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“I don't have to know why it snows, I just have to shovel it!”: Addiction Recovery, Genetic Frameworks, and Biological Citizenship

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Abstract

The gene has infiltrated the way citizens perceive themselves and their health. However, there is scant research that explores the ways genetic conceptions infiltrate individuals' understanding of their own health as it relates to a behavioral trait, like addiction. Do people seeking treatment for addiction ground their self-perception in biology in a way that shapes their experiences? We interviewed 63 participants in addiction treatment programs, asking how they make meaning of a genetic understanding of addiction in the context of their recovery, and in dealing with the stigma of addiction. About two-thirds of people in our sample did not find a genetic conception of addiction personally useful to them in treatment, instead believing that the cause was irrelevant to their daily struggle to remain abstinent. One-third of respondents believed that an individualized confirmation of a genetic predisposition to addiction would facilitate their dealing with feelings of shame and accept treatment. The vast majority of our sample believed that a genetic understanding of addiction would reduce the stigma associated with addiction, which demonstrates the perceived power of genetic explanations in U.S. society. Our results indicate that respondents (unevenly) ground their self-perception of themselves as an addicted individual in biology.

Keywords

Addiction; Substance use; Alcohol/alcoholism; Behavioral genetics

Introduction

The gene has become firmly planted within our economic, cultural, and medical soul (Rose 2007). Scientists use genetics in efforts to better understand human evolution and migration (Altshuler et al. 2005; M. Hammer et al. 2001); citizens send cell samples to companies like 23 and Me or AncestryDNA to uncover information about their medical risks or genetic ancestry (23andMe 2016; AncestryDNA 2016). Notions of the power of genetics to uncover fundamental knowledge drive research agendas and public funding in a variety of fields, from environmental protection (Shostak 2013) to addiction (Midanik 2004). There is great hope by scientists and doctors that genetics will revolutionize medicine through the identification of new pharmaceuticals to treat diseases (Wang, Fu, and Zhang 2012; David et al. 2015), genetic screening, and enhanced diagnosis (David et al. 2015; Veltman and Lupski 2015). The gene remains potent in the media, with evidence that genetic optimism – the idea that there is a gene for a disorder, that it will be found, and the results will be positive (Conrad 2001a) – continues in media coverage (Ostergren et al. 2015; Dingel et al. 2014; Bubela and Caulfield 2004).

In response to and anticipation of this “genetic revolution” (F. Collins 2010), Abby Lippman coined the term “genticization” to describe the ongoing process where “differences between individuals are reduced to their DNA codes”; most disorders and behaviors are defined, at least in part, by genetic origin; and scientists, practitioners, and others advocate for the adoption of interventions that use genetic technologies to manage health problems (Lippman 1992, 1470). More recently, scholars have pushed back against extreme forms of genticization, arguing that they mislead or oversimplify the ways genetic knowledge shifts how we think about identity and causation (Novas and Rose 2000; Rose 2007; Brekke and Sirnes 2011; Easter 2014). Nikolas Rose argues that new biological research pushes us towards becoming “biological citizens” with rights, duties, expectations, relationships, and a reconceptualization of ourselves as “somatic,” or biological, individuals (Rose 2007, 6); genetic risk is knowledge that we expect individuals to act upon in maintaining or improving their health.

Such a potent force in society is not without controversy, and many scholars express a wide variety of anxieties around such emphases on the gene. The resulting critiques and fears expressed about a reductionist genetic framework are applied to areas as broad and disparate as racial difference (Duster 2007; Epstein 2007; Roberts 2011), public health (Merikangas and Risch 2003; Carlsten and Burke 2006), and psychiatric disorders (Mayberg 2014; Navon and Eyal 2014). Others push back in various ways, for example by asking whether genetics leads to a form of biopower that is unique from previous, non-genetic conceptions (Raman and Tutton 2010) or by arguing, as Maurizio Meloni, (2014b; 2014a) does, that we are seeing a complete renegotiation of the boundaries between “biology” and “sociology” as disciplines, with a deeper understanding of the connection between the biological and social

realms (Meloni 2014a). It is clear that most scholars do not endorse a strongly deterministic form of geneticization, but most do argue, like Rose (2007, 253) does, that “in all manner of small ways, ... things will not be quite the same as they were,” since the forms of knowledge that shape our understanding of ourselves are increasingly biological. This process is less a sledgehammer, and a needle and thread: the genetic and the “high tech” inserting itself and redirecting, but being woven into, existing personal and social storylines (Easter 2014; Brekke and Sirnes 2011; Sharon 2014; Rose 2007). If these scholars are right, genetics should be woven into personal narratives in noticeable ways across a variety of contexts, including addiction.

Many clinicians and scientists maintain that addiction can be characterized through neurological and genetic research (Kalivas and Volkow 2005; National Institute on Drug Abuse 2007). Genetics is deeply intertwined with a conception of addiction as a “disease of the brain,” as can be seen by the large number of studies that seek to interrogate the biological roots of addiction by identifying genes that code for a variety of brain structures, including neurotransmitters, transporters, and enzyme targets of the dopamine, serotonin, and glutamate systems of the brain (C. R. Li and Sinha 2008; Schnoll, Johnson, and Lerman 2007; Thorgeirsson et al. 2010; C.-Y. Li et al. 2011; Bierut et al. 2007). Scientists assert that 40–60% of the risk for addiction is genetic, though recent investigations, along with difficulty replicating genome-wide association studies, point to the large number of causal risk variants that each contribute relatively small effects, as well as the complex set of phenotypes and genotypes involved (Hart and Kranzler 2015; Schuckit 2014).

Fueled by this genomic revolution, and consistent with a reshaping of our understanding of the basis of disease and disorder, an increasing number of entities have created definitions that conceptualize addiction as a disease of the brain’s reward system (American Society of Addiction Medicine 2015; National Institute on Drug Abuse 2007). For example, The American Society of Addiction Medicine defines addiction as being “a primary, chronic disease of brain reward, motivation, memory and related circuitry. Dysfunction in these circuits leads to characteristic biological, psychological, social and spiritual manifestations” (American Society of Addiction Medicine 2015, para. 1). These definitions place biology as the root cause of addiction, as opposed to contextual, social, or moral factors. Though there are significant physical sequelae of addiction, there is neither a biologically-based way to diagnose addiction, nor a clinical test for predisposition to addiction. However, many treatment programs educate patients about genetic bases of addiction (Center for Drug & Alcohol Programs 2011; Haroutunian 2010; Mayo Clinic 2007).

Of particular note is that these biological definitions implicitly marginalize contextual factors, even though the importance of the interaction between genes, brain, and environment is widely accepted (Thomas 2010; Vrecko 2010; Meloni 2014b). Along these lines, scholars have issued a variety of challenges to the disease of the brain model (Courtwright 2010); it is well documented that structural factors like poverty and unemployment, in concert with larger sociohistorical conditions, leave certain communities vulnerable to substance abuse (Acker 2010; Draus 2009; Hill, Ross, and Angel 2005; McLoyd 1990). For example, in the case of Detroit, Michigan, U.S.A., Paul Draus (2009, 361) argues that Detroit suffers from a “slow motion disaster” resulting from the intersection

of “corrosive structural processes, counterproductive social policies, and vulnerable populations.” Substance use in Detroit, he goes on to explain, is an *effect* of this crisis, but is also now a contributing factor (see also Acker 2010). In a similar vein, Courtwright (2010) notes that the prevalence and incidence of drug abuse shifts in response to broader demographic and structural variables – migration, birth cohort size, civil wars, pharmaceutical marketing strategies, and cultural norms. By contrast, “pathological understanding is still disconnected from disease control, which is unusual in the history of medicine and public health” (Courtwright 2010, 140).

In the U.S. we have alternately viewed excessive drug and alcohol use as a choice, a sin, a vice, a compulsion, or criminal, and, common to all of these conceptualizations, it has been highly stigmatized (Levine 1978; Conrad and Schneider 1992; Edwards 2009). Goffman defines stigma as an “attribute that is deeply discrediting,” though he goes on to clarify that it is not something inherent in the attribute, but how those around one in society *perceive* the attribute (Goffman 1963, 3). Those without stigma perceived those with stigma as “not quite human” and “impute a wide range of imperfections on the basis of the original one” (Goffman 1963, 5). One hope for the genetic paradigm, aside from more targeted and effective treatments, is that it will disrupt the older model of addiction as a moral problem or the result of bad choices – that it will undermine the “wide range of imperfections” associated with addiction (Campbell 2010; Keane 2002). Such a paradigm shift may thereby remove stigma from addictive disorders, increase support for funding addiction services, and encourage people to seek treatment.

Though currently, the dominant scientific framing portrays addiction as a disease, the stigmatization of alcoholism and drug abuse continues (Phelan 2005). Schnittker (2008) found that between 1996 and 2006, people in the U.S. were more likely to attribute alcohol abuse to genes (increasing from 60% to 69%), a chemical imbalance (increasing from 63% to 72%), *and* bad character (increasing from 51% to 65%). Responses for “the way he/she was raised” and “stressful circumstances” did not increase significantly, but remained high (70% and 92%, respectively). In other words, a belief that addiction is rooted in neurobiology does not affect the public’s beliefs about the responsibility of individuals for their addiction (See also Meurk et al. 2013). Scholarship is mixed with regards to the ways a perceived genetic basis of addiction affects both the social distance people want from addicts, and the perception that addiction cannot be treated (Schomerus et al. 2010; Mannarini and Boffo 2015; Kvaale, Haslam, and Gottdiener 2013). In sum, it appears that genetic etiology weakly increases or fails to decrease stigma for this highly stigmatized disorder (Canadian Health Services Research Foundation 2013; Phelan and Link 2012; Pescosolido et al. 2010).

Moving from public perception to individuals dealing with addiction, a systematic review of studies examining the effect of communicating personalized genetic risk information to individuals revealed that this information yields no long- or short- term impact on perceptions of individual control (R. E. Collins, Wright, and Marteau 2011), a finding consistent with existing research on theories of health and behavioral change that knowledge alone is not sufficient to motivate change (Bandura 2004; Webb and Seeran 2006). This finding suggests that cognizance of one’s genetic status does not influence one’s beliefs

about personal control or fatalism. A large body of research indicates few long-term changes in substance quit rates following the provision of genetic information when compared to control samples (Bize et al. 2009; Hishida et al. 2010; Marteau et al. 2010a; McBride et al. 2002; Sanderson et al. 2008; Sanderson et al. 2010; Sanderson et al. 2009). In other words, similar to the anticipated effect of this information in the general population, there is a contradiction between the “promise” of a better understanding of the genetics of addiction, and the current value of such information for patients with substance use problems. This contradiction may arise in part because of the varied way that individuals understand genes and their effects (Bates et al. 2005; McGowan, Fishman, and Lambrix 2010; Chilibeck, Lock, Margaret, and Sehdev 2011). As Chilibeck et al. (2011) note, people blend relatively abstract genetic knowledge with concrete lived knowledge (like their experiences with their families or their own addiction) in complex and variable ways (See also R. R. Hammer et al. 2012). There is far less qualitative research that explores how people understand and use information about behavioral genetics, though some recent studies have explored how those with addictions understand the neuroscience and brain-based framing of addiction (Meurk et al. 2016; Morphet et al. 2016; Pickersgill, Martin, and Cunningham-Burley 2014).

This paper explores the ways that individuals in treatment for addiction resist, react to, and accept genetic narratives of addiction in two specific moments: that of their own recovery, and in dealing with the social shame and stigma they feel as addicts. We interview people seeking treatment for addiction and ask how they see the connection between their addiction and their biological selves. Specifically, we ask whether they perceive a genetic framework to be useful to them in their own treatment and recovery. We also ask whether these individuals believe a genetic framework will change the way they are perceived by others. This descriptive study begins to map the complex and variable beliefs, understandings, and concerns about genetics among this population of people seeking treatment for addiction. In other words, though we do not examine behavior change per se, when those seeking treatment for addiction are confronted with the idea of a genetic basis of addiction, how do they respond with respect to its usefulness to them? To what degree do we see genetic conceptions infiltrating their practical definitions of themselves as addicts and motivating behavior? In Rose’s terms, to what degree do they perceive themselves as “biological citizens”?

Methods

With approval from each treatment center’s institutional review board, we interviewed 63 participants from five different treatment programs in the upper Midwest, U.S.A. (See Table 1). Most of the treatment sites offered group or individual therapy sessions, combined with pharmacological treatments. The treatment sites varied in their educational approach to substance use. Most included materials – pamphlets, videos, or other displays – that emphasized a biological basis of addiction.

We recruited participants by distributing a flyers at each site. Using a number on the flier, interested participants phoned the interviewers to schedule a meeting at their convenience. Participants were compensated for their time. Before each interview, the interviewer

reviewed informed consent with the respondent, including the risks and the benefits, and assured the respondent of confidentiality.

Treatment programs were selected to obtain a socio-economically, racially and ethnically diverse sample spanning urban and rural areas. Participants ranged in age from 25 to 73. The participants were in treatment for alcohol use (32%), smoking cessation (46%), or a combination, including in some cases illicit drugs (22%) (See Table 1). We conducted semi-structured interviews lasting 30 to 45 minutes. Interviewees were asked about a variety of topics, including: 1) the patients' perception of the causal factors of their addiction; 2) knowledge of addiction genomics; 3) benefits, risks, hopes, and fears of new genetic treatments and tests. These questions were stimulated by results obtained through a previous interview study conducted by the same team, as well as by outside research.

We recorded and transcribed the interviews, and used standard qualitative content analysis techniques, consistent with grounded theory, to analyze the transcripts (c.f. Clarke 2005; Corbin and Strauss 2008). Each transcript was coded by two members of the research team using a variety of questions inspired by previous studies, and categories that emerged from the interviews (Corbin and Strauss 2008). Code discrepancies were discussed by the two coders until consensus was reached. Below, we report on sections of the interviews regarding how patients perceived the usefulness of a genetic conception of addiction in their recovery, and in dealing with the stigma of addiction. These interview sections were carefully read, and each patient was categorized as believing that incorporating a genetic understanding of addiction 1) *was* useful to their recovery or 2) *was not* useful to their recovery. "Useful" was defined broadly for this classification, including concepts such as alleviating guilt, increased motivation for seeking therapy, or accepting treatment. They were also categorized as either believing addiction genetics would decrease, increase, or not alter the level of stigma associated with addiction. We then employed an iterative process, with further sub-categorizations made within each category. We read the quotes from each category of patient, with themes emerging from these quotes. We further refined these themes by continually referencing our evolving analysis against the original interviews to maintain validity, and taking care to identify and present the full range of responses (Clarke 2005). As with many qualitative studies, our goal was not to draw statistically representative conclusions, but instead to begin to map out the breadth of responses for our topic.

Results

About two-thirds of our sample did not explicitly incorporate genetic knowledge into their narrative of recovery, nor did they believe such information would motivate them in their recovery. By contrast, about one-third of our sample believed that confirming a genetic predisposition would help them accept and embrace treatment for their addiction, and aid them in dealing with their guilt about addiction. There did not appear to be differences regarding patient perception of the personal usefulness of genetic information by occupation, substance of abuse, age, sex, or race. Even though some treatment programs in our sample explicitly educated patients about the genetic bases of addiction and others did not, patients' perceptions of the usefulness of this knowledge did not appear to vary by treatment program. On the face of it, this does not appear to support the notion that we increasingly see

ourselves as biological entities. However, when we turn to the ways individuals feel stigmatized in society, the vast majority of our sample embrace a genetic framing of addiction, which they believe will reduce the stigma associated with addiction because it helps explain their inability to quit. Together, these findings support the increasing importance of the biological that plays out in noticeable but varied ways.

Genetic Knowledge, Acceptance of Addiction, and Alleviation of Guilt

About one-third (35%) of our sample believed that learning of a genetic predisposition to addiction would either 1) help them accept their addiction and embrace treatment; or 2) help alleviate guilt. Jack,¹ who was in an alcohol treatment program, voiced uncertainty about his diagnosis as an alcoholic:

I'm still fighting with the fact am I really an alcoholic? Even though I know I drink too much, I still fight with it a little bit....if [I am genetically] more apt to be an alcoholic, I don't think I would ever drink again.

Others thought that personalized genetic information would help them understand that addiction was a permanent condition – that they could never hope to use moderately, but instead had to abstain permanently:

...a lot of us for a long time, including me, lived on eventually, I can do this again. I just need to clean up a little bit and change this and do that or do that and try this a little different, but I never added in *forever*, that was never there for a long time. ... Now you know it is genetic; it is so much more than just willpower or you or just a drug, it is in your makeup in your very genes. (Ron, in an alcohol treatment program)

Other respondents thought that a genetic understanding would help them deal with the guilt and stigma of not being able to quit:

It is easier to believe and know that it is a disease or a genetic thing than it is to believe that I'm a rotten person. I can say, okay, it is a disease or a genetic thing and then I can work on it. But if I'm a rotten person, I might just as well stay where I am. I might as well just drink myself to death or keep smoking or whatever it is. (John, in treatment for smoking)

It is also notable that many interviewees who spoke about guilt conflated a genetic understanding of addiction with a broader conception of addiction as a “disease.” They used this disease model to buffer against a “moral” understanding of addiction – to deal with judgment and stigma. For these individuals, the genetic drives a basic understanding of themselves, their addiction, and how they need to deal with it.

Genetic Knowledge is Not Useful for Maintaining Abstinence

About two-thirds (65%) of participants thought that genetic knowledge would not change their personal narrative of recovery in a way that would motivate them to remain abstinent. The vast majority of these individuals believed that genetic factors do affect addiction, but

¹All interviewee names used throughout are pseudonyms.

rejected its usefulness towards their recovery for varied reasons. A much smaller subset did not trust the scientific information that connects genes and addiction.

Daily Work of Maintaining Abstinence—The most common reason patients gave for rejecting the integration of a genetic conception of addiction into their recovery narratives was that they believed their focus should be on what they need to do each day, accepting responsibility for their actions and doing the hard work of maintaining abstinence, regardless of the cause. Notably, this framework is consistent with the teachings of 12-step programs, where abstinence is the treatment goal and asking for help from others is central (Alcoholics Anonymous 1984). Almost half of those who did not find genetic knowledge useful expressed this sentiment. For example, Joy, who was in a smoking cessation program said, “If I put a cigarette ... into my mouth, even though I may have a genetic disposition to it, I still have control over that – putting that cigarette in my mouth. It is still a personal responsibility thing.” Similarly, Dale, in an alcohol treatment program said, “All I know is [addiction] is kickin' my butt! Whether it is genetics or it is me! ... I don't have to know why it snows, I just have to shovel it!” Of interest in Dale’s quote is that he differentiates his genes from “me,” his sense of self. The genetic does not drive his perception of his own addiction in the same way as some of the previous respondents.

These respondents did not reject the validity of biological information, but instead perceived it to be irrelevant, though benign, information with respect to their own recovery. Instead, they relied on the idea that, regardless of the cause of their addiction, they had to perform the hard work of remaining abstinent.

Fatalism—The respondents above expressed the notion that the cause of their addiction was separate from the way they thought about their work to remain abstinent. However, a few thought that a genetic understanding of addiction might be *used as an excuse* for some people’s bad choices and behavior. Tanya, in a tobacco cessation program expressed a degree of fatalism as a result of a biological understanding of addiction:

[A genetic framework] makes me feel nervous. *Very* nervous because I know that I’m addicted and I don’t know that I can stay quit because of the addictive part of my brain. I’m scared to death because I don’t want ... to be carrying around an oxygen tank. I don’t want to get COPD; I don’t want to get emphysema, but the addiction part is just so hard that it’s—it’s just hard!

Tanya explicitly blames a part of her brain for her difficulty remaining abstinent, a framing which implies a closer link between body and action’s than Dale’s above. Not just benign information, these respondents thought that genetic information could be harmful—playing into fear and anxiety about quitting—and work against their treatment goals.

Not Enough Benefits—Several participants did not believe the benefits of testing were enough to justify its use. Some explained that without a therapy, the genetic knowledge by itself was not helpful for their recovery. Others felt that information from genetic testing would not be helpful because they “already knew” they had a genetic predisposition – or that they already knew they had an addiction. Madge, in a smoking cessation treatment program articulates both of these sentiments: “I’ve got the gene, I must have it, I’m smoking, I already

know this, you know? Unless you can give me a for sure cure and guarantee, ‘oh, this is going to work,’ well, forget it!” While Madge accepts a biological framing of addiction, she does not connect it with a requirement for action in the same way as those who we classified as finding this information useful.

For Lisa, in a tobacco cessation program, the possibility of incidental findings outweighed any potential benefits:

I don't want to know what is all in my DNA at all. ... I mean you could find out, say, if there ever was a big dark secret, you weren't your parents' kid or you could find out that you are not related to them or something. You know? I think it would be scary. ... I don't know if I'd want to know if I was going to get breast cancer. ... I don't want to be worried and become a hypochondriac about what is in my blood and what is going to happen to me.

The basis of Lisa's fears is that our body contains secrets, kept from us, about our health, our basic sense of who we are that could be read through an analysis of her genes. Yet, her weighing of risks versus benefits reflects debates on the public health impact of personalized risk factors for addiction (Carlsten and Burke 2006; Merikangas and Risch 2003). For smoking, the best public health advice, regardless of individual predispositions, is to not smoke. These respondents, realizing that knowledge of their individual genetic fingerprint would not open up additional routes of recovery, rejected the notion that this information was useful to them. The fear expressed by Lisa affirms the power of biological citizenship, even as it reveals that not all are motivated by action to it.

Not All Biological—Some participants mentioned that genetic knowledge was not all that helpful because addiction was not all biological. These individuals accepted a causal link between genetics and addictive behaviors, but did not believe that genetics was the only causal factor, a sentiment supported in the scientific literature (Thomas 2010). Even if scientists could isolate the genetic portion, there were many other causal reasons for addiction:

I don't think there is a cure because I don't think it is totally biological. It is just multi-faceted. ... I think, once you become addicted you are always addicted. ... I think that we are such holistic beings, that it isn't just one thing. (Nora, in an alcohol treatment program)

Julia, in an alcohol treatment program, equated a genetic understanding of addiction with a pharmaceutical therapy, and believed the pharmaceutical/genetic paradigm to be inadequate to solve her problem with addiction:

Well, kind of the way I think about it is if I were not an alcoholic I would still drink every single day, you know, and that is crazy thinking, obviously, but I still am trying to fill it. There is something that I'm trying to fill and even if I had a pill that made me not want to drink, well, then ... I'd be miserable. I would just be miserable like I was before I ever started using. And, luckily, AA has helped in little ways just by relationships that I have formed with people that are really loving and kind. So I'm getting certain needs met that I never could get before.

These participants recognized the complexity of the causal factors involved in addiction, and because of this complexity, they also understood that biological information does not provide an easy path to recovery.

Mistrust of Information—Finally, a few participants either did not believe that genes influenced addiction, or did not trust genetic information to be accurate:

I have been through other quit smoking classes, like alcohol programs because it was mandatory to teach us about it, and I have heard different statistics and different hospitals and everything, and who is telling the truth and who is not? I don't know! ... I don't like that kind of technological stuff like that, and ... I don't think it would stop me from smoking, drinking, using drugs or anything. (Bill, in a tobacco cessation program) You are susceptible to this or you are more apt to have cancer of the liver. Do they know it, for sure? I mean how many things do they say, for instance coffee was so bad for you! I mean it was so bad you weren't supposed to drink it. Bacon! Eggs were awful – off limits, one a week! Now it is have your eggs and your bacon. Have your coffee. (Janet, in an alcohol treatment program)

These few respondents expressed mistrust of genetic and scientific information, and rejected it based on that mistrust. These participants appear not to see themselves as biological citizens.

The Societal Level

Individuals in our sample are acutely aware of societal prejudice against them. Every participant responded to the question of “how does society view addiction” that, in one way or another, society has a negative perception of addicted individuals. In line with Goffman’s definition of stigma, many believed that there was a deeply engrained societal prejudice that regarded anyone who has an addiction as “lesser” and an inherently bad person. One participant described a view that addicts are “selfish, weak, mean people that, you know, would leave their baby in a bar, in the back booth and drink all night” (Abby, in a tobacco cessation program).

”I think a lot of people are prejudiced against addicts and think that we are all really bad people. The ones that don't have the information about us, you know, the first thing they hear is addict, addict, you know, like it is a bad word. You are a bad person if you are an addict.” (Dawn, in a methadone and alcohol treatment program).

The strong perception among our sample is that the public lacks empathy for addiction and believe that addicts should just be able to quit using. Though above, Dale states that a genetic understanding of addiction is not personally useful for him, he believes it would make a difference in public opinions of addiction:

Why don't you just quit? (Laughs) you know, I hear that from--just quit! Why don't you do that? I don't know because I consider myself a fairly strong person and no, I can't just quit! They don't realize the physical or the psychological side of it; you know the mental things that drive us are somehow different from normal people. I don't think unless you know someone that is an alcoholic, been an alcoholic or have

done extensive research on it, I do not believe most of the population understands it.

Despite that most in our sample felt that this information would not be personally useful to them in their own recovery, the vast majority thought that framing addiction through a genetic lens would increase public understanding and compassion, and decrease stigma, for addiction (See Figure 1). This contradiction between individual and societal perceptions of usefulness for a subset of our sample is interesting given that research indicates that this information does not increase compassion or reduce stigma among the general population. To explain this, we argue that, while these individuals may not believe a genetic understanding of addiction to be personally useful to them, they nevertheless feel vindicated by it – as Dale describes above, the biological research stands as proof of their experience with struggling to quit. The fact that the biological research has not yet changed public attitudes is attributed to the public's lack of awareness about this research.

First I need to say that [a genetic understanding of addiction] has probably only reached less than 5% of the people out there. How it will change their attitudes – they will look at these people as having a disease at the point where they are smoking – having a disease that needs to be treated. Rather than they are, you know, a lower form of life than everybody else because they smoke or they drink... More compassion, yes, but there is more than that. More understanding, more supportive of them getting into recovery from it – like that.” (John, in a tobacco cessation program).

John goes on to describe: “I have a disease, okay? I have a disease; it is like diabetes. I didn't ask for it, no one is going to condemn me for it – as long as I take care of it.” Above, he felt that a genetic conception of addiction would be useful in his recovery. Here, he adopts a framework where as long as an addicted individual is working on improving, a genetic conception of addiction should alleviate stigma.

Only one participant thought that a genetic understanding of addiction would have a negative impact on societal perceptions of addiction. When Irene (in a tobacco cessation program) was asked about the effect of genetic research on addiction, she indicated that it would “absolutely” increase stigma. She explains:

When we get delving too deep with this DNA stuff I think we're gonna get too close to a Hitler society where we start getting rid of the lesser of us. You know what I mean by that? People with the weak genes, we only want to keep the bright, intelligent, normal, non-addictive. ... And I mean I've always known I was child of alcoholics and that's a stigma you carry. But when they get to the point where they can start [genetically] pin pointing every little thing, people are gonna start aborting like there's no tomorrow.

Fewer than 10% of respondents thought that a genetic explanation would not have an effect on the current public perceptions of addiction, largely because they felt that things never change regardless of what new information might come along.

I don't believe [a genetic understanding of addiction will change public attitudes] because it hasn't with mental illness ... I think [you can't see a reduction in stigma]

with the exception of cancer or AIDS. But, even AIDS has a stigma attached to it. (Mary, in an alcohol treatment program).

The majority of our sample believe a genetic conception of addiction will affect wider public perceptions of addiction, which we argue is a reflection of the current power of biological explanations for health and behavior. For these individuals, the biological becomes a shield against public shame and stigma, and a scientific articulation of the daily struggles they face in quitting.

Discussion

Scholars point to myriad ways that genetics shape how we think about diverse areas of both scientific research and common-sense notions of who we are. While a growing body of literature exists on public responses to genetic information, little research exists that qualitatively explores how individuals react to behavioral genetics, like drug and alcohol abuse, especially as it applies to a trait that they themselves exhibit (For recent exceptions, see Morphett et al. 2016; Meurk et al. 2016). To help fill this gap in the literature, we interviewed sixty-three individuals seeking treatment for addiction. In this article, we explore the meanings individuals assign to genetic information of addiction. In the context of their recovery and as they are perceived by society, how do they make meaning out of the notion that there are biological bases for addiction?

In the U.S., the public increasingly accept the idea that there is a genetic basis for addiction (Schnittker 2008). Reflecting this, almost all of those we interviewed accept that there is a genetic basis for addiction. These findings support scholars' contentions that in our society, we increasingly look to genetics to explain disorders and difference in humans (Lippman 1992; Rose 2007; Brekke and Sirnes 2011; Sharon 2014).

Genetic Information and Narratives of Recovery

Despite this acceptance of addiction genetics, we also see that individuals weave this genetic information into their personal narratives of their addiction in multiple ways. Consistent with recent biological research, a deterministic framework of geneticization breaks down somewhat with respect to how useful individuals find this information for their own recovery. The majority of our respondents did not believe that genetic information would be useful to their recovery, and the most common reason provided was that, regardless of the cause of their addiction, they had to do the hard work of maintaining abstinence. This sentiment is consistent with messages of 12-step programs like Alcoholics Anonymous, where addiction is framed as a disease, and abstinence is the goal, but individuals are responsible for making a daily, or even minute-to-minute, choice not to drink (Alcoholics Anonymous 1984). A second common response, exemplified by Nora, explicitly noted that humans are "holistic beings" that cannot be reduced to their genes. Nora's sentiment is also consistent with Alcoholics Anonymous, who frame abstinence under a 12-step model as a "way of life." Within this "way of life," individuals must accept that addiction is a disease and use social supports (like AA) to help them navigate through abstinence (Alcoholics Anonymous 1984, 16). Participants may have defaulted to the major messaging about addiction and recovery as is framed by Alcoholics Anonymous or related 12-step programs;

this defaulting reinforces the idea that individuals weave genetic knowledge into existing narratives.

Respondents also conceptualize their addiction within a wider worldview that may contain skepticism of scientific research, or concerns about the risks associated with uncovering individualized biological information, and thus decreasing the usefulness of a genetic understanding of addiction. That so many participants rejected the usefulness of genetic information towards their own recovery reaffirms research that knowledge alone is not enough to change behaviors (Bize et al. 2009; Marteau et al. 2010b; Shiloh 2006) and illustrates a “pluralized biological and biomedical truth” where doubt and controversy are introduced (Rose 2007, 142), but represents an uneven actualization of the biological citizen. However, we argue below that this uneven actualization of the biological citizen is mediated by participants’ near universal support of the usefulness of genetic information for alleviating the stigma of addiction.

A sizeable minority of patients believed that knowing their genetic predisposition towards addiction would help them either accept that they were addicted, or help them deal with the shame of addiction. These responses are consistent with notions of biological citizenship, especially as it relates to our responsibility to act on genetic information. Responses did not appear to vary by occupation, substance of abuse, age, sex, race, or treatment program.

Genetic Information and Public Stigma

In contrast to the heterogeneous way our sample responded to the personal usefulness of addiction genetics, the vast majority believed that a genetic understanding of addiction would decrease public stigma for addiction. The data, however, show that in the general U.S. public, a genetic basis of addiction either slightly increases or maintains the level of stigma associated with addiction (Phelan and Link 2012). Despite this disconnect, the important point is what people in our sample *believe will happen* as a result of this genetic information. These beliefs offer an important insight into the ways that biology has infiltrated these individuals’ sense of themselves as citizens in this society. When faced with stigma resulting from addiction, these individuals turn to the genetic as a buffer, a shield. That the vast majority of our sample embraced a genetic understanding of addiction as useful for dealing with stigma belies the power of genetics in society. In this way, a genetic conception of addiction becomes a scientific explanation for the lack of control they feel, at least at times, over their drug and alcohol use, and reflects that U.S. society strongly values genetic explanations.

Genetic Information and Biological Citizenship

The two major questions we ask are: will patients find framing addiction as a genetic disorder useful during recovery? And do patients believe this framing will decrease public stigma? We now consider how answers to these two questions fit together conceptually.

Finding a genetic framework useful, *and* believing it will reduce stigma fit together smoothly. In line with Rose’s notion that there are new moral duties and responsibilities that go along with genetic knowledge, these individuals in our sample believe that if they knew they were genetically inclined to addiction, they would be more likely to seek treatment, to

never drink again. It increases their responsibility to *act*, and, because doing so fulfills their “moral duty” as a biological citizen, should logically reduce the stigma of their addiction (Sharon 2014, 218). As John says above, “no one is going to condemn me for it – as long as I take care of it.” Consistent with the idea that the genetic discourse is one that pushes individuals to act, there is only a weak theme of fatalism among this group of individuals (See also Gamm, Nussbaum, and Biesecker 2004). It should be noted, however, that our sample is comprised of those who have already decided to act (by getting treatment).

While the large set of individuals in our sample who do not find genetic information useful in their recovery appears to undermine the gene-fueled rise of biological citizenship, that most of these individuals use genetic conceptions of addiction as a buffer against stigma supports it. Only one participant thought that a genetic conception of addiction would increase stigma, and fewer than 10% thought that there would be no change in public stigma as a result of new genetic information. Under a framework of biological citizenship, individuals are perceived to be somatic (Rose 2007), and therefore addiction would be perceived to be a biological disorder, and not the sole result of bad choices. Consistent with this notion of biological citizenship, the vast majority of individuals believed that a genetic framework will foster sympathy towards those who have the “genetic disease” of addiction.

Taken together, our findings indicate that most of our sample is influenced by these notions of biological identity in ways largely consistent with biological citizenship. Some find a genetic framework useful and are moved to get treatment, or believe that it confirms that they have a “real” disorder as opposed to a weak will (Easter 2014). That so many reject a biological conception of addiction as useful to their recovery undermines the widespread presence of deterministic concepts of geneticization and illustrates the ways genetic knowledge is woven into existing narratives of self and disorder. However, the fact that even these individuals believe that a genetic understanding of addiction will decrease the stigma of addiction confirms the importance and perceived power of a genetic framework in U.S. society—those in our sample believe that a genetic framework is powerful enough to reduce or even eliminate the strong stigma associated with addiction.

While a growing body of research explores social and individual perceptions of genetics and health, there is much less research exploring people’s understandings and beliefs about behavioral genetics, especially as it applies to a trait they themselves have. As such, more research in this area is warranted because it may provide clues to the diverse ways patients respond to new genetic research in addiction, how they may resist this information, and how they contextualize genetic information within their worldview and *a priori* narratives of substance use. In addition, research in this area can shed additional light on the ways in which the idea of biological citizenship continues to infiltrate our vision of ourselves, our behaviors, and how we are perceived in society.

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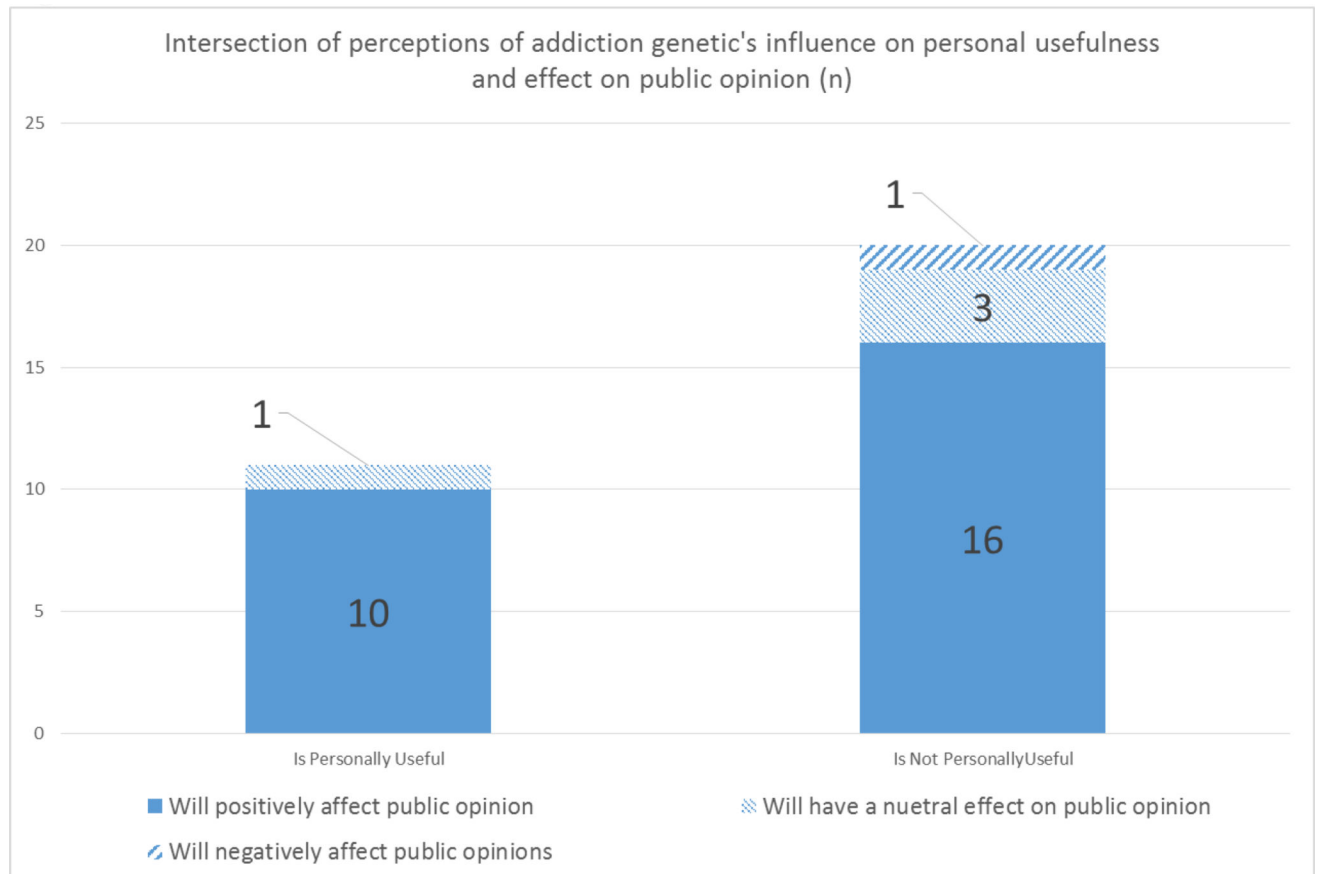


Figure 1.

**Of people who answered that a genetic framing is personally useful to them, seven had no response to how it would shape public opinion. Of people who answered that it would not be personally useful to them, sixteen had no response about how it shape public opinion.

Table 1

Participant Demographics

	n(%)
Sex	
<i>Male</i>	29(46)
<i>Female</i>	34(54)
Race	
<i>African American/Black</i>	6(10)
<i>Asian American</i>	1(2)
<i>Native American/American Indian</i>	2(3)
<i>Bi-racial</i>	3(5)
<i>White</i>	51(80)
Treatment Program	
<i>Alcohol Treatment</i>	20(32)
<i>Nicotine Treatment</i>	29(46)
<i>Polysubstance Treatment</i>	14(22)
Region	
<i>Urban Minnesota</i>	25(40)
<i>Greater Minnesota</i>	38(60)