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Transgender Women in San Francisco:  
Understanding the Nature, Extent, and Meaning of Their Negative Health Care Experiences

By

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A thesis submitted in partial satisfaction of the

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Transgender Women in San Francisco:  
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## **Dedication**

For Monika Ramos and Samuel Ace, who showed me the way.

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## Literature Review

### I. Transgender 101

#### *Transgender 101: Definition and History of the Term “Transgender”*

“Transgender” is an umbrella term referring broadly to people who identify as a gender different from that which they were assigned at birth. By most historical accounts, the term “transgender” was coined in the 1980s by Virginia Prince, an activist who devised the term to refer to individuals like herself who she considered somewhere between “transvestite” and “transsexual” (Stryker & Whittle, 2006). “Transvestite” refers to people who choose to episodically dress as a gender other their own. Conversely “transsexual,” a term popularized in the 1950s by famed gender researcher Harry Benjamin, generally implies someone who “permanently changed genitals in order to claim membership in a gender other than the one assigned at birth”<sup>1</sup> (Stryker & Whittle, 2006). “Transgender” was intended to describe everything in between—and beyond—these two categories.

Understanding the history of the term transsexual is critically important for contextualizing the significance of the term transgender. In 1954, doctor Harry Benjamin, an endocrinologist, determined that transsexualism was a “unique illness distinct from transvestism and homosexuality” that could be treated not with psychotherapy but with a regimen of hormones and surgeries (Billings & Urban, 1982). Furthermore, the term transsexual applied only to those making a binary transition: from male-to-female or from female-to-male (with most of the earlier research, literature, and publicity focusing on male-to-female persons). Benjamin made his assertions on the basis of treating dozens of transsexual patients. The prevailing medical opinion at this time was that transsexuality was not a self-selected identity per se but rather a disorder of gender that could, and should, be treated by the medical establishment (Meyerowitz, 2006).

Early behavioral criteria for the diagnosis of transsexualism, established and then refined throughout the 1960s and early 1970s, included: “a life-long sense...of being a member of the ‘other sex;’ ...early and persistent behavioristic phenomenon of cross-dressing...a disdain or repugnance for homosexual behavior” (Billings & Urban, 1982). Sociologist Dwight Billings asserts that clinicians using this early diagnostic rubric believed the most accurate indicator of transsexualism the intensity of a patient’s desire for genital surgery. (This is a particularly striking criterion in light of current findings that many transgender people do not in fact desire genital surgery.) The diagnosis of “transsexual” was gradually replaced in the 1970s with the diagnosis of “gender dysphoria syndrome,” which was ultimately replaced with the current diagnosis of “gender identity disorder” (American Psychiatric Association, 1994). That diagnosis, which is still retained in the current *Diagnostic and Statistical Manual of Mental Disorders (4<sup>th</sup> Edition)*, will be discussed later in this paper.

However, many gender-variant persons, such as Virginia Prince, sought an identity—not a diagnosis given out by psychiatrists. In 1992, activist and writer Leslie Feinberg authored a pamphlet titled *Transgender Liberation: A Movement Whose Time Has Come*. This is thought to be the first time “transgender” was used in a printed material, and was the author’s call for a social movement organized around a broad transgender identity (Valentine, 2007). Unlike the term transsexual, which encompasses only those fully switching from male to female, or vice

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<sup>1</sup> However, currently there is not consensus in the community about whether genital surgery is required for a label of “transsexual” to be applied.

versa, many other people may identify somewhere in between. The term transsexual defines people using this binary gender system, but the term transgender comprehensively includes all gender-variant people: transsexuals, drag queens, drag kings, genderqueers, fem queens, hermaphrodites, trannies, butch lesbians, feminine gay men, and many more.

Many transgender studies scholars note that the term “transgender” moves conceptions of gender away from the binary male and female identities (Stryker & Whittle, 2006). Perhaps most significant—and most vexing—from a medical perspective, “transgender” does *not* imply a specific course of medical treatment. Instead it creates a space inclusive of transgender people who may in fact make a binary identity shift, as in from male to female, but who choose only selected medical treatments in their transition. For example, many transpeople do not desire genital surgery as part of their transitions. A study of more than 7,500 transgender and gender-nonconforming people released in 2011 by the National Center for Transgender Equality, the nation’s largest advocacy organization working on behalf of transgender and gender-nonconforming people, found that 14% of transgender women do *not* desire vaginoplasty (genital surgery to construct a vagina) and 72% of transmen do *not* desire phalloplasty (genital surgery to construct a penis) (Grant, et al., 2011). Further results of this seminal study, which assessed experiences of discrimination and harassment of a remarkably large number of transgender individuals, will be discussed at length later in this paper.

The term transgender became popularized throughout the mid 1990s, and it is now “ubiquitous in progressive community-based organizations...popular media accounts...academic debates...and, astonishingly, it is even finding its way into the medical establishment, the very institution to which transgender was originally opposed” (Valentine, 2007). Indeed, a PubMed search will reveal more than 400 results for the search term “transgender,” including use of the term in large journals such as the *American Journal of Public Health* and *The Lancet*. (A search for “transsexual” returns more than 700 results.)

In this paper the term “transgender” will be used because it is the most inclusive of the widest number of identities. Both the terms transsexual and transgender are used in the literature, often interchangeably, despite their significant historic differences (E. Lombardi, 2001). Some academic journals, such as the *International Journal of Transgenderism*, use the umbrella term “transpeople” to refer to all transgender-identified persons, and that term will also be used in this paper (Ehrbar, 2010). The terms “transgender woman” (meaning a person born a male but who now lives and identifies as a woman) and “transgender man” (meaning a person born a female but who now lives and identifies as a man) have also become popularized along with the development of the word transgender, and will be used throughout this paper. “Cisgender,” also now a frequently used term in literature about gender identity, refers to individuals who are congruent between the gender they were assigned at birth, their bodies, and their lived identities (Serano, 2007). The term “cissexuals” may likewise be used to refer to non-transgender people.

However, in the issue of identity labeling, there is no panacea: as Arlene Lev points out in her pioneering book on working with transgender patients in the therapeutic setting, “many transsexuals are not comfortable being subsumed under the umbrella of the term transgender” (Lev, 2004). Transsexual woman, activist, and scholar Julia Serano argues that using “transgender” as a “one-size-fits-all category” has actually served to erase “the struggles faced by those of us who lie at the intersection of multiple forms of gender-based prejudice” (Serano, 2007). Moreover, many people will simply “not fit into traditional conceptions of transvestite, transsexual, or transgender” (E. Lombardi, 2001). Determining the best language to describe a



wide range of gender identities is an evolving discourse that will undoubtedly continue in the years to come.

### *Gender Identity Disorder: Diagnosis or Damnation?*

At the urging of many psychiatrists and physicians (including Harry Benjamin, John Money, Richard Green, and Robert Stoller, who all worked with hundreds of transsexual patients, including children), transsexualism first appeared in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (3<sup>rd</sup> Edition)* in 1980. (The diagnosis of Gender Identity Disorder of Childhood was also added in this addition to describe transsexualism in children.) To give some further cultural context from this time, it was only in 1973 that "homosexuality" was removed as a mental health diagnosis in the *DSM*. The 1970s and 1980s were times of burgeoning research on the issues of both gender identity and sexual orientation, two topics that were finally each gaining their own footing after having been regularly conflated in the minds of most Americans. By the 1970s, many clinicians and researchers were specifically investigating the phenomenon of transsexualism, and thus there were sufficient data to support its placement in the *DSM* (Drescher, 2010). In 1992 the World Health Organization followed suit and released ICD-10 codes for both transsexualism and gender identity disorder of childhood.

In the fourth edition of the *DSM*, released in 1994, "transsexualism" was replaced with "Gender Identity Disorder." (The term "transgender" appears nowhere in the *DSM*.) The criteria for a diagnosis of Gender Identity Disorder in adults in the *DSM-IV* are as follows:

- A strong and persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex).
- In adolescents and adults, the disturbance is manifested by symptoms such as a stated desire to be the other sex, frequent passing as the other sex, desire to live or be treated as the other sex, or the conviction that he or she has the typical feelings and reactions of the other sex.
- Persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex.
- In adolescents and adults, the disturbance is manifested by symptoms such as preoccupation with getting rid of primary and secondary sex characteristics (e.g., request for hormones, surgery, or other procedures to physically alter sexual characteristics to simulate the other sex) or belief that he or she was born the wrong sex.
- The disturbance is not concurrent with a physical intersex condition.
- The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Since it became formalized in the *DSM*, this so-called "medical model of transsexualism" has been simultaneously accepted, attacked, and defended by a variety of interested parties. The scope of arguments about the diagnosis is extremely large, and the topic is a heated one. Current debates center around three basic questions: Should Gender Identity Disorder remain in the *DSM*? If so, how should the Gender Identity Disorder criteria be revised? And should Gender Identity Disorder remain a single diagnosis with a range of intensities, or should it be split into several different disorders?

The *DSM* is currently being revised, with the *DSM-V* to be released in 2012. In 2008 the American Psychiatric Association announced the establishment of the Work Group on Sexual

and Gender Identity Disorders, charged with determining appropriate revisions to the current diagnosis (Drescher, 2010). The World Professional Association for Transgender Health (WPATH), the major professional group devoted to the care of transpeople, recommended that the diagnosis be changed to “Gender Dysphoria,” and the diagnostic criteria should be distress based (Knudson, de Cuypere, & Bockting, 2010). It should be noted that the issue is so contentious that the WPATH working group assigned with this task was not able to reach a unanimous conclusion, although the majority did support re-naming the diagnosis “Gender Dysphoria” (Knudson, et al., 2010). At this time it is unclear exactly what changes will be made to this diagnosis in the *DSM-V*.

A comprehensive analysis of the arguments for and against the diagnosis, as well as suggestions for how it could or should be changed, are well beyond on the scope of this paper. However, some of the primary arguments for and against the diagnosis will be briefly summarized, and are relevant for contextualizing broader medical issues faced by patients struggling with issues of gender identity.

In the 1970s, proponents of the “medical model of transsexualism” supported the placement of the diagnosis of gender identity disorder in the *DSM* because they felt it countered the “common psychiatric belief that saw trans people as severely mentally disturbed” (Drescher, 2010). This view is no longer common among mental health professionals.<sup>2</sup> Perhaps more significantly for current patients, and as proponents of the diagnosis have long argued, the diagnosis legitimizes the medical and surgical treatments that many patients desire and may even view as non-elective (Lev, 2004). Given the sizeable expense of accessing mental health and hormonal treatment, and particularly the costs of surgery, this is a prudent argument for the existence of the current diagnosis. Other proponents of retaining the diagnosis point out that it can be used to secure legal protection under disability laws that require institutions make reasonable accommodations, and can provide legal protections in a variety of other ways as well (Ehrbar, 2010).

However, the diagnosis received—and continues to receive—numerous criticisms from the medical, legal, and transgender communities. One argument against the current diagnosis, by both legal scholars and activists, is that it does not begin to capture the spectrum of gender variance phenomena (Cohen-Kettenis & Pfäfflin, 2010). However, the primary argument against the diagnosis is that it pathologizes *normal* expressions of gender variance, perpetuating the idea that gender identities outside of the binary model of gender are a form of illness (Drescher, 2010). As transgender legal scholar Dean Spade writes, “The diagnostic criteria for GID produces a fiction of natural gender, in which normal, non-transsexual people grow up with minimal to no gender trouble or exploration” (Spade, 2006). Spade goes on to detail his difficulties being told repeatedly that he was not transgender by numerous counselors because he did not meet the traditional criteria as specified by the *DSM*. Meanwhile, many patients read the diagnosis of gender identity disorder and present with exactly those symptoms in order to garner an official diagnosis and thus the hormonal or surgical treatment they desire (Bower, 2001). Numerous authors have written about this “gate-keeping function” of the GID diagnosis, which shapes the stories that clinicians hear and thus is predictably self-perpetuating (Ehrbar, 2010; Lev, 2004).

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<sup>2</sup> Unfortunately, outside of the health care profession many people still believe that transpeople are mentally ill. One study of university students found that the belief that transgender women were mentally ill was the most powerful factor motivating transphobia (Winter, 2009).

### *Prevalence of Transgenderism*

Determining the prevalence of gender variance is quite challenging given that the “prevailing social climate” of transphobia and the limited availability of medical treatments both influence prevalence data (Gooren, 2010). Moreover, studies use varying criteria for determining whether an individual is transgender. While some studies use psychiatric diagnoses made by licensed mental health professionals, others use self-report or self-identification as the metric. In the Netherlands, which has a nationalized health system and which has long offered systematized care for transgender persons through one centralized clinic, the calculated prevalence of “transsexualism” is 1:11,900 men and 1:30,400 women (van Kesteren, Gooren, & Megens, 1996). The prevalence is similar in Belgium and somewhat higher than Sweden and lower than Singapore and New Zealand. The 3:1 ratio of males to females (that is, transwomen are far more numerous than transmen) is common in the Western world (Gooren, 2010). These estimates do not include undiagnosed persons, patients who do not meet current clinical standards meriting a diagnosis of Gender Identity Disorder, and people who do not seek services through traditional health care providers. It is not known why there are more male-to-female transsexuals than female-to-male, although Lev theorizes that this may be due to the fact that transgender men “may not have commonly used the services of traditional gender clinics or cross-dressing clubs and were therefore less likely to be included in the medical and sociological research” (Lev, 2004).

The exact number of transgender persons in the United States is not known. A report issued in 2011 by the Institute of Medicine on the health of LGBT communities found population estimates for transpeople are “sorely lacking” and does not even offer an estimate on the number of transgender people in the United States (Institute of Medicine, 2011). Rosser set out to conduct a meta-review of the prevalence of transgender-identified persons in the U.S. only to discover that there were no previous demographic studies of the American transgender population (Rosser, Oakes, Bockting, & Miner, 2007). Many existing studies of transpeople focus mostly on accessible subgroups (e.g. convenience samples of inner-city sex workers), lack standardized socio-demographic measures, and have collected data over long time periods, and thus have minimal utility for determining the size of the transgender population. Given that the U.S. population in 2011 is approximately 311,000,000, it can be extrapolated from the measurements from the Netherlands that between 18,000 to 19,000 persons would have a diagnosis of “transsexualism.” Again, this would not account for persons who identify as transgender but do not meet a clinical definition of Gender Identity Disorder. However, some scholars imply that the prevalence number given by van Kesteren and Gooren may be low. For example, one publicly funded community health center in Toronto currently has “more trans clients than should exist in the entire province” given the prevalence statistics listed above (Bauer, et al., 2009).

## II. TransGender Trouble: Discrimination and Health Disparities in Focus

### *Experiences of Discrimination, Harassment, and Violence Among Transgender Persons*

“What had happened [after transitioning to live as a woman] was that I’d started being read by others ‘as a woman.’ That my body became the site of all kinds of social inspection and pronouncements didn’t surprise me. But the virulence did. I was accosted from every direction: from the men who hissed at me on street corners; to the man on the train who leaned over and said, ‘Nice tits,’ as I boarded; to the construction workers who whistled or yelled, ‘Faggot!’; to the driver who rolled down his window at a crowded intersection, the very first time I went out in a dress, to shout ‘God, you sure are uuugly!’”

-Riki Anne Wilchins

As Riki Anne Wilchin’s testimony suggests, everyday life can be a formidable experience for transgender persons (Wilchins, 2006). Most available evidence, including individual memoirs, documentary films, and formal studies done by both advocacy organizations and researchers report that transgender persons face an extremely high burden of discrimination from all sides. This section will focus on research findings documenting the prevalence of discrimination, harassment, and violence against transgender adults *outside* of the health care setting. Discrimination in the health care setting and legal protections against all forms of discrimination and harassment will be discussed in later sections of this paper.

Numerous studies, both quantitative and qualitative, have consistently demonstrated the myriad challenges that many transgender people experience every day (Bauer, et al., 2009). Qualitative research suggests that both male-to-female and female-to-male individuals face pervasive employment, housing, and health care discrimination (K. Clements-Nolle, Marx, Guzman, & Katz, 2001). One study of 402 transgender people (both male-to-female and female-to-male), co-authored by leading transphobia researcher Emilia Lombardi and activist Riki Anne Wilchins, found that more than half of study participants experienced some form of harassment or violence, with one in four reporting a violent incident<sup>3</sup> (E. L. Lombardi, Wilchins, Priesing, & Malouf, 2001). Participants in that study experienced verbal abuse as the most common form of harassment, with more than half of participants reporting experience of verbal harassment. Alarming, nearly half (47%) of the sample reported having been assaulted at some point in their lives. Younger people were more likely to report a violent experience. In a separate study of 571 transgender women from the New York City Metropolitan Area, 78.1% of transgender women had previously experienced gender-related psychological abuse, and 50.1% reported gender-related physical abuse (Nuttbrock, et al., 2010). In that study, the perpetrators of both types of abuse were most often parents or other family members during adolescence; and strangers, neighbors, friends, or police officers after adolescence.

Acts of hatred against individual transpeople can take a wide variety of forms, with murder at the far extreme, and are commonplace even in more liberal urban areas such as San Francisco. The following examples are illustrative of the spectrum of hate crimes. In December 2010 headlines were made when, after a transgender woman went to the San Francisco Department of Motor Vehicles to register her sex change and obtain a new driver’s license, a department employee illegally took her home address from the state’s electronic records and

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<sup>3</sup> In this study, a violent incident was classified as assault with or without a weapon, rape, sexual assault, or attempted assault.

mailed her a hate letter “condemning her to hell” (Egelko, 2010). In 2002 a transgender teenager named Gwen Araujo was killed southeast of Oakland after her transgender identity was discovered (Brown, 2006). During the writing of his New York City-based ethnography *Imagining Transgender*, one of anthropologist David Valentine’s transgender study participants (Vianna-Faye Williams) was murdered, and several more transgender women were murdered after the completion of his fieldwork (Valentine, 2007).

Race and class may also serve as amplifying factors for experiences of discrimination, harassment, and violence. In Lombardi’s study, Latina and African-American transgender women reported experiencing higher levels of transphobia compared to other groups (Emilia Lombardi, 2009). In a study conducted of 90 transgender people (including equal numbers of male and female born participants) with substance abuse problems, African-American transgender/transsexual participants reported the highest level of transphobic events in the past year, while white persons reported the lowest (Emilia Lombardi, 2009). Lower income was also associated with more lifetime discrimination and perceived stress from transphobia.

Economic discrimination, a term used to describe discrimination in housing and employment, is also a common experience of transpeople. In Lombardi’s 2001 study, 37.1% of participants reported that they had experienced economic discrimination. That article does not specify the nature of the economic discrimination recounted by participants, but found that those identifying as transsexual were nearly three times more likely to report economic discrimination than nontranssexuals (E. L. Lombardi, et al., 2001). The authors go on to state that “working adults who disclose their transgendered experience, or request reasonable accommodation to it, are fired, harassed, intimidated or assaulted by supervisors and coworkers, have their privacy violated, have their property defaced and destroyed, or are murdered... Workplace discrimination is so rampant that it is the norm among transgendered people” (E. L. Lombardi, et al., 2001).

Given the extremely high levels of economic discrimination, many transgender people turn to sex work as a way to obtain income. A 2001 study by Clements-Nolle including interviews with 392 transgender women and 123 transgender men documented the income sources of participants in the prior 6 months. Among transgender women, these included part- or full-time employment (40%), sex work (32%), Supplemental Security Income and Social Security Disability Insurance (29%), and General Assistance (23%) (K. Clements-Nolle, et al., 2001). In other words, nearly a third of transgender women in the sample had engaged in commercial sex work in the past 6 months, and only 40% reported some form of legal employment. Notably in this study transgender women were more likely than transgender men to have unstable housing, low education, and low monthly income. Several other studies also suggest that a large proportion of transgender women engage in commercial sex work, “attributable, in part, to social stigma and employment discrimination, which limit opportunities for income generation and challenge basic survival needs” (D. Operario, Soma, & Underhill, 2008). However, sex work can also be motivated by a variety of other non-economic factors. For example, commercial sex work can foster a sense of community (Sausa, Keatley, & Operario, 2007) and affirm a transgender person’s female gender-identity (Eyre, de Guzman, Donovan, & Boissiere, 2004).

Many gender identity scholars, including activists, sociologists, social and behavioral scientists, and medical researchers, have explored the motivations behind this widespread violence and discrimination. “Transphobia,” the feeling of “unease or even revulsion” towards people with atypical gender identities is often given as one explanation (Emilia Lombardi, 2009). Lombardi and Wilchins argue that both violence and economic discrimination may be the result

of a “larger social climate which severely sanctions” gender non-conforming persons (E. L. Lombardi, et al., 2001). Lev similarly suggests that transgender people, as well as intersexuality, “challenge fundamental assumptions about sex and gender and shift the basic paradigm of the world as a place occupied by two sexes that are opposite and different from each other to a conception of sex and gender identities as potentially fluid” (Lev, 2004). Willoughby has conducted a unique series of studies quantitatively assessing the different components of transphobia, and found that persons intolerant of transpeople “tend to be social conformists, heterosexual, religious fundamentalists, male (but not necessarily masculine), morally dogmatic, ego-defensive, homophobic, and lacking self-esteem” (Willoughby, et al., 2010).

### *The Interplay of Discrimination, Harassment, and Violence with Health*

The World Health Organization defines “social determinants of health” as the “conditions in which people are born, grow, live, work and age, including the health system” (World Health Organization, 2011). These factors are shaped by the distribution of resources—both money and power—at the global, national, and local levels. Social determinants of health, which are a widely studied phenomenon in the fields of epidemiology and public health, play a large role in health inequities within populations (World Health Organization, 2011). Within the field of social determinants of health, epidemiologists use the term “social exclusion” to specifically describe *multidimensional* disadvantage. This term refers to both economic hardship and the process of marginalization that produces such hardship; in other words, the mechanisms that divide the “included” from the “excluded.” Social exclusion has four formal elements: 1) Legal exclusion 2) Exclusion from a failure of supply of social goods or services 3) Exclusion from social production 4) Economic exclusion (Shaw, 1999). A vast body of literature demonstrates that social exclusion is strongly correlated with poor health outcomes over a wide number of metrics (Shaw, 1999). Given the criteria for social exclusion, the transgender population seems to easily fit this rubric.

Social determinants of health and social exclusion are apt concepts for understanding the relationship between the discrimination and hardships faced by transgender people and the current health crisis faced by this population, particularly transgender women. This population faces particularly high rates of HIV/AIDS and mental health problems, including substance abuse. Numerous scholars argue that the social exclusion and stigmatization that transgender people face are directly linked to this health crisis (De Santis, 2009; Lev, 2004). The prominent literature on each of these two significant health issues for transgender adults<sup>4</sup> will be discussed below.

### *Transgender Women and HIV*

Transgender women and HIV has been one of the most studied topics in the field of transgender health. (The other most studied topic is genital surgery.) Several transgender-focused meta-reviews and literature reviews have been published in the last few years that summarize the scientific evidence regarding HIV prevalence, HIV risk behaviors, and the link between commercial sex work and HIV.

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<sup>4</sup> There is a fair amount of literature addressing mental health issues and transgender youth. However, this is beyond the scope of this paper, which is primarily focused on adult health issues.

Herbst's 2008 meta-review of HIV prevalence among transpeople (both male-to-female and female-to-male) includes 29 studies assessing HIV rates in transgender women.<sup>5</sup> That study's meta-analysis found an HIV prevalence of 27.7% (95% confidence interval [CI], 24.8–30.6%) based on four studies which directly tested transgender women for HIV. In the 18 studies utilizing self-report of HIV serostatus, 11.8% (95% CI, 10.5–13.2%) of male-to-female people reported being HIV positive (Herbst, et al., 2008). Study authors note that the studies included in the analysis have a variety of methodological limitations. Foremost is the fact that a majority of the studies sampled respondents using non-probability methods (including convenience and snowball sampling). Thus due to sampling bias persons at high risk for HIV infection may have been overrepresented, ultimately causing an inflation of the prevalence of HIV infection.

Operario's 2008 meta-review analyzed 25 articles reporting on HIV status among transgender women who engage in sex work. Like Herbst's analysis, this analysis included both studies that biologically measured HIV and studies in which participants self-reported their HIV status. Operario's study reports an overall HIV prevalence of 27.3% among transgender women who engage in sex work and 14.7% in transgender women not engaging in sex work. For comparison, that study's meta-analysis found an HIV prevalence of 15.1% in male (cisgender) sex workers, and 4.5% in female (cisgender) sex workers. The study authors found that transgender women who engage in sex work have "significantly higher risk for HIV infection in comparison to all other groups" (relative risk [RR] = 1.46, 95% confidence interval [CI]: 1.02–2.09) (D. Operario, et al., 2008). Study authors note "significant heterogeneity" among the studies analyzed, with numerous methodological limitations (including those discussed by Herbst et al.), including imprecise definitions of both sex work and gender.

De Santis' 2009 literature review addresses the many risk factors that are driving the high rates of HIV in this population. Transgender health researchers have shown through numerous studies, including several meta-reviews, that transgender women engage in behaviors that put them at high risk for contracting HIV. According to De Santis' literature review, these behaviors include needle sharing (Transgender women use needles both to inject drugs as well as to inject hormones and silicone. The exact prevalence of needle use is not known.); use of alcohol and drugs; high risk sexual behaviors, such as multiple sexual partners, unprotected anal intercourse, and sex while intoxicated; commercial sex work, of which the prevalence may be as high as 44%; lack of education about HIV infection and transmission; intimate partner violence, which may make it difficult to negotiate safe sex behaviors; and mental health problems such as low-self esteem, which has been linked with high risk sexual behaviors. As De Santis points out, "A considerable amount of research data collected from members of this population provides a description of each of these risk factors separately, and some in combinations, but a study that has examined all of the risk factors in combination is lacking." In other words, the interplay among these factors is poorly understood (De Santis, 2009). Some research suggests that transgender women are in fact aware of their high-HIV risk behaviors, but HIV prevention is a low priority compared with other concerns (Don Operario & Nemoto, 2010).

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<sup>5</sup> Herbst's review found only 5 studies that also reported the prevalence of HIV among female-to-male people. The number of studies in the literature reporting rates of HIV infection and risk behaviors for transgender men was insufficient for study authors to conduct a meta-analysis. However, it is known that the prevalence of HIV among transmen is low, with estimates ranging from 1-3% (Clements-Nolle, 2001; Sevelius, 2009).

### *Transpeople and Mental Health Issues*

Mental health issues, including depression and substance abuse, are serious problems for many transpeople. Several studies have found a higher prevalence of serious mental health issues, like suicide attempts, in this population compared to other groups. Some authors, such as Lev, argue that the mental health symptoms that many gender-variant people exhibit are “really sequelae to living in a gender binary in which they do not fit” (Lev, 2004). Evidence supports Lev’s theory, with some researchers finding that discrimination and victimization (in a variety of types of populations besides transgender people) are correlated with several types of psychological distress such as anxiety and depression. Others scholars argue that “the distress inherent in gender dysphoria is real, and is not simply a manifestation of social pressure” (Bockting & Ehrbar, 2006). Certainly both of these claims could be true. Unfortunately no comprehensive literature reviews or meta-analyses have been published on the issue of mental health disorders among transpeople, although there are two small reviews of the literature on substance abuse in transgender persons. Below the results of some of the largest and most significant studies assessing mental health among transpeople are summarized.

A study published in 2006, using data collected in San Francisco in 2001, analyzed the independent predictors of attempted suicide among transgender persons. This study included interviews with 392 transgender women and 123 transgender men. The overall prevalence of attempted suicide was 32% (95% CI, 28-36%). In multivariate logistic regression analysis, younger age (<25 years), depression, a history of substance abuse treatment, a history of forced sex, gender-based discrimination, and gender-based victimization were independently associated with attempted suicide. Clements-Nolle et al. conclude that their study results somewhat support the theory, proposed by several investigators, that pervasive societal prejudice underlies elevated rates of suicidal behaviors among transgender persons (as well as other “sexual minorities,” such as gays and lesbians). Study authors advise that future studies should continue to explore the relationships between different forms of societal prejudice and suicidal behaviors (Kristen Clements-Nolle, Marx, & Katz, 2006).

A relatively small 2009 study conducted in Belgium assessed the physical and mental health of 50 transgender women who had undergone sex reassignment. Women included in the study had undergone sex reassignment surgery at least six months prior. Standardized, validated survey tools were used in this study, which allows for ready comparison between transgender and cisgender individuals. Weyers reports “women involved in a relationship tended to show similar physical and mental component summary scores compared with transsexual women not currently involved in a relationship although women in a relationship scored higher for vitality ( $P = 0.049$ ), social functioning ( $P = 0.008$ ) and mental health ( $P = 0.025$ )” (Weyers, 2009). Overall health and well being scores, including mental health scores, were not found to be significantly different from those obtained in a large sample of Dutch-speaking cisgender women in the Netherlands and in a large cohort of American cisgender women, respectively (Weyers, et al., 2009). This study did not measure specific mental health issues, such as suicide or substance abuse. Strangely, the study authors did not comment on the fact that difficulties faced by study participants may differ drastically from those of transgender women in other countries, particularly regarding the availability of health care services and sex reassignment surgery. They also did not comment on the general levels of discrimination and harassment that transgender women may face in Belgium.

A methodologically thorough study published in 2010 examined the mental health impact of interpersonal abuse across the life course of 571 transgender women from the New York City



metropolitan area (Nuttbrock, et al., 2010). In this study, a history of major depression was reported by 54.3% of transgender women. This is almost three times higher than a history of major depression in the general population (19.6%). Nuttbrock's study also found lifetime suicide ideation to be 53.5%, also more than three times higher than the estimate in the general population (13.5%). Lifetime suicide plans (35% of transgender women study participants) and attempts (27.9% of transgender women study participants) were seven to 10 times higher than the corresponding general population estimates (3.9% and 4.6%). This estimate is quite similar to that found by Clements-Nolle et al. in their study. The findings of this study, one of the few which actually assesses both experience of gender-related abuse and mental health outcomes, found that gender-related abuse had the most significant impact on depression during adolescence, but that "in contrast, the impact of abuse on suicidality (while experienced less frequently) remained strong (and may even have increased) during middle age and beyond" (Nuttbrock, et al., 2010). However, the study author cautions that further research is needed to "clarify the different effects of gender-related abuse on different types of psychiatric distress across the life course."

In 2002, Hughes and Eliason published a review of the literature on substance abuse in LGBT populations with a small section on transgender people. The researchers note that "empirical data related to [alcohol and other drug]-use patterns of transgender persons is scant" (Hughes & Eliason, 2002). Hughes and Eliason report on a study of 515 transgender persons in San Francisco, published in 1998, in which 34% of transgender women and 18% of transmen reported lifetime intravenous drug use. Other studies cited in that review found that "rates of substance abuse appear to be high in the transgender community," but did not give summary figures (Hughes & Eliason, 2002). A separate review of the literature, conducted by Lawrence and published in 2008, was focused only on three studies of substance abuse in "transsexuals." Lifetime histories of substance abuse ranged broadly in these three studies: from 11% to 62% for male-to-female transsexuals and 4% to 50% for female-to-male transsexuals (Lawrence, 2008). As Hughes writes, "clearly, much more research is needed to better understand the unique combinations of risk and protective factors associated with substance abuse in transgender persons" (Hughes & Eliason, 2002).

### *Syndemics of Disease and Discrimination Among Transpeople*

In the early 1990s anthropologist Merrill Singer devised the term "syndemic" to describe the mutually reinforcing—that is, synergistic—nature of different health crises. This included public health issues such as violence, substance abuse, and AIDS, which may simultaneously ravage communities subjected to social inequities. Singer's valuable innovation was to "interpret those connections as evidence of a higher order phenomenon," which he called a syndemic. The commonly used definition of syndemic is "two or more afflictions, interacting synergistically, contributing to excess burden of disease in a population" (Milstein, 2004). Syndemic theory is a growing field of research and has become a popular framework for conceptualizing the determinants of HIV disparities in high-risk populations (Don Operario & Nemoto, 2010).

Although the research on violence, harassment, economic discrimination and hardship, HIV/AIDS, substance abuse, depression, and suicidal behavior among transpeople is not exhaustive, it paints a clear picture of a population being ravaged by several different health crises: a syndemic in action. In 2010 Operario and Nemoto published an article making the case that "data from studies of transgender populations in the United States reveal syndemic dynamics that facilitate sexual risk behaviors and HIV transmission" (Don Operario & Nemoto, 2010).

This is the first case in the published literature that uses the term syndemic to describe the current crises of the transgender community. Like many researchers already cited in this paper, Operario asserts that given the complex, layered, and multidimensional processes at work in this population—including significant social and structural factors—complex disease prevention approaches are warranted and indeed, a matter of life and death. This includes multicomponent interventions, involving delivery of both health and social services to achieve meaningful health and quality of life improvements for transgender people. Operario suggests that:

“HIV testing and behavioral–motivational risk reduction counseling offer platforms for bundling other intervention foci and modalities, which might include transgender support groups, brief substance use counseling and treatment referrals, brief mental health counseling and referrals, life skills coaching and training, and other programs that correspond to recognized transgender syndemic dynamics. Intervention components must also consider developmental trajectories in transgender identity, including the needs of adolescents and young adults, and prevention needs that might differ according to gender transformation procedures.” (Don Operario & Nemoto, 2010)

### *What Is the Relationship Between Discrimination and Health?*

Clear evidence demonstrates the discrimination that transgender people regularly endure. For transgender people, the long term effects—in terms of both mental and physical health—of regular exposure to such discrimination is not known, and the psychological and physiological mechanisms by which such discrimination can and do influence various domains of health are likewise not established. A rapidly growing field of research seeks to assess and quantify the effect of “perceived discrimination” on health outcomes, health-related behaviors, and health care-related behaviors for a variety of other populations. Hundreds of studies, mostly although not exclusively focused on the effect of perceived race-based discrimination, have been published on this topic in the last 15 years. Given the breadth of research on this topic, this paper will focus on two comprehensive reviews of the literature—one a traditional literature review and the other a formal meta-analysis—both published in 2009.

The most recent literature review of published articles studying the relationship between discrimination, health, and racism discussed 115 articles published and listed in PubMed between 2005 and 2007. The largest number of studies included in the review assessed the relationship between perceived race-based discrimination and mental health, but five other classes of outcomes (as determined by Williams and Mohammed) were also studied. These include the effect of perceived racial discrimination on blood pressure/hypertension, physiological reactivity, other physical health problems, health care utilization, and substance use and health behaviors. Not surprisingly, these studies “document an inverse association between discrimination and health” (Williams & Mohammed, 2009). The findings in the mental health domain are perhaps most striking, as “almost without exception, studies of discrimination and mental health find that higher levels of discrimination are associated with poorer mental health status” (Williams & Mohammed, 2009). In terms of the categorization of those discriminatory events that are most stressful, the literature suggests that “stressors that are ambiguous, negative, unpredictable, and uncontrollable are particularly pathogenic.” Frequency, duration, and intensity are also important characteristics of discriminatory events.

Williams and Mohammed acknowledge that the shortcomings of the research summarized in the review are quite serious. For example, with respect to studies on mental health and perceived discrimination, the majority of existing studies are cross-sectional in design

and thus mental health status may have *resulted* in findings on perceptions of discrimination, rather than vice versa. Williams and Mohammed point out that longitudinal and prospective studies must be conducted to clarify the nature of the relationship between discrimination and mental health. The studies included in these authors' review also measure discrimination using a problematically wide array of tools. They emphasize that "there is no consensus on an optimal measure of perceived discrimination," and urges researchers to determine ways to more systematically and comprehensively quantify discrimination and its interaction with other aspects of racism, as well as other life stressors, to ultimately change health outcomes. Williams even goes a step further to state that "our review finds that failure to comprehensively and accurately characterize perceived discrimination and appropriately assess its association with health will lead to erroneous conclusions about the underlying relationship" (Williams & Mohammed, 2009). Perhaps most relevant to the study of transgender people, Williams implores researchers that in order to measure discrimination comprehensively, "more explicit attention" must be paid "to assessing the relevant forms of its manifestation in specific contexts." The pathways by which discrimination can affect health are particularly poorly understood, and Williams and Mohammed call for further research elaborating on possible mechanisms whereby discrimination affects health.

A second review article published later in 2009 is a formal meta-analysis of published or in-publication articles assessing the relationship between perceived discrimination and various health metrics. Pascoe and Smart Richman's meta-review analyzed data from 134 articles, published between 1986 and 2007. Like in Williams and Mohammed's review, the largest proportion of articles focuses on race-based discrimination (66% of articles in the meta-analysis), but the analysis also includes articles measuring gender discrimination (17% of articles in the meta-analysis), sexual orientation discrimination (6%), or unspecified discrimination and unfair treatment (15%). But the author acknowledges that not all discrimination is created equal—and it is quite possible that "different types of discrimination are related to different outcomes, with some having more detrimental effects than others." Like Williams and Mohammed, Pascoe and Smart Richman found that a wide variety of tools were used to assess discrimination, but that across discrimination of all kinds "studies generally contained scales or questions regarding perception of discrimination within a variety of domains, such as poor service and treatment in public situations, derogatory comments, and harassment" (Pascoe & Smart Richman, 2009). The meta-analysis found that, "when weighting each study's contribution by sample size, perceived discrimination has a significant negative effect on both mental and physical health." Specifically authors find that the perception of discrimination "is related to heightened physiological stress responses, more negative psychological stress responses, increased participation in unhealthy behaviors, and decreased participation in healthy behaviors" (Pascoe & Smart Richman, 2009). All of these mechanisms are "promising avenues" for studying the pathway between perceived discrimination and changes in health. Overall, Pascoe and Smart Richman note many of the same methodological shortcomings in this field of research as Williams and Mohammed, and likewise encourages more prospective studies.

Perhaps of most relevance to this paper is Pascoe and Smart Richman's summary of the influence of covariates that may or may not moderate the discrimination/health link. Significant findings include the fact that "social support was more likely to buffer the relationship between perceived discrimination and negative mental health," but that these outcomes varied depending on the "type of social support sought, the specific health outcome studied, or the amount of discrimination stress experienced by individuals" (Pascoe & Smart Richman, 2009).

Furthermore, research has found that not all coping behaviors are equally effective in moderating the effect of perceived discrimination on health, and “conditional research suggest that the most effective way of coping with discrimination stress may vary by ethnicity, culture and gender.” Pascoe urges further study of this issue of discrimination mediators.

This expanding field of research on the relationship between experiences of discrimination, health, health-care utilization, and health-related behaviors can be readily applied to understanding transgender people. Given the increasingly well-established relationship—albeit perhaps with a poorly understood mechanism—between perceived discrimination and problems in a wide variety of areas, it follows that many transgender people’s physical and mental health is likely affected by perceived discrimination. To their credit, authors of both of the reviews mentioned in this paper make it clear that not all discrimination is equal, and that in fact there is overall a failure of discrimination measures to take into account all of the variables that may be involved in discrimination for any particular population. Nevertheless, Pascoe and Smart Richman’s remark that “Although the expression of outright discrimination has been greatly reduced in recent decades, more subtle and chronic forms of discrimination are still very real for certain groups in our society” demonstrates a clear lack of familiarity with the extraordinarily high levels of discrimination—including overt harassment and even hate crimes—that transgender people regularly face.

Given this context, it seems that development of tools that would thoroughly and specifically assess perceived transgender-based discrimination, and then the use of those tools to begin to quantify the role of discrimination in this population’s overall health, would greatly benefit our knowledge of transgender health. Williams and Mohammed poetically concludes their study by reminding readers that “as research continues to accumulate evidence that perceived discrimination can lead to adverse changes in health,” further effort must be made in “dismantling the institutional structures, processes, and policies that undergird societal racism” (Williams & Mohammed, 2009). The same statement could be made about discrimination that transgender people commonly endure.

#### *The State of Transgender Health Research: The 2011 Institute of Medicine Report*

In 2011, the Institute of Medicine released a comprehensive report on the state of health research on the LGBT community, entitled *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. The authors of this report reviewed hundreds of studies in order to compile a comprehensive set of recommendations to guide further research. Overall, study authors found that most research on LGBT persons uses nonprobability samples, and calls for more probability based research, while still acknowledging the difficulty of using probability-based methods on relatively small sectors of the overall U.S. population. The report also shines light on the fact that a lack of standardized measurements of sexual orientation and gender nonconformity is a barrier to conducting comprehensive research, while also acknowledging that “because of concerns about stigma and privacy, individuals may be reluctant to answer research questions” about their sexual orientation or gender identity (Institute of Medicine, 2011).

Regarding transgender issues specifically, the Institute of Medicine identifies a range of stark absences in the research literature, concluding that “all aspects of the evidence base for transgender-specific health care need to be expanded.” For example, “no evidence-based HIV prevention interventions have been identified as effective for members of the black transgender community,” despite high rates of HIV among this population; “little research has examined the

prevalence of mood and anxiety disorders” among transpeople, despite solid evidence that suicidal ideation is common; long term health outcomes research with transgender people is very limited, “although some studies suggest that long-term hormone use may increase the risk for cancer;” and finally, “very little research has been conducted on the quality of care experienced by sexual and gender minorities” (Institute of Medicine, 2011). Of relevance to this paper, the report does note that “limited data” suggest that in fact transgender people receiving trans-specific care from knowledgeable providers are highly satisfied with those services.

### III. Transgender Health Care Experiences

#### *Health Needs and Health Care for Transgender Patients*

Thus far this paper has reviewed the literature on discrimination and harassment experienced by transpeople outside of the health care setting, and has addressed some of the major public health problems of this population—namely, high rates of HIV and mental health problems. But what is the situation that a transgender person encounters when they seek health care? And what unique needs do they bring to the health care situation? This section will address the literature focused on these topics.

Transgender people have unique health needs. In addition to the health needs that all people have, transgender people have two other separate categories of needs. The origin of these needs is two-fold. One set of needs stem from being transgender itself. Most, although not all, transgender people desire either hormonal and/or surgical treatment as part of their transition from their assigned gender to their chosen gender. These hormones, often referred to as “gender confirming hormone therapy,” and surgical treatments can be used to masculinize or feminize the person’s appearance (Williamson, 2010). Like all medical treatments, hormones and surgeries do come with risks, to which providers need to be sensitive (Feldman & Bockting, 2003). As part of the transition process many people will also receive mental health services both to gain approval to receive hormonal or surgical treatment and to deal with the mental health issues that may be exacerbated by their gender dysphoria (Bockting, Robinson, Benner, & Scheltema, 2004). Second, in many cases transgender persons require services to deal with health issues that arise as a consequence of the discrimination, harassment, or rejection (by family, social network, etc.) they may have faced for being transgender.

#### *A Story of Unmet Need: Transgender People and Health Care*

A significant body of evidence demonstrates that many transgender people have difficulty meeting their healthcare needs in almost all categories. Lev’s assessment of the state of health care for transgender people is stark: “Virtually every area of health and human service care is deficient regarding gender-variant people” (Lev, 2004). Many different types of studies, including studies of discrimination as well as more general needs assessments, confirm the picture that Lev paints. Summarizing the findings of these studies is challenging because they vary widely in their scope, study objectives, and methodologies. Even the study populations vary, with some studies assessing only transwomen, some assessing only transmen, some assessing all transpeople and gender-nonconforming people, and so on. This difficulty in defining the population is a fundamental barrier to accurate assessment of their needs, and ultimately contributes to a lack of data about transpeople. Many studies assess both health services utilization, health-related behaviors, and discrimination, while others are more traditional public health-focused needs assessments. As a further challenge, no meta-reviews summarize the state of this population’s current overall health status and health care services utilization. Given these disparities, each article will be discussed individually, and direct comparisons across studies are not appropriate. Many of the medical issues that frequently come up in the literature have already been discussed in this paper, such as HIV/AIDS, suicide, and violence.

The largest and most comprehensive study available assessing discrimination against transgender people was released in 2011 by the National Center for Transgender Equality (NCTE), the nation’s largest advocacy organization working on behalf of transgender and

gender-nonconforming people. This study, of more than 7,500 people—75% of whom identified as transgender and 25% of whom identified as gender-nonconforming—is the most extensive survey of transgender discrimination ever undertaken (Grant, et al., 2011). (Non-health care-related results of this study are discussed earlier in this paper.) The study assessed a variety of health-related metrics, including discrimination in the health-care setting, rates of health care usage, and health-related behaviors in the study population. As is typical of studies conducted by advocacy organizations, the results were released directly by the organization, rather than in a peer-reviewed journal. With respect to discrimination, nearly one in five (19%) of respondents reported that they were refused medical care due to being transgender or gender-nonconforming. Rates of discrimination were higher among people of color and among transgender women (compared to transgender men). Study participants also stated that they postponed medical care when sick or injured due to fear of discrimination (28%). With respect to health-related behaviors, 30% of study participants reported smoking tobacco daily or occasionally, compared to 20.6% of U.S. adults. Despite these barriers, 76% of transpeople surveyed were able to access hormone therapy, which study authors conclude indicates “a determination to endure the abuse or search out sensitive medical providers” (Grant, et al., 2011). However, it is not clear in the study results what proportion of the 76% of transpeople accessing hormone therapy always accessed it through health care providers, or the frequency with which it was accessed through other means, such as friends or the internet.

Participants in many other studies have also reported that they have been denied health care due to their transgender status. One such study, published in 2005, summarizes the results of a needs assessment conducted in Philadelphia in 1997. This study included surveys with 113 male-to-female individuals and 69 female-to-male persons. In this study, 26% of respondents reported that they had been denied medical care because they were transgender (G. P. Kenagy, 2005). Among transmen, 58.7% reported that they had a doctor, and 71.8% of transwomen reported the same. Overall rates of having a doctor were higher among whites (83.1%) than people of color (59.5%), again highlighting the intersection of race and gender to produce an even more difficult situation for transpeople of color. Many participants in this study also reported that they had difficulty accessing dental care (72%).

A methodologically identical study conducted by the same researcher in Chicago in 2001, and published in 2005, included 78 male-to-female and 33 female-to-male participants. In this study, 72% of participants reported they had a doctor. Twelve percent of participants said they had been refused routine medical care because of their transgender identity, and 23% stated they had been refused transgender-related medical care. Among study participants, top service needs were dental care (36%) and health care (31%). Legal services, education, and job training were also reported as highly needed (G. Kenagy & Bostwick, 2005).

A study conducted in San Francisco focused on the health needs, service utilization, and perceived barriers to services among male-to-female transpeople of color. The study entailed focus groups with a total of 48 participants and 332 survey interviews. The focus groups revealed “persistent dissatisfaction with existing service programs” among the study population, as well as “frequent references to biased and insensitive staff and clients” (Nemoto, Operario, & Keatley, 2005). Discontent with health care services was divided into four factors, including inadequate programs, inadequate spaces and facilities, staff’s insensitivity toward transpeople’s issues, and “prejudice expressed by other clients.”

Unlike in some other studies, participants in the quantitative portion of Nemoto’s study reported fairly high levels of access to or use of most health services, likely attributable to the

fact that numerous transgender-specific clinics exist in San Francisco. The least available service in this study was substance abuse treatment. The vast majority of participants who stated that they needed substance abuse treatment in the last year were not able to access it (79%). Impressively, 88% of participants who reported needing counseling services accessed them, and 98% of participants needing STD screening were able to access those services. With respect to access to gender-related medical treatment, 91% of study participants had received hormone therapy, and 75% were currently using hormones. Nemoto found that perceptions of barriers to health care showed ethnic disparities, with Latina transgender women reporting a higher rate of perceived barriers to health care and drug treatment. Perceived barriers to health services were “significantly associated with increased depression, transphobia, economic pressure, and lower self-esteem, as well as with health risks such as lower self-efficacy to use condoms with private partners and increased unprotected receptive anal sex with private partners” (Nemoto, et al., 2005). Study authors do specifically point out that their findings pointed to strengths among health and social services for this population in San Francisco, with participants in multiple focus groups specifically praising some programmatic efforts.

### *Improving Transgender Health Care: Advice from the Experts*

In the face of significant evidence of discrimination and barriers to accessing health care, many researchers and health care providers have published guidelines for how to better serve transgender patients. These guidelines are often informed by years of experience working with transpeople in either a service or scholarly capacity. Although nearly a dozen or so such articles exist, many recommend similar changes.

Emilia Lombardi is a leading transgender health researcher and professor of infectious diseases and microbiology at the University of Pittsburgh. She has lectured and written extensively on best practices for working with transgender persons (E. Lombardi, 2001, 2007). Her 2007 piece discussed specific solutions to address the problem she describes as “genderism,” which refers to “how a person is ascribed a gender and to the response people have to any individual who fails to fit within their normative understanding of men and women,” resulting in “the policing of gender identities and expression” (E. Lombardi, 2007). The solutions she proposes for more sensitive, respectful, and inclusive care for transpeople include “an explicit, open-ended option for any sex/gender information” on intake forms; that health care providers respectfully ask patients which pronouns they prefer; that rehabilitation and shelter facilities work to accommodate the needs of transgender clients and patients; that staff and providers are explicitly trained in working with transgender patients and have ongoing access to information about working with transpeople; that clinic leaders “make it known that discrimination against any client would not be tolerated;” and to publicly post nondiscrimination policies that refer to gender identity and expression explicitly.

Researchers and advocates from the Center of Excellence for Transgender Health, a program within the University of California, San Francisco, are focused on researching and promoting the provision of “comprehensive, effective, and affirming health care services for trans and gender-variant communities.” They have published guidelines for effective data collection on transpeople, and specifically recommend asking two questions (instead of one) to “both validate a person’s present gender identity and also understand their history” (Sausa, Sevelius, Keatley, Iñiguez, & Reyes, 2009). These questions include one about the patient’s sex or current gender (with the possibility to check more than one box or to “decline to state”), and one about the patient’s assigned sex at birth (with the option to “decline to state”). Like



Lombardi, Sausa et al. recommend not just changing the intake and study enrollment forms, but to also train staff in working with transgender persons, to widely advise health departments and other agencies to similarly update their databases, and to disseminate information on transpeople gathered through research and ultimately to use this data to improve services for this underserved population.

These resources, as well as other publications by health departments, transpeople, and physicians, provide a clear framework for improving service provision for transpeople.

### *Mistreatment of Transgender Patients in the Health Care Setting: Where Are the Specifics?*

The largest, most comprehensive, and most recent study available, like the many smaller studies presented, paints a picture of a population that is routinely denied medical treatment or even delays seeking treatment due to fear of discrimination. However, despite significant evidence transgender people are discriminated against in the health care setting, few studies have focused on understanding the specific types of negative events happening and the effect of such events on transgender people's mental health, physical health, health-related behaviors, and health care-seeking behaviors. The National Center for Transgender Equality (NCTE) study documented important findings about harassment and violence in the medical setting, and these findings will be reviewed shortly. Three qualitative studies also uncover important themes in the mistreatment of transgender patients through their direct exploration of the health care experiences of transpeople.

The NCTE study, discussed earlier in this paper, included surveys with more than 7,500 transgender and gender-nonconforming persons. Verbal harassment in a doctor's office, emergency room, or other medical setting was reported by 28% of respondents. Two percent of respondents stated that they were physically attacked in a doctor's office (Grant, et al., 2011). Populations reporting the highest rates of physical attack in a doctor's office or hospital were unemployed persons, African-Americans (of whom 6% reported they had been attacked in a doctor's office), and persons who had done sex work or drug sales. Attacks in the emergency room were reported by 1% of study participants, with rates highest among undocumented persons (6%), persons who had engaged in sex work or drug sales (5%), unemployed persons (4%), and Asian respondents (4%). Although it includes no formal qualitative component, this study includes quotes from numerous transpeople in its pages. These quotes include experiences of being made fun of by staff at a suicide center; being forced to have an unwanted pelvic exam after seeing a doctor for a sore throat and then having other staff examine the patient's genitals; and rarely or never disclosing their transgender status to health care professionals.

A qualitative study comprised of four focus groups, interviewing a total of 34 transgender people, assessed access to health care in Boston. One focus group included adult transwomen, another adult transmen, another young (under age 25) transmen, and one young (under age 25) transwomen. Published in 2005, this needs assessment found "a system that was anything but high quality in meeting the needs of [transgender and transsexual] individuals," and details many of the specific problems in health care as they are experienced and explained by transgender patients (Sperber, Landers, & Lawrence, 2005). Every focus group included participants who stated they had encountered "humiliating treatment from providers" and "outright refusal to provide services." Specific descriptions of a handful of negative incidents in the study participants' own words are included in the article. Study participants reported that they frequently encountered health care professionals who will not treat them and "blatantly say so." Participants also expressed concern about lack of provider training in working with transgender

patients, including unwillingness to use a transperson's requested pronoun in addressing the patient, as well as lack of substantive knowledge on providing gender confirming hormonal therapy, gynecologic care, and HIV prevention counseling. Participants were divided in their approach to disclosure of their transgender status. Some study participants felt that they should and would disclose that they were transgender only a "need-to-know basis," out of concern for protection of their privacy and safety. At least one participant stated that due to past negative health care experiences he disclosed that he was transgender only a very selective basis. However, other study participants felt that disclosure to health care professionals was imperative to ensure high quality medical care. In summary, "the lack of provider training on transgender issues creates insensitivity to simple issues of respect for trans people," and "based on past experiences, [transgender and transsexual] people mistrust providers and expect not to be listened to in a health care setting" (Sperber, et al., 2005).

A qualitative study published in 2008 examined transgender and transsexual-identified patients and their involvement with health care professionals in the Midwestern United States. The study included data from 22 in-depth interviews and a year of participant observation conducted by the study author at three different trans-focused organizations. Almost all of the study participants were transgender women. Dewey found that although most participants in the study did not report outright refusal of medical treatment (although some did), "many sense a discomfort with their medical encounters" (Dewey, 2008). The article includes numerous reports of specific incidents in the words of the participants. Like Sperber, Dewey concludes that many of the study participants do *not* expect medical attention as a right and some even "believe their requests [for medical care] are perhaps inappropriate or unreasonable." Dewey asserts this is not surprising given the stigma that transpeople face, and found that some study participants distinguished between the doctor's "job of treating their medical condition from how doctors treat them as a person" as a way of understanding their uncomfortable health care experiences (Dewey, 2008).

A third qualitative study, published in 2009 by Bauer, is part of a larger project in Ontario, Canada, "that aims to broadly understand how social exclusion impacts the health of trans people" (Bauer, et al., 2009). A total of 85 persons were interviewed in seven semi-structured "community soundings" (similar to focus groups) ranging in size from 3 to 27 participants. Data on the current gender identities of participants is not given, but a wide range of gender identities (woman, genderqueer, male-to-female, bigendered) was represented, as well as a range of socioeconomic statuses. The vast majority of participants (84.6%) were Canadian citizens. Major thematic concerns with health care were similar to those in the other studies discussed in this paper. Transgender study participants experienced "income instability, barriers to accessing trans-inclusive health care services, [a] lack of relevant and accessible information, systemic social service barriers, self-esteem and mental health issues, challenges to finding help, and relationship and sexual health concerns." Participants also recounted "pervasive and diverse experiences of transphobia" in their interactions with health care.

Bauer goes somewhat beyond the other authors to devise and develop a theoretical framework including processes of "institutional erasure" and "informational erasure," whereby systems are fundamentally not equipped to deal with transpeople, often causing great distress for members of this population and putting the onus on transpeople themselves to change such systems. "Informational erasure" essentially concerns the fact that most institutions, including research establishments, are strongly cisnormative and thus do not even include spaces for identification of trans participants/clients or specific issues relevant to transpeople. Through this

process transpeople's experiences are systematically excluded from institutional knowledge production, resulting in a lack of formal information about transpeople. Authors found that "this pervasive absence of information, along with stunted knowledge production and dissemination, greatly affect the ability of trans people to access health care services" (Bauer, et al., 2009). Many first person accounts of problematic health care experiences are included in this article, giving the reader a real sense of the experience of transgender people in seeking health care in the Ontario area. "Institutional erasure" is described as a lack of policies accommodating transpeople. This is actualized through the lack of means to identify transpeople on "referral forms, administrative intake forms, prescriptions, and other documents." Both forms of erasure were characterized as either passive, wherein there is a "lack of knowledge of trans issues and the assumption that this information is neither important nor relevant," or active, wherein the transgender person experiences "a range of responses from visible discomfort to refusal of services to violent responses that aimed to intimidate or harm" (Bauer, et al., 2009). Bauer ultimately concludes that cisnormativity (the assumption of cissexuality, e.g. that all people born male will grow up to identify as men) underlies the processes of erasure. Given cisnormativity, health care personnel and systems are essentially unprepared for the reality of transpeople, and have taken insufficient actions to accommodate them. Bauer concludes with specific recommendations for including transpeople in institutional and information contexts.

As evidenced by the literature, there is sound and compelling documentation that discrimination is occurring in the health care setting, and that the lack of services is widespread in several major American cities. However, very few studies have specifically addressed the exact nature of negative health care experiences or the impact of these experiences on the various domains of individual and community health and related behaviors.

#### *Broader Literature Assessing the Impact of Negative Health Care Experiences*

Transgender participants in several studies discussed in this paper stated that they delayed or failed to seek medical care due to previous negative experiences in the health care setting. Furthermore, hundreds of studies on perceived discrimination *outside* of the health care setting reviewed earlier in this paper demonstrate that perceived discrimination is negatively linked to physical and mental health. A small number of studies assess the specific effects of negative health care experiences on a variety of populations.

In 2003 the Institute of Medicine released a mammoth study entitled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. The committee authoring the report reviewed more than 100 studies assessing the health care of various minority groups, and "was struck by the consistency of research findings: even among the better-controlled studies, the vast majority indicated that minorities are less likely than whites to receive needed services, including clinically necessary procedures" (Institute of Medicine, 2003). The report discusses structural factors (e.g. wealth disparity, immigration status) that contribute to this disparity. However, of relevance to this paper is the Institute of Medicine's finding that "indirect evidence indicates that bias, stereotyping, prejudice and clinical uncertainty on the part of healthcare providers may be contributory factors to racial and ethnic disparities in health care." In other words, the Institute of Medicine acknowledged that provider-side issues play a role in poor health outcomes. However, relatively little evidence to this end is discussed in the report.

A study conducted in 2001 used health care surveys with a diverse population of 6,722 adults living in the United States to assess patient reports of disrespect in the health care setting and its impact on health care utilization (Blanchard & Lurie, 2004). The measures of disrespect

used were: feelings of being treated with disrespect or being looked down upon, a belief that unfair treatment was received due to race or language spoken, and a belief that better treatment would have been received had the respondent been of a different race. These measures of disrespect were correlated with various measures of health care utilization, including receipt of a physical exam within the prior year, receiving necessary health screenings, delay of needed care, and not following the doctor's advice. Authors found that minority patients, including blacks, Hispanics, and Asians, were significantly more likely to report being treated with disrespect or being looked down upon in the patient-provider relationship. People who thought they would have received better treatment if they were of a different race had suboptimal levels of health care utilization in several metrics, including that they were less likely to receive optimal chronic disease screening and more likely to delay care or not follow a doctor's advice ( $P < 0.01$ ). The study authors concluded that perceptions of disrespect and unfair treatment are prevalent and that these perceptions do influence health care utilization, and "may contribute to existing health disparities" (Blanchard & Lurie, 2004).

A study published this year assessed continuity of cancer screening among 313 Latino and white women who reported healthcare mistreatment (Betancourt, Flynn, & Ormseth, 2011). Mistreatment was quantitatively assessed using an 11-item "perceptions of interpersonal healthcare mistreatment scale," which "represented instances of healthcare mistreatment as reflected by a lack of respect, privacy concerns, and communication issues" (Betancourt, et al., 2011). The scale assessed both exposure to mistreatment and the intensity of any perceived mistreatment. Authors found that for white women, a stronger perception of mistreatment was negatively related to screening continuity. However, in the group of Latina women study participants, it was not perception of mistreatment per se but rather *anger at mistreatment* in the healthcare setting that was negatively related to continuity of care. Study authors conclude that more research needs to be done to fully explore how psychological effects mediate the relationship between perceptions of mistreatment and health care utilization.

These two studies clearly do not represent an exhaustive review of the literature on the effect of mistreatment, although very few studies assess the role of negative health care experiences on health. However, they confirm that perceptions of mistreatment *do* affect health care utilization. It follows that further understanding transpeople's negative experiences in health care may also help to understand their health care-related decisions.

#### IV. Regulations Protecting Transgender People from Harassment and Discrimination

##### *Ethics Codes of Health Care Professionals: Which Regulations Protect Transgender Patients?*

Legal, ethical, and professional frameworks can guide our understanding of the rights of transgender people in the health care setting. Most health care professional groups maintain codes of ethics. This includes the American Medical Association's *Code of Medical Ethics*, American Nurses Association's *Code of Ethics for Nurses*, American Academy of Physician Assistants' *Guidelines for Ethical Conduct for the Physician Assistant Profession*, and so on. Each of these ethics codes—which are updated and reviewed regularly by boards within the corresponding professional organizations—contains dozens of guidelines dictating standards of ethical and professional behavior. Within these codes, various specific regulations prohibit discrimination and harassment against gender-nonconforming patients.

In the American Medical Association's *Code of Medical Ethics*, Opinion 9.12, "Patient-Physician Relationship: Respect for Law and Human Rights," dictates that "a physician may decline to undertake the care of a patient whose medical condition is not within the physician's current competence. However, physicians who offer their services to the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, *gender identity* [emphasis added], or any other basis that would constitute invidious discrimination" (American Medical Association Council on Ethical Judicial Affairs, Southern Illinois University at Carbondale. School of, & Southern Illinois University at Carbondale. School of, 2008). This provision is significant in that it specifically mentions "gender identity" as a protected trait. In other words, physicians cannot decline to accept patients simply because they are transgender.

A second regulation within the *Code of Medical Ethics*, Opinion 9.123, entitled "Disrespect and Derogatory Conduct in the Patient-Physician Relationship" states that:

The relationship between patients and physicians is based on trust and should serve to promote patients' well-being while respecting their dignity and rights. Trust can be established and maintained only when there is mutual respect. Derogatory language or actions on the part of physicians can cause psychological harm to those they target. Also, such language or actions can cause reluctance in members of targeted groups to seek or to trust medical care and thus create an environment that strains relationships among patients, physicians, and the health care team. Therefore, any such conduct is profoundly antithetical to the Principles of Medical Ethics (American Medical Association Council on Ethical Judicial Affairs, et al., 2008).

In fact, the language in this code is particularly relevant given the evidence that some transgender persons are delaying or foregoing medical care due to past experiences with discrimination.

The American Medical Association has gone beyond these two provisions in its protection of transgender persons' right to health care. To further elucidate its stance on gender identity and discrimination, in 2008 the American Medical Association passed a resolution officially supporting "public and private health insurance coverage for treatment of gender identity disorder" (American Medical Association Council on Ethical Judicial Affairs, et al., 2008). The American Medical Association also states in its resolution entitled "Civil Rights Restoration" that "there is no basis for the denial to any human being of equal rights" because

of their transgender status (American Medical Association Council on Ethical Judicial Affairs, et al., 2008).

Although the American Medical Association has demonstrated political dedication to the issue of protecting transgender rights, this seems to be of largely symbolic import. The teeth of anti-discrimination protection for gender-nonconforming persons lie in local, state, and federal anti-discrimination legislation and court rulings.

### *Legal Protections for Transgender Persons*

While it is fairly clear based on the aforementioned codes of ethics that physicians cannot ethically harass or discriminate against transgender patients, the area of legal protections for gender-nonconforming people is far murkier. A growing body of literature is devoted to the issue of “transgender rights.” Three legal scholars published a compilation of essays on this issue in 2006, entitled *Transgender Rights*. A key question these authors raise is “Why transgender rights?” given that conceptually the general concept of gender equality already includes gender nonconforming people (Currah, Juang, & Minter, 2006). In practice, though, many institutions have failed to include transpeople within the principle of gender equality. Currah et al. argues that it is for this reason that the transgender movement has been more closely allied with lesbian, gay, and bisexual political movements than feminism.

Specific legal arguments for the protection of transgender people’s rights are varied, and include arguments regarding sex discrimination, disability discrimination, and human rights. Judicial findings have historically been mixed, with some courts holding that transgender people are protected by laws prohibiting sex discrimination and others holding that they are protected by laws prohibiting disability discrimination (Currah, et al., 2006). Many courts have not upheld such findings—instead finding that transgender people are not a protected class—and thus transgender advocates have turned to legislative means of ensuring that nondiscrimination laws “should and do include gender nonconforming people” (Currah, et al., 2006). The first such anti-discrimination law that specifically included protection on the basis of gender identity was passed in Minnesota in 1975, and other laws have since been passed in eight states, including California. According to Currah, as of 2006, nearly a third (30%) of the U.S. population lived in jurisdictions with transgender rights legislation.

Since 1990, federal disability antidiscrimination laws have specifically *excluded* protection for transsexualism and “gender identity disorder not resulting from physical impairments” (Levi & Klein, 2006). However, courts or administrative agencies in at least seven states have upheld protections for transpeople on the basis of state disability laws (Levi & Klein, 2006). But many people—in and out of the transgender community—are “profoundly uncomfortable” with using a disability explanation for transgender rights. This is particularly because it perpetuates the notion that transpeople are “disabled” in the colloquial sense of the word, even though the legal definition of disability differs vastly from the colloquial one. In fact, state disability discrimination laws protect people with a wide range of health conditions. Levi argues that most of the reservations about using disability protections as a basis for antidiscrimination rights for transpeople stem from misinformation about disability laws and that in fact use of disability protections is a useful method for protecting transpeople (Levi & Klein, 2006).

### *A Human Rights Approach to Transgender Rights*

In the last decade, most of the major international human rights organizations such as Amnesty International and Human Rights Watch have committed to protection of LGBT persons (Marks, 2006). Historically, the discrimination and harassment that transgender people face when seeking health care services can be characterized as human rights violations on at least two grounds. Article 5 of the Universal Declaration of Human Rights states that no one should be subjected to degrading treatment, and Article 25 asserts the human right of access to medical care. As numerous authors and legal experts conclude in the gender identity literature, transgender rights are human rights (Currah, et al., 2006). The primary issue is one of universality: all persons deserve protection of their basic human dignity.

In 2007, protection of sexual orientation and gender identity was formalized into the Yogyakarta Principles on the Application of Human Rights Law in Relation to Sexual Orientation and Gender Identity (known as the Yogyakarta Principles). Intended as “coherent and comprehensive identification of the obligation of states to respect, protect, and fulfill the human rights of all persons regardless of their sexual orientation or gender identity,” the 29 principles are considered an explication of rights that are *already* outlined in other major human rights treaties, such as the Universal Declaration of Human Rights (O’Flaherty & Fisher, 2008). Simply stated, the Yogyakarta Principles are not considered a new set of human rights, but rather a full explanation of the protections that can already be extrapolated from central human rights documents. The principles had several intended purposes, including serving as a resource for local and national governments as a guide to policy-making, and to eliminate any confusion about the rights for LGBT persons included in current human rights law (O’Flaherty & Fisher, 2008).

Of the 29 principles, two deal directly with rights to health and health care. Principle 17, “The Right to the Highest Attainable Standard of Health,” affirms “Everyone has the right to the highest attainable standard of physical and mental health, without discrimination on the basis of sexual orientation or gender identity.” Principle 18, “Protection from Medical Abuses,” states that “No person may be forced to undergo any form of medical or psychological treatment, procedure, testing, or be confined to a medical facility, based on sexual orientation or gender identity. Notwithstanding any classifications to the contrary, a person’s sexual orientation and gender identity are not, in and of themselves, medical conditions and are not to be treated, cured or suppressed.” In combination, these two principles make it clear that a human rights approach to the issues presented in this paper—such as the right to health care and the right not to be pathologized for being transgender—is a useful framework.

#### **IV. Looking Ahead: What Are the Negative Health Care Experiences of Transgender Women?**

As this paper has demonstrated, transgender people face significant hurdles in almost every area of life, from school to employment to family relationships. They are deeply stigmatized in our society, and encounter transphobia in a variety of settings. The health issues associated with the syndemic of problems that many transgender people face—most especially transgender women—are significant, including high rates of HIV/AIDS, substance abuse, and attempted suicide. A sizeable body of research has focused on the issue of high rates of HIV/AIDS. A smaller (but still respectable) body of research has assessed the mental health of persons in this population.

Despite their significant health needs, several studies have documented that approximately one in four transpeople (exact figures vary in different studies) report experiencing discrimination in the health care setting. A few studies have even reported outright physical abuse or verbal harassment in medical settings. Studies have found that transgender participants have delayed or failed to seek needed medical care in part due to past experiences with discrimination and/or fear of future discrimination and/or harassment. A rudimentary body of research has assessed the general relationship between negative health care experiences and subsequent health care utilization, although the few studies reviewed in this paper did find that perceived discrimination is negatively associated with health care utilization.

No single study has focused solely on negative health care experiences among transpeople. Given that transgender women currently face a more severe health crisis than transmen—particularly with respect to high rates of HIV/AIDS—we propose a study qualitatively investigating the health care experiences of adult transgender women in San Francisco, with a focus on understanding mistreatment and negative experiences in the health care setting. Qualitative methods are appropriate given that relatively little quantitative data exists on this subject, and given that at this time a depth of understanding about how individuals perceive mistreatment and their understanding of their response to this mistreatment is in order.

For this qualitative research study twenty to thirty participants will be recruited from multiple venues (e.g. transgender clinics and community resource centers). Participant referral will also be used to increase access to those people who may not utilize clinic-based services. *Self-identification* as a transgender woman, or male-to-female transgender person, will be the primary inclusion criteria. Participants must be English-speaking. In order to ensure that participants bring a relatively long history of medical treatment to the interview, study participants must be at least 25 years old. Subjects will participate in a confidential approximately one-hour semi-structured qualitative interview in which they will discuss their health care experiences. All interviews will be digitally recorded. Subjects will receive \$30 for their participation. Interview tapes will be transcribed. Transcripts will be coded using the software program Atlas.ti. Data will be analyzed using grounded theory in order to construct a framework of understanding the health care experiences of this population, with a focus on understanding mistreatment by health care providers.

The immediate goal of this project is to document and understand the specific forms of mistreatment in the health care setting affecting this population. Such information can be used to drive quantitative research establishing the epidemiologic prevalence of such experiences, including the development of transgender-specific measures of negative health care experiences and perceived discrimination. Given that currently information on negative health care



experiences has been released primarily by an advocacy group, additional peer-reviewed research is critical to document the mistreatment of transgender patients in the health care setting. Such research would further justify the provision of gender sensitivity and ethics training among health care providers. Understanding negative health care experiences and health professional misconduct is also part and parcel of a human rights approach to health care, in which all persons are entitled to treatment with dignity and respect.

## Original Research: Background

### *Introduction*

Hundreds of studies have documented the negative impact of perceived societal discrimination on health. The majority of these studies focused specifically on understanding the effect of racial discrimination. Literature reviews summarizing this body of work conclude that there is an inverse relationship between discrimination and health (Pascoe & Smart Richman, 2009; Williams & Mohammed, 2009). Some studies have found that mental health, in particular, is negatively associated with perceptions of discrimination. However, a much smaller number of researchers have attempted to address the impact of perceived discrimination *occurring in the health care setting itself*. In general, studies report that racial and ethnic minority patients are significantly more likely to report being treated with disrespect or being discriminated against by their clinicians than white patients (Blanchard & Lurie, 2004; Sorkin, Ngo-Metzger, & De Alba, 2010). Another study found that HIV-positive adults are also likely to report discrimination in the health care setting (Schuster, et al., 2005).

The impact of discrimination in the health care setting has yet to be fully characterized in the literature. While some authors have found that discrimination in the health care setting is associated with underutilization or delay of needed care (Blanchard & Lurie, 2004; Burgess, Ding, Hargreaves, Van Ryn, & Phelan, 2008), or delaying filling needed prescriptions (Van Houtven, et al., 2005), another author found no statistically significant independent relationship between perceived negative discrimination and the utilization of standard preventive health services (L. Hausmann, Jeong, Bost, & Ibrahim, 2008). Further research has shown that perceptions of past racism and classism in health care may negatively impact the tone of subsequent patient-provider communication (L. R. M. Hausmann, et al., 2011).

The last decade has seen a dramatic increase in health-related research on transgender people, a stigmatized group that endures a high burden of discrimination. “Transgender” is an umbrella term referring broadly to people who identify as a gender different from that which they were assigned at birth<sup>6</sup>. Epidemiologists, public health experts, social scientists, and advocacy organizations have increasingly documented the extremely high burden of discrimination, harassment, and stigma that transgender people face in virtually all areas of their lives (K. Clements-Nolle, et al., 2001; Kristen Clements-Nolle, et al., 2006; Edwards, Fisher, & Reynolds, 2007; Eyre, et al., 2004; Garofalo, Deleon, Osmer, Doll, & Harper, 2006; G. P. Kenagy, 2005; E. Lombardi, 2007; Emilia Lombardi, 2009; E. L. Lombardi, et al., 2001; Sanchez, Sanchez, & Danoff, 2009). While a comprehensive discussion of these burdens is beyond the scope of this paper, a few descriptive statistics help contextualize the daily experiences of transgender people. The largest and most comprehensive study of transgender people in the United States, including surveys from 6,450 transgender and gender nonconforming people, found that study respondents had twice the rate of unemployment compared to the general population. Nearly all (90%) study respondents reported discrimination, harassment, or stigma at work, with 26% reporting they had lost a job due to their gender status. Police harassment and disrespect were also common (reported by 29% of participants), and 57% experienced rejection by their families (Grant, et al., 2011). The same study found that transgender people of color reported worse experiences of harassment, discrimination, and economic marginalization compared to their white counterparts.

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<sup>6</sup> The terms “transgender woman,” a person born a male but who now lives and identifies as a woman, and “transgender man,” a person born a female but who now lives and identifies as a man, will be used throughout this paper.

The aforementioned hardships have greatly contributed to, if not directly precipitated, high rates of HIV/AIDS, depression, suicide attempts, and other health problems. From a public health perspective, perhaps the most critical problem is a startlingly high prevalence of HIV/AIDS among transgender women, with estimates that 11.8% to 27.7% of transgender women are HIV positive (Herbst, et al., 2008; D. Operario, et al., 2008). Contributing factors to this high burden of disease include needle sharing (of needles for drugs as well as hormones), use of alcohol and drugs, high risk sexual behaviors, commercial sex work, lack of education about HIV infection and transmission, intimate partner violence, and mental health problems (De Santis, 2009). Depression and substance abuse are also serious concerns for both transgender men and women, with studies finding that 32% to 41% of all transgender people have attempted suicide (Kristen Clements-Nolle, et al., 2006; Grant, et al., 2011).

In the early 1990s anthropologist Merrill Singer devised the term “syndemic” to describe the mutually reinforcing—that is, synergistic—nature of different health crises (Milstein, 2004). Syndemics involve public health issues such as violence, substance abuse, and AIDS, which may simultaneously ravage communities subjected to social inequities through a variety of complex and interwoven causal pathways. More recent literature on the issues transgender people face conceptualizes syndemic dynamics, including both social and structural factors, which contribute to the grave health outcomes among transgender people (Don Operario & Nemoto, 2010). This theoretical background offers a framework for understanding the layered and multidimensional problems transgender people encounter. Ultimately this more nuanced and comprehensive understanding may be able to inform more effective interventions, particularly in the area of HIV prevention. However, missing from that discussion is research focused directly on the extent to which *health care itself* is detrimental to the health of transgender people.

### *Discrimination and Harassment of Transgender People in the Health Care Setting*

Many transgender individuals face significant difficulty in meeting their health care needs. Medical needs include access to standard primary care services as well as access to gender-affirming care, such as cross gender hormones, surgery, and individual and family psychotherapy. (Gender-affirming treatments induce or maintain the physical and psychological characteristics of the gender that matches the patient’s gender identity.) Studies have found that transgender people face significant barriers to both categories of care. Transgender people are regularly denied health care and are often dissatisfied with available services, which are frequently provided by clinicians who are neither transgender-friendly nor transgender knowledgeable (Grant, et al., 2011; G. Kenagy & Bostwick, 2005; G. P. Kenagy, 2005; Nemoto, et al., 2005). The largest and most recent study reports that 19% of transgender and gender nonconforming people have been refused care due to their gender status, and that 28% have delayed or postponed needed medical care out of fear of harassment or discrimination (Grant, et al., 2011).

Despite these difficult circumstances, transgender people may actually be uniquely motivated to receive health care because of the role of gender-affirming treatments, such as hormones and surgical procedures, in their transition processes. Many HIV-positive transgender people also wish to receive health care services. Use of gender-affirming hormones is widespread among both transgender women (of whom 80% had accessed hormones) and men (69%) (Grant, et al., 2011). However, in that study it was not clear what proportion of study participants accessed hormone therapy through health care providers versus other channels. It is well-documented that many transgender people access hormones through other means, including

friends or the internet (Herbst, et al., 2008). Primarily due to the cost of genital surgery and the fact that it is frequently not covered by insurance, only 23% of transgender women have had vaginoplasty (surgical construction of a vagina), and 64% of transgender women desire—but have not had—vaginoplasty (Grant, et al., 2011). The proportion of transgender men having phalloplasty (2%) and desiring phalloplasty (27%) are much lower. Thus the literature illuminates the quandary that many transgender people face: on the one hand the majority desire medical services, but they may be afraid to seek care because they fear being denied care or simply mistreated in the health care setting.

Although mistreatment of transgender patients is known to be widespread, no single study has focused solely on understanding the nature, extent, and meaning of negative health care experiences among transgender people, and the ways in which members of this population respond to negative and discriminatory events. As Hausmann et al. point out, understanding discrimination in the health care setting is important for three reasons. First, health care providers are morally, ethically, and legally obligated to provide equal care for all patients. Second, as suggested by the literature presented earlier in this paper, discrimination may induce changes in patient's health and health care-related behaviors, and potentially cause disengagement from the health care system. Finally, and perhaps most optimistically, discrimination in the health care setting can be systematically addressed—as opposed to broader social discrimination (L. R. M. Hausmann, Kressin, Hanusa, & Ibrahim, 2010).

Given the importance of understanding the role of negative experiences in the health care setting for the overall health of transgender people, this study conducted an exploratory qualitative investigation of the negative health care experiences of adult transgender women in San Francisco. Because transgender women currently face a more severe health crisis than transmen, especially with respect to high rates of HIV/AIDS, this study focused exclusively on negative experiences of transgender women. Qualitative methods were chosen in order to elucidate the complex experiences and decision-making of study participants. The detailed information obtained through in-depth interviews is vital for informing facilities and providers working with transgender patients, who may not understand or even know about the fear and long history of mistreatment that transgender people bring to the health care encounter.

## **Methods**

### *Participants*

From October 2010 to July 2011 the author interviewed 25 transgender women about their experiences with health care. Study participants were recruited primarily through flyers posted in the common areas of three clinics in San Francisco specializing in treating transgender patients. Other study participants were reached through a notice printed in a transgender community newsletter and through referral by other study participants. Persons were eligible for the study if they self-identified as a transgender or transsexual woman, were at least 25 years old (in order to ensure a significant length of exposure to the health care system), able to speak English, and reported at least one negative health care experience. Participants were reimbursed \$30 for participation in the study. Interviews ranged from 30-90 minutes. The Institutional Review Board at the University of California at San Francisco approved the study. All participants granted written informed consent.

### *Study Procedures and Analysis*

Interviews were conducted using a semi-structured interview guide designed to broadly

collect information about participants' gender identity, history of health care usage, and positive and negative health care experiences. The end of each interview included a brief series of demographic questions concerning age, race/ethnicity, and socioeconomic status. Audio recordings of each interview were transcribed. Transcripts were coded in batches of 5 to 10 interviews using Atlas.ti, a qualitative data management program. Using an iterative approach, memos were written after each batch of coding to explore specific areas of content elucidated by participants. The interview guide was subsequently adjusted to reflect new topics that had emerged in the previous group of interviews. Memos and key transcript selections were regularly reviewed and discussed. Collection of data ceased when the study reached saturation of the major topic of negative health care experiences.

Although information was collected about a broad range of health care experiences, this paper focuses on participants' discussion of negative health care experiences. Participants' positive health care experiences were not included in the analysis and will be presented elsewhere.

## **Results**

### *Demographics*

The 25 transgender women interviewed represent a diverse cross-section of Bay Area residents. Participants ranged in age from 29 to 66, with a mean age of 46. Half of those women interviewed (48%) were white, 36% were African American, 8% were of mixed race, and one Native American woman and one Asian Pacific Islander woman were interviewed. Overall the sample was well educated, with only a quarter of participants having completed high school or less and the vast majority (58%) having attended some college or completed college or even completed graduate school (17%). Despite the generally high level of education, the majority of participants (58%) reported having been unemployed for all of the prior 12 months. Only five participants reported having been employed or in school continuously over the past year. Although HIV status was not explicitly asked about during the interview, seven participants (28%) voluntarily disclosed that they were HIV positive. Nearly half of the women interviewed (44%) voluntarily disclosed histories of abuse of alcohol and/or illegal drugs. Women interviewed live throughout the Bay Area, including San Francisco, the East Bay and South Bay.

### *Introduction to Results*

The results of these interviews are divided into those themes directly characterizing the nature of negative health care experiences; the extent of mistreatment, or the general range of perceived severity of negative experiences; and participants' responses to mistreatment, which are characterized as either proactive or avoidant.

### *The Nature of Mistreatment: Stratification of Care*

Although all of the transgender women interviewed lived in the Bay Area at the time of the study, many women had previously received medical care in other cities, states, and even countries. San Francisco's extensive and high quality transgender health services were described as a major factor that motivated four study participant to re-locate to this area. In sum, the interviews included accounts of experiences with medical, dental, and mental health care received in such diverse settings as transgender-focused clinics in San Francisco and a handful of other major metropolitan areas; at community hospitals and academic medical centers; at HIV/AIDS-focused clinics; at substance abuse rehabilitation facilities; and in prison and jail. The

large majority—but very significantly, not all—of the negative health care experiences recounted by study participants took place at health care facilities that *do not specifically focus on transgender care*. Nevertheless, many of the facilities where mistreatment was reported do see *high volumes* of transgender patients, even if they do not purport to be transgender-focused clinics.

Regarding their care at explicitly transgender-focused clinics, or with providers who were considered transgender experts and saw a high volume of transgender patients, the majority of participants were satisfied with their current transgender-specific care, including hormone therapy, primary health care services, and HIV-related care. Many women spoke in glowing terms about their primary care clinicians. One patient who received care at a clinic specifically offering services to transgender patients said:

*[The care I get from my current provider] makes me feel really good. I feel safe with my health care with him. I feel safe in the sense that he makes decisions for my best interests, not for his own, and it feels good. I'm very, very happy with it. I feel like I'm being taken care of for the first time in my life. It's awesome.*

However, the disadvantage of the development of specialty centers may be that health care providers outside of such centers have no training in working with transgender patients. Providers outside of specialty clinics may also view transgender patients as outside of their domain, even if they require standard primary care services (and not gender-related care). One participant recounted how a health care provider at a hospital in San Francisco advised her to go to a transgender-focused clinic:

*Oh, there was another doctor who did that same thing. In fact, she almost refused to treat me, because I had a really bad sinus infection. She said, "Well, you don't have to come [to this hospital]. You should have waited until the clinic opened up." I'm going, "Why?" "Well, we have a hard time treating your kind here." I'm like, "Excuse me? Really? No, I'm coming here. I'm supposed to live in pain, because you have an attitude with me? Screw you."*

Given these experiences, and the marked difference between care at different facilities, many participants remarked that they felt gender sensitivity training should be required of all health care personnel at all facilities, and not just facilities that specifically serve transgender patients.

### *The Nature of Mistreatment: Negative Perceptions of Transgender Patients*

Transgender study participants frequently reported that health care providers have negative perceptions of transgender women patients. Among the most commonly mentioned concerns about health care providers, discussed by 11 out of 25 transgender women interviewed, is their perception of transgender women as “whores,” “drug addicts,” “HIV positive,” “sluts,” “nasty,” and “drama queens.” One participant stated she felt that her doctor saw her as “just one of the trannies.” In other words, many study participants felt that they had already been stereotyped prior to even arriving in the health care setting, thus limiting their provider’s ability to truly listen and diminishing the provider’s ability to provide appropriate, individualized care. One participant recounted how she felt that her provider’s stereotype of transgender patients prevented him from fully hearing her health concerns:

*So [the doctor] basically disregarded my information. It's common for us to be considered drama queens. So they ignore things we say, which in a medical situation is very bad. We report symptoms. You have to listen to everything we say and grant us the*

*benefit of the doubt.*

In some cases, perceiving clinician's stereotypes resulted in actively denigrating experiences. One participant recounted a dehumanizing example in which she was hospitalized in San Francisco:

*I had to stay in a hospital, because as a junkie, I got cellulitis. I had to stay in there for like two weeks, and they were having their little interns come into the room and talking. I felt really like a circus freak. They would talk about me and transgenders and all this stuff like it was an illness. I mean, literally just talk about it like I'm just this case study. The part that I remember most is that it was actually surprising that I didn't have HIV or full-blown AIDS, because most transgenders that are drug addicts do, and they said that right in front of me, and they were taking their time, and it was a surprise, like wow. It was really shocking.*

This depersonalizing effect caused participants to feel judged, offended, angry, and disappointed. Some participants poignantly expressed these feelings of disappointment and betrayal at being stereotyped by their clinicians:

*I asked the doctor one time, "Do you ask all of your female patients all of these types of questions or is it just because of who I am and what I represent?" He didn't say that transgenders are promiscuous, but that's what he implied, and I was just so offended by this kind of doctor. Doctors are supposed to be these people you go to, you can tell anything or talk to about anything. They're supposed to be nonjudgmental. They're supposed to be care providers.*

Nearly half of the women in this study were women of color. Nearly half also had histories of substance abuse. Participants from both of these groups pointed out that they had to deal with a "double whammy" of prejudice during the health care experience given that they were both African American *and* transgender, or a "junkie" and transgender. One transgender woman, who had previously used intravenous drugs, describes her experiences as follows:

*[If you have an abscess due to injection drug use] you are placed at wound care, and some of the staff are nice, and the nurses are really nice. But you have some people that come in there, like doctors, and they just are so disgusted by you. They don't even attempt to have any kind of demeanor.*

LR: *And you think that's mostly related to being a drug user, or being transgender?*

P: *Both. I think it's hard for me, because it's both, you know?*

### *The Nature of Mistreatment:*

#### *Providers and Staff Are Poorly Educated Regarding Transgender Patients*

Transgender study participants frequently reported that most staff and providers *outside of specialty transgender clinic settings* had little education about transgender issues and thus little or no skill in handling the special needs of a transgender patient. However, likely because transgender care is widely available in San Francisco, only four study participants actually described difficulty finding transgender-knowledgeable care in San Francisco. One woman found that some providers in the Bay Area who purported to be transgender knowledgeable in fact had cared for a very small number of transgender patients:

*So my insurance just recommended this guy, and it's really hard to find not just transgender friendly, but transgender knowledgeable. A lot of people say 'trans friendly' on their little website, but they don't say, 'Oh, yeah, I had like three other patients,' and that made me ill at ease.*

Particularly outside of San Francisco, those study participants who chose to discuss their transgender identity with their health care providers found that their clinicians had “no idea how to deal with it” and that they often had to educate their providers about transgender issues. One woman, who first disclosed her transgender identity to a primary care physician outside of the Bay Area, describes how her relationship with her doctor changed after her disclosure:

*My doctor was so sweet and helpful and kind and nurturing, and then when I told her, “I’m pretty sure I’m transgender,” there was this, “Okay, what do I do? The book says ‘transgender.’ I’m supposed to respond like this.” I’m glad that she had a book, and she still cared, but the relationship took a step backward.*

However, having a clinician who had little to no experience with transgender patients was not universally experienced as negative. Some participants remarked that it was not problematic that their providers did not have previous experience working with transgender patients. Those providers established a trusting relationship and were open to accepting their patient’s gender identity and then learning the appropriate clinical guidelines. One patient describes her productive experience with her primary care provider:

*She was like, “Yeah, let’s do this. We’ll try it,” and she had never [prescribed hormones] before with a client. So she went and found out all the information for us. We kind of discovered it together. She totally took the time to go through the books with me and everything. I feel very comfortable with her. Like I’ve never had that in my life in a doctor’s setting. It’s always uncomfortable.*

#### *The Nature of Mistreatment: Refusal to Treat*

Five women interviewed described experiences with health care providers and institutions that had refused to provide treatment for them as transgendered individuals. Refusal ranged from outright denial of specific services (such as hormone therapy or substance abuse rehabilitation services) to more subtle refusals, such as when a physician transferred care to another colleague. Participants described a diverse array of explanations dispensed to them after they were denied care.

One individual, who resided outside of California at the time, was admitted to a substance abuse rehabilitation facility only on the condition that she not dress as a woman. The same patient also stated that, due to high levels of transphobia in the state in which she lived, she could not find a surgeon who would perform a routine non-gender-related surgery. A different transgender woman initially saw one doctor in the ER who refused to treat her; at which point another doctor stepped in, which the study participant perceived as being due to her transgender status. Multiple women described doctors who refused to prescribe gender-affirming hormones, with a study participant in one case stating that the doctor would not provide hormones because it was against their “personal beliefs.” A woman had multiple psychotherapists tell her that she could not discuss her transgender-related issues because they were “not covered by MediCal.”

Another study participant, who resided on the East Coast and was living part time as a man and part time as a woman, could not find a psychiatrist (for a non-gender related mental health problem) who would see her as a transgender person. She described how she ultimately handled this situation:

*Finding a psychiatrist who would see me was impossible. I literally got the point, because I just had to have medication, where I would just lie. I would not tell [psychiatrists] that I’m transgender. Because they will not see you otherwise. They will not see you.*

The range of responses and meanings attributed to refusal to treat varied. Participants



described humiliation, sadness, anger, and feeling “less than.” Some women described a feeling of betrayal:

*I had a doctor that I had for years, and he wouldn't prescribe [hormones] to me, but he said he would find a way to keep track of my blood work, in case anything went dangerously wrong, which I was grateful for. But being denied the hormone was discomfiting. It was humiliating.*

#### *The Nature of Mistreatment: Refusal to Use Requested Names and Pronouns*

The most commonly discussed negative health care experience, mentioned by 13 out of 25 participants, was the failure of security guards, receptionists, nurses, and physicians to use the correct pronoun (she/her) or female name of the patient. This problem occurred in every setting in which the study participants received or attempted to receive health care, including transgender-focused clinics in San Francisco.

Many of the women interviewed described humiliating incidents in which they were called by their male names or by male pronouns, often in front of other patients or staff. Women described feeling devastated, angered, insulted, belittled, and frustrated by these experiences. Others described these incidents as “awkward” and “nerve-wracking” as well as simply “painful.” Some participants described crying either during these experiences or immediately after, and one woman stated that she would get so depressed after being called her male name that she would stop taking her medications, including HIV medication. Another woman remarked on her disappointment that this problem occurred even in San Francisco:

*For transgender people, at least for me for sure, I spent so much of my life trying to deny that I had this feminine part. And then when I finally, finally I go through all of this living hell to get to the point where I say, okay, this is me. I'm predominantly female, that's how I'm going to live my life and that's how I want to present myself, and then to have someone call you sir. It's almost like somebody stabbing you right here [points to chest] in the middle of your chest. It's like SHRRP. It hurts that bad. Especially when you're new, and you know, I was in San Francisco. See one thing was, you know, remember I said the Emerald City on the Hill? That's what I thought, oh my god, I'm going to utopia. Well San Francisco ain't utopia.*

#### *The Extent of Mistreatment: Trauma in the Medical Setting*

Study participants also described a range of negative experiences that are not easily classified but which made participants feel particularly “violated” or “unsafe.” Such encounters varied widely on a person-to-person basis but do not easily fit into any of the aforementioned thematic categories. However, because of the high levels of humiliation and degradation surrounding these specific incidents, these results can be considered a significant finding of this set of interviews.

A study participant describes her experience trying to access a women's bathroom:  
*When I went to [East Bay hospital], they called my [male name]. I said, “I'm a woman.” They kept calling me sir this and all that. They were laughing. They thought it was real funny. You could hear their coworkers laughing. I said, “I need to use the restroom. Can I have the key?” And they gave me the man key. I said, “I need to use the women's restroom.” “No, you can't use the women's restroom.” “I can't go in the men's restroom.” So I really had to use the bathroom. So I go in the men's restroom. “Excuse me, ma'am. You're in the wrong restroom,” and stuff, some of the guys in there. They*

*said it and stuff. They're going to stop and stuff while I'm getting ready to use the restroom. I sit down and stuff. I sit down and stuff. They're watching me as I'm going, so I don't feel safe in there, because someone might want to attack me, beat me up, or some might try to make me do things to them and for them and stuff like that. So I was just kind of, "God, I don't know what to do."*

Other negative experiences include a woman who had recently been raped being placed in a hospital room with an intellectually disabled man; a woman being prescribed antipsychotics when seeking help for gender-related endocrinologic problems; and a few women who were told by cisgender<sup>7</sup> women physicians that they would "never be natal like me."

Only one participant in this study described a physical component to a negative health care experience:

*The doctor came in the room and I think he said, "Drag?" I think that's what he said. He said, "Please take those clothes off and meet me in the next room." It was a weird experience. They had this big room. So he said to meet me out there in whatever chair, whatever gurney, and I was just like, "No, this man did not just call me a drag queen, and no, he did not just tell me to take my clothes off." I get out there, and he was handling me. He was handling me like roughly, and I'm like, "Get your fucking hands off me." He said something like, "Drag's not going to save your life" or something like this. And he said all of these cruel things to me, and it fucked me up. I was like, "What the fuck is this guy doing? I'm here for my life. I'm here for HIV treatment, and this guy is telling me all of this shit about drag." He's fucking me up. He fucked me up to this day. It's been about five years, and I've had a hard time being normal again.*

### *The Need for Gender-Affirming Care: Responding to Negative Health Care Experiences*

Study participants described a range of strategies used to mediate the likelihood that they would have to deal with the negative issues elucidated in this paper and to respond to mistreatment once it had occurred. These responses must be considered in the context of the many struggles (both internal, external, and structural in nature) that the transgender women interviewed described in coming to understand themselves as transgender or simply as female/woman. It is hard to overstate the emotional gravity with which women interviewed discussed the issue of understanding and accepting themselves as transgender. As one woman stated:

*I fought [the urge to transition] my whole life, fought it for forty-three years, weightlifting, and trying to deny it and crush it and destroy that whole urge of what I knew what I really wanted to be. My whole entire life, I was denying and trying to defeat it until my little girl just said, "I ain't going away," and I finally listened to her, you know? "Okay, girl, you're not going away no matter what I do, no matter how bad it was, no matter how many people I beat up. You ain't going away."*

These struggles eventually resulted, for some women, in coming out to others, including partners, family members, and health care providers, as transgender. This identity development process typically incurred a great emotional cost, with many participants describing the pain and confusion of experiencing a "fractured" identity prior to coming to accept their current identification as a transgender person. (Indeed, not all persons interviewed described a complete acceptance of themselves as transgender.) In other words, coming to identify, and to accept oneself as transgender, was described as a deeply challenging. This struggle has resulted in an

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<sup>7</sup> "Cisgender" refers to non-transgender persons.

identity of great value to most study participants, and one that must be supported by both internal and external environments.

It follows that this hard-earned, yet fragile, identity very much needs to be insulated from a wide variety of threats encountered or *potentially* encountered in the health care setting. The potential for such threats must also be balanced against the severity of one's need for health care. Like coming to identify as a transgender person or living full-time as a woman, securing one's gender identity is not a one-time event—it is an ongoing process that responds to myriad health care challenges *and health care needs* as they arise, until eventually a clinic or provider is found who affirms the transgender person's gender identity, and provides a safe and empathic space. Several of the women interviewed had succeeded in finding such a space, and described extremely long relationships (including some more than 10 years in length) with their primary care providers. Alternatively, a small number of persons interviewed in this study found a health care provider who did not necessarily provide a feeling of safety and well being, but who simply was not a threat to the individual's safety or identity.

Participants' strategies for obtaining gender-affirming care can be generally categorized as either avoidant or proactive. Avoidant strategies, which include avoiding certain establishments or providers, not disclosing one's transgender identity, and opting out of health care treatment entirely, involve averting a negative or potentially negative health care experience. Proactive strategies include directly confronting disrespectful staff or establishments (an act often referred to as "setting it straight") and seeking care only at specialty clinics.

Relatively few participants described simply ignoring mistreatment. However, a few women did state that they would eventually—if other strategies failed to work—ignore negative experiences:

*Participant: I was recently [at a San Francisco hospital], and a lot of the staff, the nurses knew that my name was (female name), and that I was transgender, but they kept referring to me as "he" and "him," and that was very hurtful. That was just a month ago.*

*Interviewer: Did you respond in any way?*

*Participant: I think I said something to one nurse within the first day I was there, but then I realized...well, then it was still going on. So I just tried to ignore it.*

#### *Avoidant Strategy: Avoiding Providers or Establishments*

In the process of securing gender-affirming care, many study participants directly articulated looking for a balance between managing their psychological well being and meeting their health care needs. Numerous participants tried to eliminate the possibility of repeated negative experiences by absolutely swearing off certain providers or facilities after particularly malignant experiences. These women emphatically stated that they would never return to specific facilities in which they experienced mistreatment, even if that came at an immediate cost to their health:

*I will never go back to [San Francisco hospital]. Never. I will stop taking my meds. If I couldn't go to [my current doctor], I will stop taking my meds, and I will search other places. I will not go to [community hospital] ever. It was so bad for me, and I don't like how they treat my fellow sisters. So I just will not do it.*

#### *Avoidant Strategy: Not Disclosing Transgender Status*

Participants expressed a range of opinions regarding whether or not providers should

know their transgender status. Some participants felt strongly that they wished to be in a doctor-patient relationship in which they could safely disclose that they were transgender, while others felt that its relevance depended entirely on the specific medical situation. Other participants tried to prevent negative health care experiences by choosing to selectively disclose their transgender status.

However, non-disclosure as a strategy works only for those who are able to “pass” as a woman or for those people who are simply viewed as “men,” not transgender. Many of the people interviewed in this study described a period, ranging from months to years in length, in which they lived part time in each gender. Several participants described visiting their health care professionals dressed as men, and intentionally elected not to inform their providers—nor did their providers ask—that they were transgender. Other persons interviewed in the study also described instances in which they *wanted* to disclose their transgender status, but did not feel it was safe and thus chose not to disclose. This lack of safety was attributed partly due to past experiences as well as the previously discussed assumption, held by many transgender women, that clinicians have little to no training in working with transgender patients.

Participants able to pass as cisgender women recounted numerous examples of how they managed disclosing their transgender identity. One transgender woman provided urine specimens from a penis without the nursing staff discovering she had a penis in order to prevent any possible problems:

*I had to go to [San Francisco hospital], and they needed a urine specimen. So I kind of moved things so they didn't see. So they took the specimen, but they never knew. I'm just not afraid, but I don't know how their attitude would change if they knew. So the nurse took the specimen, as far as she was concerned, from a female.*

According to some study participants, disclosure depends on numerous factors, including the specific medical issue for which attention was being sought and the type of provider being seen. As one respondent put it:

*When I went to the [hospital in Los Angeles], I just didn't feel comfortable, because, first of all, they didn't put me in a room, and the curtain was open, and everyone was like looking and peeping in. I didn't tell the doctor I was transgender. I feel like it's not important. I'm there to get medical treatment. My gender is unimportant, you know. I think for the most part, it's not relevant, but it also depends on the medical situation. So, for some things, you know, if I'm going in there for having a severe headache, that's probably something that they don't need to know. But if it's something where they have to check my genitalia or, you know, then that's something that I should inform them about.*

#### *Avoidant Strategy: Opting Out of Health Care*

Multiple participants described having one or more negative experiences which caused them to simply stop getting health care for a period of days, weeks, or even years. These women ultimately determined that the threats to their transgender/female identity were simply insufferable, or that the pain of being mistreated was actually more harmful than not getting medical care. A participant describes her experiences responding to being referred to with the wrong names and pronouns:

*Sometimes I'll go cry and leave without getting the help I need, or I'll get kicked out because I'll throw such a fit. Yeah, usually one of the two. I don't get my treatment. Whatever I'm going for, I don't get, because I either throw a fit or I cry and leave.*

Another woman, who described a long history of negative health care experiences,

including being called a “faggot” by a receptionist at a clinic (not in San Francisco), stated:

*[After all these experiences], I was just like, “Forget it. Whatever happens, happens.” I wasn’t going to the doctors or anything and stuff. I said, “I’m losing more T cells coming in here than I am just walking around the street, just taking care of myself and stuff.” So I started to be just like walking every day and eating more healthy and stuff. That’s what I was basically doing instead of going to the hospital. I tried to eat like all fruits and vegetables, stuff like that.*

#### *Proactive Strategy: Seeking Care Only at Transgender-Focused Clinics*

The proactive counterpoint to avoiding certain facilities is simply choosing only to seek health care services at establishments known for offering respectful care to transgender people. Many of the women knew that this was an effective strategy for eliminating or significantly reducing their exposure to mistreatment in the health care setting. One transgender woman, who moved to San Francisco in part for the large population of transgender people here, describes her experience:

*I happen to be very lucky with my health care experiences, because I have only gone to specific types of places. Of course I came specifically to San Francisco, because it’s very, very accepting. So I’ve only really put myself into situations that will be that way. I wouldn’t be doing this down South in Georgia or Alabama or anything like that, or I wouldn’t expect any health care to be remotely as well received as I got at these places. Even amongst here, I’m sure that there can be very bad places. The reason I don’t think a lot of my experiences are that bad is because I have specifically sought out places that would be for me.*

A few women interviewed also described frequently switching providers or clinics if they felt a particular clinic was not sufficiently sensitive to their needs as a transgender person:

*So I went from [a clinic in San Francisco] to [a clinic in the East Bay]. I was at that clinic, and then I felt that I wasn’t getting enough quality of care there. So I went to [an East Bay Hospital] where I’ve been now for about seven years.*

#### *Proactive Strategy: Setting it Straight*

Fully half of the women interviewed described specific proactive ways in which they directly responded to mistreatment. These included requesting that an individual change his/her behavior; filing a formal complaint with a supervisor or hospital administrator; informing another staff member about the problem (for example, informing a physician about the problems encountered with a nurse or receptionist); or filing a complaint with a legal advocacy organization such as the Transgender Law Center. Several participants remarked that transgender women “have a tendency to put people in their place” and are quick to address instances of disrespect:

*I’m very quick to set it straight. That’s just who I am. The admissions clerk at [East Bay hospital], because she kept putting “he” everywhere [on the paperwork]. I’m like, “Girl, I’m not signing that.” She’s like, “Well, your paperwork said...” I said, “No, my paperwork said “female.” If you would read, you would see that” and I.D. and all of that. So she said, “Oh, well, I’m sorry.” Okay, well, if you had read, and you had stopped being arrogant, then we wouldn’t be going through this. So that’s where I stood with that one. I’m quick to address issues.*

A handful of women described an inner process by which they learned to deal

specifically with negative encounters in which the wrong name or pronoun was used. While at first they experienced these incidents as devastatingly painful, over time (typically months or years) they grew to simply find these experiences angering, and would confront the person using the wrong name or pronoun and request that they use the correct name. One woman described her perseverant approach:

*It was difficult at a lot of the clinics or just the hospital in general at first. Then after a while, maybe a year or two or so, they started calling me by my name, my female name, instead of my boy name. I really appreciated that, because I kept on addressing it. 'Look, I look like this. Can you please call me by my female name?' And after a while, several of them were still jerks. They'd still call me my boy name, but for the most part of them, they did address me as my female name.*

Participants described little institutional consistency in responding to such complaints. Sometimes participants described that their complaints were met with very high levels of concern and even followed up with gender sensitivity training for the entire staff of a particular facility. Other persons reported that despite asking for complaint forms, “no one ever says anything or comes back” with such forms.

### **Study Limitations**

Qualitative methods give researchers the ability to begin understanding processes and phenomena that have not yet been well-explored in academic literature. The purpose of qualitative studies, which are typically much smaller and use different sampling methods than quantitative studies, is not to produce generalizable findings. Thus this study should not be viewed as a comprehensive summary of mistreatment of transgender women in the health care setting, but rather contextualized in light of its specific geographic, temporal, and demographic characteristics.

First, although the sample included a large number of African American transgender women, no Latinas were interviewed for this study despite the fact that San Francisco has a large population of transgender Latinas. Many of these women seek services at the recruitment sites for this study. This group likely faces different issues than those of white and African American transgender women, including language barriers. If interviews had been conducted in Spanish, this population might have been reached.

Second, nearly all of the study participants were recruited through flyers posted in facilities offering medical care to transgender people. Thus, only those women who are currently in contact with health care services—at least to some extent—were interviewed in this study. Furthermore women had to actively volunteer to participate in a study about their health care experiences. Thus participants may represent a more motivated, more care-seeking, and more care-involved portion of the transgender population in San Francisco. In light of our finding that some transgender women stop seeking health care after particularly negative experiences, women who had recently experienced mistreatment in the health care setting may have been less likely to participate in this study.

Third, because this study was conducted in San Francisco, a city with a large population of transgender people and a community of providers and clinics explicitly dedicated to transgender health, the results are not generalizable to other localities that may have fewer services. However, the fact that so many negative experiences were reported even in San Francisco, a city to which multiple study participants had moved specifically because of its services, may be an indicator of the severity of mistreatment in other locales.

Finally, because of limitations of resources and space, this paper presents only the negative findings of this set of interviews. In fact the participants described many powerfully healing relationships with therapists, physicians, substance abuse counselors, and occasionally spoke in glowing terms about entire facilities. Participants also described many health care personnel who took reports of negative experiences very seriously. Thus given its focus on negative health care experiences this paper presents a selective lens into the overall health care experiences of transgender people.

## **Discussion**

The findings of this qualitative study of the negative health care experiences of a group of transgender women in San Francisco are consistent with the existing literature. Participants reported rampant experiences of discrimination and mistreatment, with common themes of humiliation, betrayal, anger, disappointment, and hurt. Refusal to use patients' requested names and pronouns and refusal to provide requested services were particularly common types of negative experiences. African American women and women with histories of alcohol and substance abuse described further discrimination. However, just as prominent in the data was this population's prioritization of gender-affirming care, and the many avoidant and proactive strategies they used to ensure knowledgeable and respectful care and steer clear of potential harms.

These results paint a picture of a population of health care users who are actively prioritizing gender-affirming care, and build upon other studies also reporting on the ways in which transgender people manage their care in order to obtain the most gender-affirming treatment. One such finding is Dewey's observation that transgender patients "do engage in forms of resistance and challenge medical knowledge," including by switching providers in cases of sub-par care (Dewey, 2008). A handful of studies have likewise found that transgender people selectively disclose their gender status in order to prevent potential discrimination (Dewey, 2008; Sperber, et al., 2005).

This study's findings about denial of care, refusal to employ requested names and pronouns, humiliating experiences, additional discrimination against drug users and African American patients, and lack of provider knowledge about transgender patients replicate other authors' findings (Grant, et al., 2011; G. Kenagy & Bostwick, 2005; G. P. Kenagy, 2005; Sperber, et al., 2005). This study can be compared most directly to Nemoto et al.'s much larger study of transgender women of color in San Francisco, who actually described high levels of access to most medical services, despite having many complaints about the services that were offered (Nemoto, et al., 2005). However, our findings about transgender patients' perception of clinicians' stereotypes have not been reported elsewhere.

Bauer et al.'s qualitative study, which analyzed focus groups with a total of 85 transgender people (including transgender women but also many other transgender-identified individuals) in Ontario, Canada, similarly reports that clinicians frequently have little knowledge regarding how to deal with transgender patients and that patients must frequently educate their providers (Bauer, et al., 2009). Bauer et al. use a framework of institutional and informational erasure to describe a pervasive "lack of knowledge of trans issues," including active erasure of transgender people through staff and clinicians' "visible discomfort to refusal of services to violent responses that aimed to intimidate or harm." The framework of erasure was taken from Namaste's work elucidating erasure as "a defining condition of how transsexuality is managed in culture and institutions, a condition that ultimately inscribes transsexuality as impossible"

(Namaste, 2000).

Certainly Ontario, Canada, and San Francisco differ in both their transgender-focused services and the size and demographics of their transgender populations, and Bauer et al.'s study should be understood in that context. Nevertheless, as a core concept erasure does not fully capture the outright degradation described by many participants in this study. In particular, the large number of people in this study who reported that negative stereotypes of transgender women have a detrimental impact on their care points not to passive erasure but to active discrimination and denigration. However, this finding may also be due to generally increased visibility of transgender people in San Francisco, or to the recent increased media coverage of transgender people.

### *Study Implications*

This study's findings suggest several important ways in which negative health care experiences may harm this population's health. First, the transgender women interviewed described the emotional pain induced by encounters of disrespect, mistreatment, and harassment in the health care setting. That health care itself would contribute to the emotional suffering already described by many transgender people is anathema to the professional guidelines that dictate ethical behavior. This is particularly important in light of the high prevalence of suicide attempts in this population. The results of this study suggest that health care facilities serving transgender patients need to establish clear internal guidelines for working with transgender patients in addition to developing and enforcing policies for responding to patient's claims of mistreatment. Fortunately numerous researchers and organizations have already made thorough and thoughtful guidelines for working with transgender patients widely available (E. Lombardi, 2007; Sausa, et al., 2009).

A handful of participants in this study were so influenced by their negative health care experiences that they stopped seeking health care for a period of time, switched clinics, or delayed care. Some of those women were HIV positive. Dropping out of health care services may be the most serious health consequence uncovered through these interviews, and interventions that focus on improving treatment of transgender patients may also serve to keep transgender patients in contact with the health care system.

Like other authors, this study found that one of the ways that transgender people try to prevent discrimination is to selectively disclose their transgender status. While this behavior is an adaptive way for individuals to ensure their own emotional well being, from a medical perspective this approach is problematic. As one example, persons who are taking estrogen are at increased risk for thrombotic events, and thus physicians need be informed when patients are on estrogenic therapy. Clinicians providing estrogenic therapy need to go beyond just informing transgender patients about these health risks, as is the standard practice of clinical care. Health care providers should specifically educate their patients about the import of disclosing use of gender-affirming hormones—at least to their treating physician—in emergency medical situations.

Many researchers, research dollars, community members and advocates are dedicated to studying HIV/AIDS among transgender women. All evidence indicates that this population is experiencing a veritable public health emergency and that novel interventions—of both treatment and prevention—are warranted. However, an unintended consequence of such focused research on this subject may be that it creates or reifies clinicians' negative stereotypes of transgender women as all being HIV-positive and all engaging in high-risk behaviors, such as commercial



sex work and injection drug use. Thus clinicians must determine strategies for accurately assessing patients' actual health and behavioral risk factors while still maintaining respectful relationships. Clinicians must also actively reduce stigma around being HIV-positive, engaging in commercial sex work, and using illegal drugs.

Although the findings of this study likely do not surprise those persons who have a long history of working with transgender women, these findings may give some further background for people new to working with and researching transgender women. All staff working with transgender patients, particularly during intake encounters, should be aware of the history of negative experiences that transgender people may bring to the health care experience. Given that negative health care experiences are common in this population, many transgender women may present for care very fearful that they will be mistreated. This fear includes not just fear that the nurses and physicians may be disrespectful, but that the security guards, receptionists, and other staff will not welcome this group of patients. These findings underscore the importance of providing gender sensitivity training for *all persons who may interact with a facility's clients*. In particular, persons working in the health care setting may not appreciate how deeply threatening misuse of names and pronouns is for the average transgender patient.

Finally, the results of this study must be contextualized within the broader research on both the health effects of long-term discrimination and the effect of perceived discrimination in the health care setting. In light of the intensity of perceived mistreatment described by many of the women interviewed in this study, we question whether "discrimination" sufficiently describes the outright hatred that characterized many of the experiences recounted by study participants. More work needs to be done in assessing not just the health effects of discrimination in the health care setting, but in fully illuminating and quantifying the variety of intensities of different encounters. Studies should also investigate the individual characteristics that may determine whether a person is likely to respond to experiences of mistreatment in an avoidant or proactive manner.

Of note for transgender people, the literature suggests that "stressors that are ambiguous, negative, unpredictable, and uncontrollable are particularly pathogenic" (Williams & Mohammed, 2009). Unfortunately, such a description closely describes the negative health care experiences—and daily experiences—of many of the women interviewed, which often followed no easily predictable pattern. Williams and Mohammed call for comprehensive population and contextually-specific measures to be developed for the accurate assessment of discrimination. The findings of this study may be used in the development of such measures.

### *Recommendations for Future Research*

This study has focused exclusively on transgender women's perceptions of mistreatment in the health care setting. It follows that further research should focus on documenting and understanding staff and clinicians' opinions and beliefs about transgender patients and the degree to which these may contribute to transgender women's perceptions of mistreatment and discrimination. Given the inconsistent institutional responses to complaints filed against institutions described by women interviewed in this study, further research should also investigate institutional policies for dealing with reports of gender-based discrimination so that such responses can be standardized.

Although excellent guidelines exist for working with transgender patients, limited research exists establishing the extent to which such guidelines, in combination with gender sensitivity training, effectively changes attitudes and behavior. Further research into strategies

that health care organization can take to ensure respectful treatment of all patients, including transgender people, might serve to benefit this population as well as other marginalized groups.

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