



## Managing uncertainty: A grounded theory of stigma in transgender health care encounters

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### ABSTRACT

A growing body of literature supports stigma and discrimination as fundamental causes of health disparities. Stigma and discrimination experienced by transgender people have been associated with increased risk for depression, suicide, and HIV. Transgender stigma and discrimination experienced in health care influence transgender people's health care access and utilization. Thus, understanding how stigma and discrimination manifest and function in health care encounters is critical to addressing health disparities for transgender people. A qualitative, grounded theory approach was taken to this study of stigma in health care interactions. Between January and July 2011, fifty-five transgender people and twelve medical providers participated in one-time in-depth interviews about stigma, discrimination, and health care interactions between providers and transgender patients. Due to the social and institutional stigma against transgender people, their care is excluded from medical training. Therefore, providers approach medical encounters with transgender patients with ambivalence and uncertainty. Transgender people anticipate that providers will not know how to meet their needs. This uncertainty and ambivalence in the medical encounter upsets the normal balance of power in provider–patient relationships. Interpersonal stigma functions to reinforce the power and authority of the medical provider during these interactions. Functional theories of stigma posit that we hold stigmatizing attitudes because they serve specific psychological functions. However, these theories ignore how hierarchies of power in social relationships serve to maintain and reinforce inequalities. The findings of this study suggest that interpersonal stigma also functions to reinforce medical power and authority in the face of provider uncertainty. Within functional theories of stigma, it is important to acknowledge the role of power and to understand how stigmatizing attitudes function to maintain systems of inequality that contribute to health disparities.

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### Introduction

A growing body of literature supports stigma and discrimination as fundamental causes of health disparities (Krieger, 1999, 2012; Link & Phelan, 1995; Meyer & Northridge, 2007). Stigma has been defined as a social process of “othering, blaming, and shaming” that leads to status loss and discrimination (Deacon, 2006, p. 418). Stigma researchers, Link and Phelan further define discrimination as the process by which stigmatized groups are devalued through the exercise of social, cultural, economic, and political power (Link & Phelan, 2006). Structural and institutional discrimination includes both intentional and unintentional policies and practices

that result in restricted opportunities for stigmatized people (Corrigan, Markowitz, & Watson, 2004).

Norton and Herek (2012) recently published a study that analyzed data from a national probability sample of heterosexual U.S. adults ( $N = 2281$ ) and described respondents' self-reported attitudes toward transgender people (i.e. those whose gender differs from their sex at birth). Attitudes toward transgender people and other groups were measured with a series of 101-point feeling thermometers in which higher numbers indicated more favorable attitudes with 50 serving as “neutral.” The mean score for transgender people was 32.01. No strata of respondents had a mean score greater than 50. These findings of generally negative attitudes toward transgender people are consistent with studies among transgender people in which they report widespread stigma and discrimination (Grant et al., 2011; Norton & Herek, 2012).

Published literature on health care provider attitudes toward transgender people is quite limited. Most studies examine attitudes

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toward lesbian, gay, bisexual, and transgender (LGBT) populations, in general, rather than transgender patients in particular (Dean et al., 2000; Dorsen, 2012; Lurie, 2005; Vanderleest & Galper, 2009). A recent review of literature on nurses' attitudes toward LGBT patients showed evidence of negative attitudes in all 17 articles (Dorsen, 2012). A study of 427 LGBT physicians found that 65% had heard derogatory comments about LGBT individuals and 34% had witnessed discriminatory care of an LGBT patient (Eliason, Dibble, & Robertson, 2011). These studies may underestimate transgender discrimination given that Norton and Herek (2012) found that attitudes toward transgender people are significantly less favorable than toward LGB. A recent study examining the LGBT content of medical curricula in the United States have found little to no education on transgender health (Obedin-Maliver et al., 2011).

The stigma and discrimination faced by transgender people (i.e. those whose gender differs from their sex at birth) have been associated with increased risk for depression, suicide, and HIV (De Santis, 2009; Dworkin & Yi, 2003; Lawrence, Meyer, & Northridge, 2007; Lombardi, Wilchins, Priesing, & Malouf, 2001; Risser et al., 2005). Transgender people also face significant barriers to accessing health care. A national study found double the rate of unemployment among transgender people, compared to the general population. Not surprisingly, transgender people were also less likely than the general population to have health insurance and less likely to be insured by an employer (Grant et al., 2011). Among a sample of 182 transgender people in Philadelphia (Kenagy, 2005), one-third reported having no primary care physician and one quarter had no access to general medical care compared to 10% of the general population (National Center for Health Statistics, 2007).

One in four respondents in the Kenagy (2005) study had been denied medical care just because they were transgender. In a more recent national study of health care experiences of LGBT people and people living with HIV (PLHIV), 70% of 397 transgender respondents reported experiencing some form of health care discrimination, compared to 56 percent of LGB respondents and 63 percent of PLHIV (Lambda Legal, 2010). Over a quarter of all transgender respondents (26.7%) reported being denied care because of their transgender identity, compared with 7.7% of LGB respondents denied care because of their sexual orientation and 19% of PLHIV denied care because of their HIV status.

Even when transgender people are able to access health care, the care they receive is often far from ideal. A statewide needs assessment conducted in Virginia (Xavier, Hannold, Bradford, & Simmons, 2007) found that 46% of transgender respondents had to educate their regular doctors about their health care needs. The National Transgender Discrimination Survey (NTDS) (Grant et al., 2011) of over 6000 transgender and gender non-conforming individuals throughout the U.S. found that 50% of respondents reported having to teach their medical providers about transgender care. Beyond this lack of clinical competence, some transgender people experience outright mistreatment from medical providers. Lambda Legal (2010) found that 20.9% of transgender respondents had been subjected to harsh language, and 20.3% of them reported being blamed for their own health problems. Fifteen percent reported that health care professionals refused to touch them or used excessive precautions, and 7.8% experienced physically rough or abusive treatment by a medical provider. The prevalence of mistreatment among transgender respondents was twice that of lesbian, gay, and bisexual respondents.

Given their experience, many transgender people are wary of the health care system. Ninety percent of transgender people surveyed by Lambda Legal (2010) believed there are not enough medical personnel who are properly trained to care for them, and 52% worried about being refused medical services when they need them. This wariness has significant consequences for the health of

transgender people. In the NTDS (Grant et al., 2011), 33% of respondents reported that they postponed preventive medical care due to discrimination, and 28% postponed care even when they were sick or injured.

Mistrust of the health care system also leads some transgender people to seek care outside the formal sector. Xavier et al. (2007) found that half of the hormone-experienced study participants had obtained their hormones from someone other than a doctor, and nearly 46% of them had injected themselves with hormones or received a hormone injection from someone other than a doctor or nurse, including 71% of transmen and 37% of the transwomen. While there is little data on the effect of gender-affirming medical care on the physical health of transgender people, one study from New York City found that transgender people with access to such care had lower rates of risky health behaviors such as cigarette smoking and illicit use of syringes for hormone injection (Sanchez, Sanchez, & Danoff, 2009).

It is clear that transgender people face stigma and discrimination in health care settings; and that this stigma influences their health care access and utilization. Thus, understanding how stigma and discrimination manifest and function in health care encounters is critical to addressing health disparities for transgender people. In order for change to take place, this understanding must take into account both provider and patient perspectives on the health care encounter. To date there has been no published literature exploring how discrimination functions in health care encounters between transgender patients and medical providers. This qualitative study was conducted to address this gap.

## Methods

This paper presents a Grounded Theory analysis (Charmaz, 2006) of field notes and in-depth interviews conducted with medical care providers and transgender adults as part of a larger study examining stigma, access to care and HIV risk among transgender people. Consistent with the principles of Grounded Theory, the review of stigma theory literature was deferred until after data analysis. To ground the study in the community, two community advisory boards (CABs) were convened before data collection began. One CAB was made up of transwomen and the other was made up of transmen. Each CAB met approximately monthly before and during data collection and as needed after data collection was complete. CABs provided input into the development of study materials, assisted with recruitment, and offered suggestions for interpreting preliminary findings. The busy schedules of health care providers prevented the formation of a CAB of medical providers.

## Data collection

Purposive sampling was used to identify transgender participants and clinicians who provided medical care for transgender people. Sampling for transgender participants was stratified by gender in order to ensure adequate participation by both transmen and transwomen. In addition, efforts were made to achieve variability along lines of race, engagement in medical care, and use of hormone therapy, as these characteristics were theorized to affect both discrimination and health care experiences.

In-depth interviews were conducted with both transgender adults and health care providers in a small industrial city in the mid-Atlantic from January to July 2011. Interviews were audio-recorded and transcribed verbatim. Field notes were handwritten immediately after each interview and typed once transcription was complete. Transgender adults were recruited by placing flyers in the city's LGBT health center as well as through announcements

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