarily as technologies of the consumerist self, sold to patients as devices for proactively managing their health and learning to know themselves. In the case of 23andme, this is quite an accurate depiction of the discourse; where Psynomics is concerned, however, their products are marketed in large part to psychiatrists as technologies of the professional expert self – as tools used to assess others’ risk in order, partially, to mitigate one’s own risk of making an error, or of not doing all that could be done.

The second view of relationality present in the texts sees the patient as primarily enmeshed in a web of familial relationships. This model is more prevalent on patient advocacy websites, in particular, as well as to some extent in the academic articles focused on genetic counseling. Here the boundaries are a lot fuzzier between who makes decisions, on whose behalf they are made, and who is an expert. Families are the locus of risk, stigma and blame, but also of support and responsibility. There is overlapping ground between the support provided by families and the support provided by professionals, but in this case families are accorded a more central role.

Families have always played a large role in decisions surrounding the care of mentally ill persons, and will likely continue to do so. It is clear that responsibilities for care are largely located at this level. When this care involves genetic testing, or even genetic counseling, the responsibilities of kinship become bound up with notions of shared risk. This seems to place the locus of action – whether of an advocacy nature or in terms of an individual hunt for proper diagnosis and treatment – “naturally” within the family.

However, some limitations remain on the capacities of families in this model. While patient advocacy organizations may emphasize the ability of mentally ill persons and their families to act as teachers, role models, and support providers to their relatives and peers, in the specific context of genetic testing, there appears to be less of this sense of lay expertise. This may change if the business model of 23andme, which involves customers in a long-term process of exploration and connection (centred on notions of

genetic kinship), becomes more widely adopted – though this may be a difficult sell in the context of mental illness.<sup>31</sup>

A final relationship is present in many of the texts. This relationship, however, is seen as deeply problematic, in contrast with the other two, which are promoted as desirable and natural. This relationship is with the corporation, or the forces of the market. Many of the texts evinced some discomfort with the delivery of diagnostic or predictive services being determined by market forces, and with the idea of those at risk of, or already suffering from, mental illness being encouraged or required to act as consumers in that marketplace. Hazelton & Clinton, in regard to mental health policy discourses in Australia, have observed that:

Two constructions of the mentally ill emerge from this (...) discourse. One, a ‘consumer’ of services, enjoys ‘the [same] rights, choices, and opportunities’ as other citizens. The other, constituted as powerless, is vulnerable to discrimination and various rights infringements. One, having wishes, wants and desires, will actively pursue these. The other, being vulnerable and having needs, requires protection. (2002, p. 92)

These countervailing subject positions are clearly visible in the discourse surrounding genetic testing for bipolar disorder. Here, as in the discourses Hazelton and Clinton examined, it appears that the reluctance of doctors to cede authority (or agency) to mental health patients may stand in the way of the consumer subject position becoming truly dominant. As noted above, concerns about the ways in which tests can be employed without physician involvement are central to the construction of genetic testing as “risky.” The construction of doctors and researchers as experts, and patients as lacking in

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<sup>31</sup> An orientation toward the open “sharing” of personal information is evidenced throughout the website; although nods are made to privacy, the clear intention of 23andme is to expand access to data, and to expand lay participation in the creation of knowledge. As co-founder Anne Wojcicki’s profile copy claims: “By encouraging individuals to access and learn about their own genetic information, 23andMe will create

the requisite knowledge to make choices about testing, or in reaction to the results of testing, is also noted above. Thus there is a strong tendency in many of the texts for potential test users to be framed as passive, irrational, insufficiently wise, or otherwise unable to act as the good consumers the marker relies upon. This is particularly prevalent in the academic articles (even those discussing “non-directive” counseling implicitly suggest that individuals at risk are *not* capable of interpreting the information provided about, or by, genetic tests in an appropriate manner, and express deep concern over their sale to the public). However, it is also visible in the news articles, and to a certain degree on the Psynomic website itself, where, despite their assertion that “You have the right to go further. You have the right to test your own genetic makeup for bipolar disorder. *And now you have the ability,*” customers are not in fact permitted to order tests without the approval of their psychiatrist.

Yet there are other threads within the texts that oppose this framing, embracing the marketplace as a locus of health maintenance and health decision-making, and thus making available a subject position that is endowed with capacities of choice, rationality, desire, and financial solvency. Most obviously, 23andme has adopted the consumerist model very strongly.

Psynomics is marketing a very targeted product: a diagnostic tool for a particular disease, and a complementary test for response to a drug related to that disease. Their target market is made up of people *already showing symptoms* of bipolar disorder – and further, the advertising is aimed primarily toward the physicians caring for those individuals. Therefore their appeal is largely crafted toward psychiatric professionals,

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a common, standardized resource that has the potential to accelerate drug discovery and bring personalized medicine to the public.” (23andme, 2010)

perhaps more than toward individual test users, which makes for a number of mixed messages emanating from the website. 23andme, on the other hand, aims at a very wide market segment: anyone who might be at risk of one of hundreds of diseases (i.e. the entire population), who is desirous of finding out their risks, and is capable financially of doing so. The target market is *not* mental health care users, who are often not able to act in this manner, but appears to be rather (1) the worried well, and (2) the well-off novelty-seekers who view the product as more of a form of entertainment than a health necessity.

23andme is therefore concerned with ideal-typical “consumers,” who are expected to act in a particular way in relation to the providers of services: they are expected to pay money to those providers to access their products, which they have chosen from among an array of others. This entails the possession of several qualities that become troublesome in the context of mental illness. Consumers, in order to exercise this choice fully, must be rational, autonomous (not operating under another person or agent’s control), and concerned with their own wellbeing. As Bauman (1998) has noted, to be a consumer in today’s society means more than just that one consumes – that is, after all, a feature of every living being in every society – it means that one’s role within society is most predominantly defined by their consumption behaviours (p. 24). And the most important feature of consumption is not – Bauman argues – the amount consumed, but rather the abundance of options from which to choose what to consume: “To embrace the modality of the consumer means first and foremost falling in love with choice” (1998, p. 30). When a person is assumed to be mentally ill, however, their capacity to choose in this way is in doubt.

The implications of these relational frames for the genetic testing industry are potentially major. If the doctor-patient relationship is placed in the central position, as seems to be a common practice, companies offering tests may find it necessary to provide more in the way of personal counseling or psychiatrist involvement. Psynomics did require this involvement, and in fact 23andme's home page now indicates that they have engaged a genetic counseling company to provide this service to customers who are willing to pay extra for it. However, physicians and other professionals may feel that the tests are risky, both to patients and themselves, and may not always wish to be involved in this process, or may place strict limitations on its use. Thus this relationship is potentially at odds with the consumer-provider model of genetic testing, rather than complementary to it.

If, on the other hand, the family relationship is emphasized, there appears to be no such barrier to commerce. In fact, the shared nature of genetic risk may mean that once one customer's allegiance is captured, his or her family members might be easier to reach. Additionally, if family is framed, as noted above, as "a vehicle (...) for genetic governance" (Polzer, p. 88) – as the locus of responsibility as well as risk – the tests may be framed as a means of fulfilling familial duties rather than serving individual needs, and therefore may reach a broader section of the population than just those seeking diagnosis.

Each of these relationships may be influential in determining how the others are defined – how prominently they feature in the discourse, and what their characteristics are seen to be. However, I suggest that the relationship that is widely perceived as the most problematic – that between test users and commercial companies – is also likely to

be the most influential in shaping the psychiatric genetic testing industry. As David Healy has noted, the interests of commerce have long been a defining factor in how mental illness is understood, and how treatments for it are developed and sold (2008). With the structure of North American society shaped around a telos of capital accumulation, it seems likely that the needs of capital will to a great extent continue to define the relationships that are seen to fulfill the “needs” of individuals.

#### **7.4 Defining Test Users: Responsibility**

What are the qualities of the test users who are enmeshed in these relational dynamics? Rather than a list of attributes that they are seen to possess, what my research has provided is insight into the qualities and capacities that are contested, and around which important questions form when we consider both the discourses of psychiatric genetic testing and the business models evidenced in the industry.

First of all, agency is at stake. This capacity is placed in question by the biological nature of bipolar disorder: if, as the determinists would have it, genes dictate the qualities, behaviours, and eventual fate of a person, then there is little room for agency. Some of the older writings on geneticization (Nelkin & Lindee, 1995; Lippman, 1991, 1992) feared this notion greatly. More recent scholarship has suggested that the notion of risk that is so central to current understandings of genetics runs counter to determinism, and that in fact what we see is the assumption that persons indeed do possess the ability to alter their circumstances – and should do so through any means available (e.g. Petersen, 1997; Bunton & Petersen, 2005). In the texts I examined, genes are framed conceptually as “basic” to bipolar disorder, implying that environmental factors – and lifestyle choices – may contribute only minimally to outcomes. However, the whole



notion of taking a susceptibility test relies on the premise that its results are actionable. Whether it is test users themselves who act upon the provided information, though, or clinicians, or perhaps family members, who may be making choices that extend beyond treatment choices into the realm of family planning, is at question. In these texts, the actions of test users upon receipt of results were not discussed in any detail, and where they were, they were often framed in a negative light, as involving misinterpretation or poor choices. Clinicians' capacities for (more appropriate) action tended to be highlighted, suggesting that agency, and therefore responsibility, is largely attributed to doctors rather than to test users in this context

Both rationality and autonomy are also at stake. Whether those at risk of, or diagnosed with, a mental illness can be considered fully rational is a fundamental question that informs marketing strategies, regulatory policy, and the role of patients – or test users – in decision-making at all levels of practice. A “patient” is defined by his or her ongoing relationship with medical professionals, and is usually assumed to be actually sick. In the context of mental health, patients, then, are assumed to be mentally ill. As Martin (2007) describes, this designation and the treatments that accompany it place into question not only one's rationality, but one's autonomy (p. 87-88). If one's mood and behaviour are regulated by medical treatment (mood stabilizers, antidepressants, and so on), is the patient controlling their own behaviour, or are the drugs in control? What about the doctor on whose orders the patient is taking the medication? Who ultimately controls the patient's choices? Martin argues that there is no simple hierarchy of control in place (p. 97-98). Patients generally frame drugs as tools to aid in the project of self-management, and doctors encourage self-responsibility and self-

monitoring, which implies a sense that patients have the capacity to perform this task; however, in many contexts, this frame is replaced by one in which patients are seen (particularly by psychiatrists, but also by other patients, or themselves) as fundamentally in need of external guidance (both pharmaceutical and professional) in order to maintain their mental stability. This may mean that “autonomy” is exchanged for “rationality” in some instances. Of course, as Martin notes, “psychiatrists, patient advocates, and people living under the description of manic depression constantly (like anyone else) move back and forth across the arbitrary line between the rational and the irrational” (2007, p. 98). It is not the *actual* capacity of patients to act autonomously or rationally that I question; rather, it is their framing as such, and the implication that the word “patient” carries places these qualities in serious doubt, placing individuals in a relationship of deeply unequal power.

However, even given rationality, autonomy, and agency, test users (and their families, who are also potential test users) cannot always be expected to be experts, in possession of all the information they might need to make a wise decision. Because the field of genetics, and of psychiatry, are so complex, even the knowledge of specialists is placed in question (e.g. Austin & Honer, 2007). Are test users, then, expected to understand the results of tests? Without understanding them fully, is it expected that they can truly exercise the type of consumerist subjectivity demanded by the capitalist market?

Finally, should all these conditions be met (or even if they are not), the remaining question is one of responsibility. Does the capacity to act imply a duty to do so? Here, the clinical utility of the tests (or lack thereof) is an essential piece of the puzzle. If the results of tests are *not* clearly actionable – by test users, by physicians, or by family members –

where does responsibility lie, and for what are people responsible? For taking the tests even with the understanding that the information they provide is limited in its utility? For engaging in *processes* of self-learning and self-management even without the promise of a clearly defined outcome? Or would a “responsible” health care user choose not to purchase such a “risky” product? Is it the responsibility of physicians to prevent such an occurrence?

Many theorists working in a Foucauldian framework have suggested that genetic tests are “technologies of the self,” accompanying a conceptualization of their users as responsible and self-managing subjects. However, in the texts I examined, “responsibilization” appears to be occurring in an alternative manner to what most of the genetic testing literature would suggest. Rather than being urged to be proactive on their own behalves, people are encouraged to do so on behalf of their families. Perhaps because those at risk of mental illness are *not* assumed to be capable of self-interested, rational, action, this role is diverted onto those close to them. However, in this context, these very same family members are also at risk – thus there is a fundamental difficulty in asking them to assume a double load of responsibility.

This is not to say that responsibility (or control) is totally shifted off the medical profession. Doctors and other professionals continue to be invested with a great deal of responsibility for their patients’ welfare – this now extends to making sure their patients do *not* take proactive actions that might harm them. Here, it is less “support” that is the central responsibility at play, but guidance or direction. Because mental health care users are not viewed as “experts,” either in genetics or in the other, traditional, means of managing their own disorders, professionals must play this role – providing, in some

cases, information to enhance choice, but also providing direction when patients are expected to make the wrong choices, and their autonomy is therefore not desirable.

## **7.5 Implications for Policy and Practice**

What does the foregoing analysis imply for health care policy? One of the major questions that may face us in Canada is whether or not to provide public funding for the purchase of psychiatric genetic tests. At this point in time, the tests are not viewed by a majority of clinicians as something that is medically necessary (the chief standard for the provision of services through Medicare), nor even necessarily medically desirable. Even their medical “nature” is in question, with 23andme promoting their product line as more of an entertainment/educational service than a clinical need (making genetic testing fun and informative, rather than “risky” or frightening). In this context, there appears to be little desire for public funding for tests. However, should the tests develop to the point where they are judged to provide a greater predictive or diagnostic value, by patients, clinicians, or both, calls for their public provision may arise. Should the tests prove to be of clinical value in determining appropriate treatments for persons suffering from mental illnesses, it would be hard to justify withholding them, allowing access only to those patients who could afford private purchase. However, should they be covered under Medicare, determining who is an “at-risk” population and therefore requires access to the tests may not be straightforward. Should only those exhibiting symptoms receive testing? What about those at risk by virtue of having a diagnosed family member? What about those with a family member diagnosed with another mood disorder? Potentially, everyone could be considered at risk, to a greater or lesser degree, and with the current emphasis on proactive management of health, it is not hard to imagine psychiatric genetic

tests truly becoming the technology of the proactive self that other genetic tests have been suggested to represent, particularly if their target population spreads beyond those suspected to be currently mentally ill to the much larger and more easily reached market of worried well consumers.

However, if everyone is potentially at risk by virtue of their family history, and if everyone bears genetic risk factors (to a greater or lesser degree, admittedly), what we are likely to end up with is a large number of “false positive” tests alongside a few circumstances in which diagnosis is indeed clarified. But what does a “false positive” mean in this circumstance? I use the term in this context to refer to the potentially very common situation where risk factors for bipolar disorder appear to be elevated yet the individual is not feeling or behaving in a manner consistent with illness. Of course, most clinicians and even companies would claim that this is not a basis for diagnosis of bipolar disorder. However, if the genes are seen to be “most basic” in determining illness, is it not likely that individuals receiving such results will indeed feel marked by it? I do not necessarily mean that stigmatization will occur, but that they are more likely to consider “normal” behaviours as potentially indicative of incipient illness (such as might happen for the daughter of a Huntington’s patient, who sees the shadow of her parent’s illness mirrored in every false step or tremor of her own, regardless how “normal”). Such an expansion of the use of diagnostic tools into new populations could in this way result in a great expansion of actual diagnoses (or at the very least, of the expansion of the sticky label of “at risk”) – a symptom of the present-day need for identification of any potential problem to be immediately followed by an intervention. We may want to reconsider that

risk (genetic or otherwise) is a normal part of life, and the knowledge that it exists should not always imply a concurrent responsibility to address it.

Additionally, I suggest that rather than providing the means for geneticization to contribute to the further expansion of the diagnostic category of bipolar disorder (an already widening diagnosis, as noted by the NIMH, 2007), we would do better to recognize that even if we can identify genetic “risk factors,” this will in most case be less useful than identifying and addressing the less equitably distributed environmental causes of disorder. As so many theorists of geneticization have pointed out, seeking to locate illness at the genetic level can be a means to justify the retraction of collectively oriented action and socially just policies. In this case, I suggest that genetic research itself may actually provide a basis for redirecting our attention *toward* such actions and policies. The very complexity of genetic contributions to mental illness, and the fuzziness of boundaries, suggests that more could be gained from addressing known environmental risk factors like poverty and discrimination than from trying to pin diagnostic labels onto elusive combinations of common alleles. It is commercial interests in genetics, rather than genetic research itself, that make this shift in focus unlikely.

Even better, however, would be a concerted effort to question just why so many people are seeking diagnosis and treatment for mood disorders in the first place. If bipolar disorder is a genetic disorder, and is both common and serious, as it is framed in the texts, then how did evolutionary processes allow for this situation? We should be looking to question not only whether bipolar disorder is fundamentally genetically caused, but also whether it is truly both so devastating and common as it is imagined to be. Is it possible that some of the traits we currently define as “flaws” or “disorders”

would be more appropriately regarded as non-pathological variations? Or that the complex of symptoms that together comprises the fuzzy entity of bipolar disorder is very much a socially constructed syndrome? How bipolar disorder is expressed and understood is not static over historical time, as David Healy notes (2008). The same symptoms that might in other times and places have been defined as character traits (and not necessarily deleterious ones) are often now defined as “genetic flaws” – but this definition is by no means inevitable.

Where the traits associated with bipolar disorder are defined as genetic flaws, we are encouraged to seek genetic means of address – even if those means are as flawed as anything else. In the texts I examined, it can be observed that even where a technology is of doubtful utility at a practical level, it may still be surrounded by responsibilities relating to its use, marketing, and interpretation. The traditional view of responsabilization has been that responsibility for health care is offloaded from a receding state to its individual consumer-citizens, who are encouraged to take proactive measures to maintain their own fitness. In the context of genetic testing for bipolar disorder, this discourse is present, but in muted form, clearly visible only where mental illness is downplayed, as on the 23andme site. Instead, the responsibilities for both action and decision-making are emphasized, and these responsibilities are largely located with professionals and families – both private entities enmeshed in privately mediated relationships with test users. The implications this has for policy are many. As Bauman (1997) has pointed out, one of the great and ongoing problems with the shifting of responsibility to the family and community sector (from its erstwhile home with the state) is that in post-modern social life, even the “traditional” ties of kinship and community

networks are less stable than they once were. When the “family” itself is a struggling institution, the shifting of duties once performed by the state onto kin networks may, rather than functioning to “re-embed” individuals, simply place one more strain upon already attenuated bonds. We may want to consider whether the continued privatization of the provision of care (including mental health care and decision making) is tenable in the present context. Whether the solution is a rein(state)ment of collectivized responsibility through government (involving both centralized provision of care, and a willingness to regulate private companies), or the facilitation of the capacity of individuals and “communities” to take on these new responsibilities is a question that has been answered differently by various commentators, and may not be a clear either/or decision. What does seem clear, though, is that without providing individuals, families, and communities with the means to adequately support themselves and each other, and providing those means equitably, allocating to them the responsibility for doing so will continue to be disadvantageous to many. In the context of bipolar disorder, locating responsibility for testing decisions and support within a private market is already clearly understood to be problematic by many commentators. Regulation, and government provision of not just genetically-oriented health care services but socially just policies could go some way to alleviate these concerns. However, it is not necessarily undesirable for communities or families to be encouraged to care for each other. What is needed is not a shifting of responsibility *off* of private individuals, but a recognition that in order to fulfill such responsibilities, there is a need for resources to be adequately and equitably distributed in our society.



## **7.6 Directions for Future Research**

Clearly, the characterization of genetic test users is not a matter of a straightforward list of traits, or roles, or even responsibilities that a person is expected to embody, perform, or embrace. Instead, my research pointed out a series of tensions and contradictions both within and between individual texts as well as within and between categories of texts. Fundamental ambiguities remain regarding the subject positions of test users, as evidenced in the very different business models and discursive practices of the two companies whose websites I examined. As the industry continues to expand, we may see one or the other model begin to take precedence; however, both are understood by commentators to present serious ethical dilemmas in relation to the sale of “risky” products to what are generally thought to be vulnerable populations. How these charges will be addressed – what model of the ideal-typical test user will be adopted in order to proceed, and what assumptions this model will entail – will continue to be an important subject for research.

One factor which may impact what model of test user eventually becomes predominant in corporate discourses, and likely in other genres, is the response of test users to the subject positions that are available to them. Although this was not possible considering the limited scope of the present research, examining the ways in which those considering using psychiatric genetic tests, and those who do make the decision to do so, understand their own choices will be essential in determining how those choices are framed. The interpretation of discourse by its referents, and their responses to it – challenging, embracing, transforming, or accepting without comment – is central to the

function of discourse in constituting subjects. Future research would ideally aim to explore these issues through long-term ethnographic research.

Such research could also go a long way toward detangling American from Canadian discourses. One of the limitations of the present study has been that the small sample employed was biased toward American sources, and did not contain sufficient Canadian material to do more than make passing suggestions as to the points of divergence between discourses originating in each country. Future research taking a comparative approach could investigate the ways in which the discursive constitution of test users is enacted differently in regions where the delivery of health care services bears such different relationships with the state.

Another of the themes that emerged from my research may have a great impact on the constitution of the subjects of genetic testing is the shifting terrain of diagnosis. As current research moves us toward a more gene-based model of diagnostic practice, the very nature of bipolar disorder, and indeed, mental illness, is changing. Whether bipolar disorder comes to be understood as a grayish area of a broad spectrum of “mental illnesses” including schizophrenia, major depression, ADHD, and others, or as multiple fragmented categories based, perhaps, on endophenotypes, the implication for the subject positions available to patients are potentially large. As Martin (2007) notes, mental illnesses are imagined in very different ways from one another: even for a person who has accepted a diagnosis of bipolar disorder, being prescribed a medication that is normally used to treat epilepsy or brain damage may cause anxiety, as the entailments of that diagnosis are seen to be quite different (p. 167-8). Similarly, the ongoing debates about whether Asperger’s syndrome and autism should be regarded as separate diagnoses

or two ends of a spectrum are fraught with meaning for the subjectivities of those living under either diagnosis.

Further, the nature of genetic risk is that it applies to large swaths of populations, particularly when it comes to common, multifactorial conditions. If we come to understand mental illness as the effect of a particular combination of many common genetic variations, activated by an (also common) combination of environmental stressors, the deeply shared nature of these contributions may lead to a situation where these illnesses do begin to lose some of their stigmatizing potential. Paradoxically, the same genetic research that has been singled out for promoting an individualizing ethos may come to be seen as open to collective amelioration rather than being matters of solely individual responsibility: if the genetic (i.e. “basic”) risk factors for bipolar disorder are shared by all, to some degree or another, then it may come to be seen as less of a “fundamental” difference and more as one possible expression of our “fundamental” similarity, as Rabinow has suggested (1992). Future research into the ways in which genetic research is transforming the categorization systems used to diagnose mental illness, as well as the technological means of placing person in those categories, is essential if we are to find ways of encouraging transformations that are commensurate with subject positions that recognize both the agency and interdependence of those “at risk” of mental illness – in other words, all of us.

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## Appendix A: Psynomics Texts

Page Title	Web Address
Home Page	<a href="https://psynomics.com/">https://psynomics.com/</a>
About Psynomics: Intro	<a href="https://psynomics.com/about.php">https://psynomics.com/about.php</a>
About Psynomics: Key Scientific Papers	<a href="https://psynomics.com/about_papers.php">https://psynomics.com/about_papers.php</a>
About Psynomics: About Psynomics Leadership	<a href="https://psynomics.com/about_leadership.php">https://psynomics.com/about_leadership.php</a>
About Psynomics: What Psynomics Does	<a href="https://psynomics.com/about_what.php">https://psynomics.com/about_what.php</a>
Contact Us	<a href="https://psynomics.com/contact.php">https://psynomics.com/contact.php</a>
Disorders: Intro	<a href="https://psynomics.com/disorders.php">https://psynomics.com/disorders.php</a>
Disorders: Bipolar*	<a href="https://psynomics.com/disorders_bipolar.php">https://psynomics.com/disorders_bipolar.php</a>
Disorders: Bipolar Treatment*	<a href="https://psynomics.com/disorders_bipolar_treatment.php">https://psynomics.com/disorders_bipolar_treatment.php</a>
Disorders: Major Depression*	<a href="https://psynomics.com/disorders_depression.php">https://psynomics.com/disorders_depression.php</a>
Disorders: Major Depression Treatment*	<a href="https://psynomics.com/disorders_depression_treatment.php">https://psynomics.com/disorders_depression_treatment.php</a>
Disorders	<a href="https://psynomics.com/disorders_resources.php">https://psynomics.com/disorders_resources.php</a>
Patients	<a href="https://psynomics.com/patients.php">https://psynomics.com/patients.php</a>
Physicians: Intro	<a href="https://psynomics.com/physicians.php">https://psynomics.com/physicians.php</a>
Physicians: The Science	<a href="https://psynomics.com/physicians_science.php">https://psynomics.com/physicians_science.php</a>
Physicians: The Vision	<a href="https://psynomics.com/physicians_vision.php">https://psynomics.com/physicians_vision.php</a>
Physicians: What Psynomics Provides	<a href="https://psynomics.com/physicians_provides.php">https://psynomics.com/physicians_provides.php</a>
Products	<a href="https://psynomics.com/products.php">https://psynomics.com/products.php</a>
Consent Form	<a href="https://psynomics.com/pdf/consent.pdf">https://psynomics.com/pdf/consent.pdf</a>
Mailer Instructions	<a href="https://psynomics.com/pdf/mailer_instructions.pdf">https://psynomics.com/pdf/mailer_instructions.pdf</a>
Privacy Policy	<a href="https://psynomics.com/pdf/privacy_policy.pdf">https://psynomics.com/pdf/privacy_policy.pdf</a>
Model Report	<a href="https://psynomics.com/pdf/model_report.pdf">https://psynomics.com/pdf/model_report.pdf</a>

\*Content borrowed in part or in whole from the NIMH.

## Appendix B: 23andme Texts

Page Title	Web Address
Home Page	<a href="https://www.23andme.com/">https://www.23andme.com/</a>
Bipolar Disorder: Sample Report: Example Data	<a href="https://www.23andme.com/health/Bipolar-Disorder/">https://www.23andme.com/health/Bipolar-Disorder/</a>
Bipolar Disorder: Sample Report: How It Works	<a href="https://www.23andme.com/health/Bipolar-Disorder/howitworks/">https://www.23andme.com/health/Bipolar-Disorder/howitworks/</a>
Bipolar Disorder: Sample Report: Technical Data	<a href="https://www.23andme.com/health/Bipolar-Disorder/techreport/">https://www.23andme.com/health/Bipolar-Disorder/techreport/</a>
What Is Established Research?	<a href="https://www.23andme.com/you/faqwin/establishedresearch/">https://www.23andme.com/you/faqwin/establishedresearch/</a>
The Spittoon: Researchers Look for Common Themes in Bipolar Disorder Genetics	<a href="http://spittoon.23andme.com/2009/06/23/researchers-look-for-common-themes-in-bipolar-disorder-genetics/">http://spittoon.23andme.com/2009/06/23/researchers-look-for-common-themes-in-bipolar-disorder-genetics/</a>
The Spittoon: SNPwatch: SNPs in Ion Channels are Associated with Type 2 Diabetes and Bipolar Disorder	<a href="http://spittoon.23andme.com/2008/08/18/snpwatch-snps-in-ion-channel-genes-are-associated-with-type-2-diabetes-and-bipolar-disorder/">http://spittoon.23andme.com/2008/08/18/snpwatch-snps-in-ion-channel-genes-are-associated-with-type-2-diabetes-and-bipolar-disorder/</a>
The Spittoon: SNPwatch – Researchers Show the Importance of Common DNA Variants in Schizophrenia	<a href="http://spittoon.23andme.com/2008/08/18/snpwatch-snps-in-ion-channel-genes-are-associated-with-type-2-diabetes-and-bipolar-disorder/">http://spittoon.23andme.com/2008/08/18/snpwatch-snps-in-ion-channel-genes-are-associated-with-type-2-diabetes-and-bipolar-disorder/</a>

## Appendix C: Academic Texts

Title	Author(s)	Journal/Year	Corresponding Author's Affiliation
The genomic era and serious mental illness: A potential application for psychiatric genetic counseling.	Austin J.C., & Honer, W.G.	<i>Psychiatric Services</i> 58(2), 254-61 (2007).	Department of Psychiatry, University of British Columbia, BC; BC Women's Health Research Institute.
Clinically responsible genetic testing in neuropsychiatric patients: A bridge too far and too soon.	Braff, D., & Freedman, R.	<i>American Journal of Psychiatry</i> 165(8), 952-955. (2008).	Department of Psychiatry, School of Medicine, University of California, San Diego, CA; Consortium on the Genetics of Schizophrenia (NIMH)
Translational research: Genetics of bipolar disorder.	Escamilla, M.A., & Zavala, J.M.	<i>Dialogues in Clinical Neuroscience</i> 10(2), 141-152 (2008).	University of Texas Health Science Center at San Antonio, TX
Review: Genetic counseling in psychiatry.	Finn, C.T., & Smoller, J.W.	<i>Harvard Review of Psychiatry</i> 14(2), 109-21 (2006).	Department of Psychiatry and Psychiatric Genetics, and Program in Mood and Anxiety Disorders, Harvard Medical School; Massachusetts General Hospital, Boston, MA; Harvard Partners Center for Genetics and Genomics, Boston, MA
Predictive and diagnostic genetic testing in psychiatry.	Mitchell, P.B., Meiser, B., Wilde, A., Fullerton, J., Donald, J., Wilhelm, K., Schofield, P.R.	<i>Psychiatric Clinics of North America</i> 33(1), 225-243 (2010).	School of Psychiatry, Prince of Wales Hospital, University of New South Wales, Sydney, Australia.

## Appendix D: News Texts

Title	Author	News Organization	Web Address
In Brief: Genetic Counseling in Psychiatry	(Faculty of Harvard Medical School)	AOL Health	<a href="http://www.aolhealth.com/conditions/in-brief-genetic-counseling-in-psychiatry">http://www.aolhealth.com/conditions/in-brief-genetic-counseling-in-psychiatry</a>
Canadian Hospital Pioneers Mental Health Treatment	Anne McIlroy	Globe & Mail	<a href="http://www.theglobeandmail.com/news/national/canadian-hospital-pioneers-mental-health-treatment/article1210036/">http://www.theglobeandmail.com/news/national/canadian-hospital-pioneers-mental-health-treatment/article1210036/</a>
Bipolar Disorder At Home Test Causes Stir	Marcus Wohlsen (Associated Press)	Huffington Post	<a href="http://www.huffingtonpost.com/2008/03/24/bipolar-disorder-at-home-t_n_93087.html">http://www.huffingtonpost.com/2008/03/24/bipolar-disorder-at-home-t_n_93087.html</a>
Update from the Medical Journals: August 2008	Mary Pickett, (Harvard Medical School)	Aetna Intellihealth	<a href="http://www.intelihealth.com/IH/ihtIH/WSDSC/35320/35329/812747.html?d=dmtHMSCContent">http://www.intelihealth.com/IH/ihtIH/WSDSC/35320/35329/812747.html?d=dmtHMSCContent</a>
Researchers Refine DNA Testing For Predisposition To Bipolar Disorder	(Indiana University)	Medical News Today	<a href="http://www.medicalnewstoday.com/articles/185012.php">http://www.medicalnewstoday.com/articles/185012.php</a>
Indiana University Neuroscientists Identify Bipolar Disorder Genes	(Adapted from press release written by Mary Hardin, Indiana University)	Medical News Today	<a href="http://www.medicalnewstoday.com/articles/130455.php">http://www.medicalnewstoday.com/articles/130455.php</a>
Blood Test Could Reveal Bipolar Disorder	Steve Mitchell	MSNBC	<a href="http://www.msnbc.msn.com/id/23337532/">http://www.msnbc.msn.com/id/23337532/</a>
Neuroscience Advances Force New Thinking on Ethics	Mark Moran	Psychiatric News, APA	<a href="http://pn.psychiatryonline.org/content/43/8/18.l.full">http://pn.psychiatryonline.org/content/43/8/18.l.full</a>
At-Home Test for Bipolar Disorder Causes Concern	None listed	RedOrbit	<a href="http://www.redorbit.com/news/health/1307756/athome_test_for_bipolar_disorder_causes_concern/">http://www.redorbit.com/news/health/1307756/athome_test_for_bipolar_disorder_causes_concern/</a>

## Appendix E: Patient Advocacy Organization Texts

<b>Organization</b>	<b>Title</b>	<b>Description</b>	<b>Web Address</b>
Depression and Bipolar Support Alliance (DBSA)	Home page	Home page	<a href="http://www.dbsalliance.org/">http://www.dbsalliance.org/</a>
	DBSA Ask the Docs Chat with Melvin McInnis	Transcript of Q&A session with Melvin McInnis, psychiatric geneticist	<a href="http://www.dbsalliance.org/site/PageServer?pagename=events_mcinnistranscript">http://www.dbsalliance.org/site/PageServer?pagename=events_mcinnistranscript</a>
	The State of Depression in America	Excerpt from research report done on contract for DBSA*	<a href="http://www.dbsalliance.org/pdfs/wpsresearchable.pdf">http://www.dbsalliance.org/pdfs/wpsresearchable.pdf</a>
National Alliance on Mental Illness (NAMI)	Home page	Home page	<a href="http://www.nami.org/">http://www.nami.org/</a>
	Top Story: Bipolar Disorder Blood Test	News item	<a href="http://www.nami.org/Content/NavigationMenu/Top_Story/Bipolar_Disorder_Tests.htm">http://www.nami.org/Content/NavigationMenu/Top_Story/Bipolar_Disorder_Tests.htm</a>
	Top Story: Genetic Testing	News item	<a href="http://www.nami.org/Content/NavigationMenu/Top_Story/Genetic_Testing.htm">http://www.nami.org/Content/NavigationMenu/Top_Story/Genetic_Testing.htm</a>
	Update for Family-to-Family Teachers Manual	Excerpt (p. 27-38) of Updated Manual for Family-to-Family Teachers	<a href="http://www.nami.org/Content/Microsites180/NAMI_Dallas_Inc_/Home167/Programs83/Education_Programs3/Family_to_Family11/Teacher_Resources1/2008update_for_teachers(1).pdf">http://www.nami.org/Content/Microsites180/NAMI_Dallas_Inc_/Home167/Programs83/Education_Programs3/Family_to_Family11/Teacher_Resources1/2008update_for_teachers(1).pdf</a>

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