EXPLORING THE FEASIBILITY AND ACCEPTABILITY OF BIOMARKER COLLECTION FOR HIV INFECTION AND CHRONIC STRESS AMONG TRANSWOMEN IN PUERTO RICO*

EXPLORANDO LA VIABILIDAD Y ACEPTABILIDAD DE LA RECOLECCIÓN DE BIOMARCADORES PARA LA INFECCIÓN POR EL VIH Y ESTRÉS CRÓNICO EN MUJERES TRANS EN PUERTO RICO

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ABSTRACT
The assessment of biomarkers related to HIV and chronic stress increases opportunities for the design of more comprehensive research and intervention efforts on the health of transwomen within the context of Health Psychology. In this paper, we present data from a study implemented in Puerto Rico that aimed to: document the feasibility/acceptability of collecting biomarkers for chronic stress and HIV among transwomen; qualitatively document the factors related to the collection of biomarkers in this population; and explore the feasibility of collecting other types of biological specimens from transwomen in future studies. We implemented an exploratory mixed-method study with a sample of 10 transwomen. Quantitative information was gathered via saliva and hair biomarkers for chronic stress and HIV, while qualitative data was obtained via in-depth interviews. Twenty percent had positive results for HIV antibodies and 30% had hair cortisol levels that exceeded the normal range. The main motivations behind the provision of biomarkers were the desire to know about their health; contributing to a better understanding of health in the transgender community; and having previous positive experiences with our research team. We discuss the incorporation of biomarkers as powerful tools to better describe and understand the health of transwomen.

KEYWORDS: Transwomen, HIV, cortisol, chronic stress.

RESUMEN
La inclusión de biomarcadores relacionados al VIH y el estrés crónico en mujeres trans favorece el desarrollo de investigaciones y esfuerzos preventivos más exhaustivos en el campo de la Psicología de la Salud. Presentamos datos de un estudio realizado en Puerto Rico dirigido a: determinar la viabilidad/ aceptación del recogido de biomarcadores para el VIH y el estrés crónico en mujeres trans; documentar de manera cualitativa los factores relacionados a la toma de biomarcadores; y explorar la viabilidad para tomar otro tipo de muestras biológicas en estudios futuros. Implementamos un estudio exploratorio con métodos mixtos (N=10). La información cuantitativa se obtuvo mediante la toma de biomarcadores a través de muestras de cabello y saliva, mientras que los datos cualitativos se generaron mediante entrevistas semi-estructuradas. El 20% de las participantes arrojó positivo al VIH y el 30% presentó niveles de cortisol elevados. Las motivaciones para proveer muestras se relacionaron a su deseo de conocer más sobre su salud, entender mejor la salud de la comunidad trans, y a experiencias previas positivas con nuestro equipo de investigación. Discutimos la inclusión de biomarcadores como una estrategia importante para describir y entender el estado de salud de las mujeres trans.

PALABRAS CLAVE: Mujeres trans, VIH, cortisol, estrés crónico.

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There has been a recent increase in interest on the inclusion of objective biomarkers in health-related research, as reflected in numerous scientific articles on the application of biomarkers in mental health research (Boksa, 2013; Kennedy, Downar, Evans, Feilotter, Lam et al., 2012; Singh & Rose, 2009). In the public health field in general, and Health Psychology in specific, biomarkers constitute an important tool to document how social determinants may affect certain health-related outcomes among vulnerable populations. However, difficulties in specimen collection are common and are mostly linked to refusal to participate in such initiatives among members of the community (Verstraete, 2004). There is a scarcity of research including biomarker collection among transwomen (DuBois, 2012; Liu, Glidden, Anderson, Amico, McMahan et al., 2014), specifically studies addressing the factors that could facilitate or impede this endeavor among this population. In this paper, we present data from a study implemented in Puerto Rico that documented the feasibility and acceptability of biomarker collection among male-to-female transgender individuals (heretofore transwomen). The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient—which can be measured accurately and reproducibly) (Strimbu & Tavel, 2010).

Considering that most research efforts in Puerto Rico with transwomen have included self-reported measures (Rodriguez-Madera 2009), determining the feasibility and acceptability of gathering biomarkers among this community could contribute to the design of clinical and public health research and interventions to address the fundamental causes of health disparities in this marginalized population.

Transwomen in the Puerto Rican Context

Transwomen are individuals whose gender identity and expression differs from the male sex they were assigned at birth. They often express their gender identity through physical changes such as hormone use, silicone injections, and surgeries to embody their self-ascribed identities (Padilla, Rodriguez-Madera, Varas Díaz, & Ramos-Pibernus, 2016; Rodriguez-Madera, Ramos Pibernus, Padilla, & Varas Díaz, 2015). In Puerto Rico gender norms place cultural value on adherence to traditional and sometimes rigid definitions of gender and sexuality (Rodriguez-Madera & Toro-Alfonso, 2008; Rodriguez-Madera, 2009). Consequently, transwomen are highly stigmatized due to their gender non-normativity, face multiple challenges in their daily lives, and are frequently overlooked in health-related research, interventions and services.

HIV Infection and Chronic Stress among Transwomen in Puerto Rico

HIV/AIDS continues to affect the Latino community disproportionately, with more than 220,400 cases in the United States (US) attributed to this population (CDC, 2015). Puerto Ricans are United States citizens living in the Caribbean and are a significant part of the growing epidemic among Latinos. With more than 34,400 reported AIDS cases on the Island of Puerto Rico alone, current research estimates that 1% of the population is living with HIV (Centers for Disease Control and Prevention, 2016). Nationally, the proportion of transwomen living with HIV is increasing, as evidenced by the growth from 3% to 8% in new reported cases per year (CDC, 2017). Previous research with transwomen in Puerto Rico reported an HIV prevalence of 14% (Rodriguez-Madera & Toro-Alfonso, 2008). However, this research did not use a probability sample and prevalence was assessed by self-report, not corroborated by HIV tests.

Research has shown that gender/sexual minorities are heavily affected by HIV and are frequently exposed to social determinants that increase their vulnerability to HIV infection and disease progression.
(Brooke Steele, Meléndez-Morales, Campoluci, DeLuca, & Dean, 2007; Fox, 2010). Meyer (2003) has demonstrated that those occupying socially marginal statuses are more likely to experience stigmatization and subsequent stress, which in turn can negatively impact health and promote HIV-related risk behaviors (Dentato, 2012). Several studies based on self-reports of stress in the US and Puerto Rico have shown that transwomen experience high rates of minority stress due to their gender identities (e.g., challenges in accessing social and health services, lack of social support, interpersonal and institutional violence) (Bockting, Miner, Swinburne Romine, Hamilton, & Coleman, 2013; Rodríguez-Madera et al., 2016). However, the effects of chronic stress on transwomen’s health have not been adequately explored. Although previous research documented stress-related experiences in this population (Jokic-Begic, Lauri Korajlija, & Jurin, 2014; Kelleher, 2009; Rodríguez-Madera & Toro-Alfonso, 2008; Sugano, Nemoto, & Operario, 2006), biological measures would provide a clearer picture of the influence of social stigma and chronic stress on health outcomes and HIV risk/progression. The inclusion of biomarkers has the potential to play an important role in this respect, but their collection among a population that may have an understandable suspicion or resistance toward health professionals is a potential challenge in pursuing such a research agenda.

The Use of Rapid Test and Hair Samples as Biomarkers for HIV Status and Cortisol Levels

Although gathering biomarkers from transwomen might seem a routine procedure, the reality is that collecting biological samples from this population could be affected by their mistrust of health care personnel due to previous negative experiences (Rodríguez-Madera, Ramos-Pibernus, Padilla, & Varas-Díaz, 2015). Therefore, understanding the feasibility and the barriers and facilitators to obtaining biomarkers while conducting research with this population is important for the successful implementation of studies that intend to combine self-report with biomarkers. We set out to test this feasibility by conducting a study to collect saliva and hair samples to assess cortisol levels and HIV antibody from a small sample of transwomen in Puerto Rico.

HIV Status Via Rapid Testing

To date, studies with transwomen in Puerto Rico have not used biomarkers to assess HIV prevalence. Rapid HIV testing can be particularly useful as being tested and knowing your status is the most crucial step in the HIV treatment cascade. Rapid tests are ideal for facilitating testing for persons who do not perceive themselves at risk, who may not have ongoing relationships with HIV testing providers, and who cannot otherwise access medical care (Armington, 2005). Rapid tests can be administered in different non-clinical settings by certified personnel. Between 40% and 90% of people prefer rapid testing and 20% of individuals who take a rapid test receive a positive result (Broeckaert & Challacombe, 2015).

Stress Assessment Via Cortisol Measure

Ideally, the assessment of chronic stress includes a set of multiple biomarkers (e.g., neuroendocrine, metabolic and immunological) collected via diverse means (i.e., saliva, serum, urine, hair), while also using behavioral and attitudinal surveys to measure exposure to stressors and stress appraisal. In the case of cortisol, it is typically measured through saliva, urine and serum (Sauvé, Koren, Walsh, Tokmakejian, & Van Uum, 2007). While each of these measurements has advantages and limitations, all these methods require multiple samples to provide an assessment of cortisol levels over prolonged periods of time. Because of that, it could be very challenging to assess cortisol among highly marginalized populations such as transwomen; who are extremely hard to reach and may not have the time, resources, or interest to commit to such protocols. One method that addresses
many of these difficulties is the collection and analysis of hair samples.

Hair analysis has been increasingly used to assess long-term exposure to cortisol (European Society of Endocrinology, 2011). According to Sauvé et al. (2007) measurement of hormone levels in human hair has several advantages which include: 1) non-invasive collection that can be performed by non-health care workers at any time of the day; 2) samples can be stored at room temperature and be sent by mail, making it potentially useful in population studies; and 3) cortisol levels reflect average hormone levels over the last two months, as opposed to serum, saliva and urine samples, which reflect acute or daily cortisol levels. Results from hair sample analyses correlate highly with traditional saliva measurements for cortisol (Sauvé et al., 2007). Of importance for any potential study with transwomen, hair dye/coloring has not been found to influence cortisol results (European Society of Endocrinology, 2011).

The assessment of biomarkers related to chronic stress (i.e., cortisol) and HIV infection (i.e., rapid testing) among transwomen is a crucial centerpiece in developing a better understanding of their health and needs. Biomarkers can help characterize chronic stress and HIV infection objectively, without the limitations of self-report. Literature evidence that HIV prevalence based on self-reports are much lower than HIV prevalence based on HIV testing (Fishel, Barrère, & Kishor, 2012). On the other hand, empirical information on the validity of self-reports is limited and it is known that subjects are prone to systematic error in reporting (Massod, Ahmend, Choi, & Gutierrez-Osuna, 2012). Although the use of biomarkers is ideal for having a clearer understanding of how chronic stress impacts Puerto Rican transwomen’s health and HIV risk/progression, there is a gap in the current research literature addressing the feasibility of gathering these biomarkers among this population. Therefore, our study aimed to document the feasibility and acceptability of collecting biomarkers for chronic stress (i.e., cortisol) and HIV (i.e., rapid test) among a sample of transwomen in Puerto Rico. Our study’s specific aims were to: (1) document the feasibility and acceptability of collecting biomarkers for chronic stress (i.e., cortisol via hair sample) and HIV (i.e., oral rapid test) in a sample of transwomen in Puerto Rico’s San Juan metropolitan area - where the majority of transwomen live; (2) qualitatively document the factors that facilitated or impeded the collection of biomarkers among transwomen; and (3) explore other types of biological specimens that transwomen are willing to provide for future studies on chronic stress and HIV.

METHOD

This study had the institutional review board approval (A9980114) of the University of Puerto Rico’s Medical Sciences Campus (UPR-MSC). To achieve our objectives, we implemented an exploratory mixed-method study design. Quantitative information was gathered via saliva and hair biomarkers for HIV and chronic stress, while qualitative data was obtained via in-depth interviews with all participants to understand factors related to acceptability and refusal. Below we describe the process of implementation of our research design.

Participants

Recruitment was conducted in collaboration with existing transgender community partners. Our research team has been continually embedded in areas of San Juan that are heavily frequented by transwomen as part of our ongoing projects (Padilla, Rodríguez-Madera, Varas-díaz, & Ramos-Pibernus, 2016). We visited different settings where transwomen socialized and/or work and explained to them the nature of the study. Once we explained the study we proceeded to screen participants for three specific inclusion criteria: (1) 21 years of age or older (the age of adulthood in Puerto Rico); (2) self-identified as a Puerto Rican; and (3) self-identified as a transwoman. The
sample consisted of 10 transwomen between the ages of 21 and 41 years old. We chose this sample size based on the scope of this feasibility study and because it represented 10% of the sample size of transwomen (N=98) we recruited in a previous study implemented in the San Juan metropolitan area (Padilla et al., 2016; Rodríguez-Madera et al., 2015).

Most participants (n = 6) self-identified as transsexual women. Half of them reported having finished High School; the others did not complete their education. The source of income most frequently reported was commercial sex work (90%). Five out of ten participants reported an approximate monthly income of $501 to $1,000.

Measures and Data Gathering Forms

To collect the data, we used a combination of questionnaires, interview guides and biological sample collection.

Demographic Data Questionnaire. We developed this 12-item questionnaire for our previous studies with transwomen in Puerto Rico (Padilla et al., 2016; Rodríguez-Madera et al., 2015). It included questions regarding participants’ age, gender identification, sexual orientation, education, family economic status, birthplace, area of residence, employment, and income. All questions had multiple choice response options. The questionnaire was administered via a face-to-face interview and responses were entered onto an iPad by the interviewer.

Interview Guide. The qualitative Interview Guide explored factors that facilitated or impeded the collection of chronic stress and HIV biomarkers via hair samples and saliva. The interview guide included 25 open-ended questions on different factors that might facilitate or impede their participation in providing specimens (e.g., community perception, distrust, social support, motivations, peer pressure). We also included questions on their willingness to provide other types of biological samples (e.g., blood, cerebrospinal fluid), engage in other tests (e.g., Magnetic resonance imaging [MRI] and Computed Tomography [CT scan]), and explored under which conditions and contexts these would be provided (For example: What would be an ideal situation for you to provide a blood sample? Describe it to me. Under what conditions you would consider having an MRI as part of a research project?).

Rapid HIV test. We used the OraQuick Advance® Rapid HIV-1/2 Antibody Test, which detects antibodies to HIV-1 and HIV-2 in oral fluid (saliva) or finger-stick whole-blood specimen. This is an FDA-approved rapid assay that can be used with oral fluid (Armington, 2005)

Cortisol test. We used the hair collection protocol recommended by the Behavioral Immunology and Endocrinology Laboratory. This protocol assesses cortisol levels via a small hair sample. Details of the protocol are explained below.

Procedure

Once eligibility was determined and the nature of the study was explained in detail, screened participants were invited to engage in our study. The sample collection and interviews took place in our research field office, which was centrally located in the Santurce sector of San Juan (within a 5-minute walking distance from where most of the transwomen community works during the weekends). Once arrived at our field-based office, participants completed an informed consent form. We then explained to them in detail how the biological samples would be gathered, that is, we were going to collect approximately 5mg of hair from the posterior vertex on the back of the head. A unique numeric identifier was used to protect confidentiality. Next, a rapid HIV test (OraQuick Advance®) was carried out via an oral swab. Participants were instructed to swab saliva from between the teeth and upper and lower gums once. A team member
who was a certified HIV counselor assisted with both sample collections.

After the saliva and hair samples were obtained we invited them to participate in an in-depth interview. The in-depth interview, which was conducted in Spanish, took place immediately following collection of these biomarker samples. Interviews were audio-recorded and transcribed. After completion of the interview, participants met with the HIV counselor to receive the HIV test results and relevant treatment information (i.e., referral to the AIDS Clinical Trial Unit (ACTU) for a confirmatory test in case of a positive result, counseling and treatment) and support. We purposefully followed this sequence so that interviews would not be affected by receiving a positive test result first. Participants received $75 incentive to cover their time and effort related to their participation.

Analysis

Analysis of biomarkers. The saliva sample was analyzed according to the instruction of the OraQuick Advance® standard operating procedure. Results were known approximately 20 minutes after the collection of saliva. The collection of hair samples was implemented per the protocol of the Behavioral Immunology and Endocrinology laboratory in Colorado where the samples were sent for analysis.

Analysis of in-depth interviews. Transcriptionists at the UPR-MSC transcribed all interviews. To ensure the quality of the transcripts, we supervised the transcription process to guarantee fidelity with the audio-recordings (Markle, West, & Rich, 2011). After transcriptions were carried out, the team read the transcriptions while listening to the audio-recording to identify inconsistencies between them. The team met and corrected all errors in the transcriptions. Once this process was completed for each audio-recorded interview, the content analysis began. All transcripts were coded and analyzed using NVivo software (V10). Coding occurred in two stages. Stage 1, included “in vivo” coding grounded in participants’ verbalizations. This stage involved and open coding using summary statements of emerging themes. This process led us to the development of a focused codebook. The application of the codebook marked the beginning of Stage 2, which entailed the application of codes by assigning each transcript to two team members who coded, co-reviewed, and discussed coding decisions during team meetings for this purpose. Once data were coded in NVivo, we performed a systematic analysis using several procedures that included the examination of the variation along individual codes across our sample and the analysis of the variations in the data by examining how specific instances of codes are related to the context of meaning and experience for specific individuals.

RESULTS

Provision of Biomarkers

Although the final sample of our feasibility and acceptability study was 10 participants, we had initially planned to recruit 20 to account for participants who would decline to engage in a research effort that included biomarkers. This would have allowed our team to document reasons why transwomen would not want to engage in this type of study. However, contrary to our expectations, all transwomen we approached agreed to participate in our study. This was the first important finding of our effort: All contacted individuals engaged in our study and provided both saliva and hair samples.

All participants reported being tested for HIV between 3 and 8 months prior to our study. Before the administration of the OraQuick Advance®, two participants mentioned they were sure their results would be HIV-negative, the others (80%) were unsure or felt worried about the results. After the administration of the rapid test, two participants had positive results for HIV antibodies (20%) and were referred to ACTU for confirmatory analysis and treatment.
Cortisol levels varied between participants and ranged from 8.64 to 42.32 pg/mg (See Table 1). Some participants \((n = 3)\) had hair cortisol levels that exceeded what laboratories have established as norms (5.9 to 22.6 [Rocky Mountain Analytical, 2014]), but still we need to take into consideration that range of cortisol levels is known to vary across populations (e.g., racial/ethnic, gender and age variations).

**TABLE 1.**
Cortisol Level of Participants (N=10).

<table>
<thead>
<tr>
<th>Participant</th>
<th>Hair weight (mg)</th>
<th>pg/mg (cortisol)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>9.52</td>
<td>8.64</td>
</tr>
<tr>
<td>2</td>
<td>12.54</td>
<td>9.52</td>
</tr>
<tr>
<td>3</td>
<td>13.26</td>
<td>29.52</td>
</tr>
<tr>
<td>4</td>
<td>11.06</td>
<td>12.56</td>
</tr>
<tr>
<td>5</td>
<td>11.79</td>
<td>13.84</td>
</tr>
<tr>
<td>6</td>
<td>5.85</td>
<td>24.88</td>
</tr>
<tr>
<td>7</td>
<td>19.42</td>
<td>18.48</td>
</tr>
<tr>
<td>8</td>
<td>16.26</td>
<td>42.32</td>
</tr>
<tr>
<td>10</td>
<td>16.97</td>
<td>11.04</td>
</tr>
</tbody>
</table>

Note: Normative range is 5.9 to 22.6 pg/mg. \(^{2} n=10\)

Interestingly, most participants mentioned they expected their level of cortisol to be high because they were typically extremely stressed due to the nature of their work (i.e., sex work). Others shared additional stressors such as the pressure of having many debts, anxiety related to difficulties accessing hormones, and, uncertainty of not knowing if they would be successful in obtaining sex reassignment surgery.

**Reasons for Participation**

As stated above, all participants agreed to provide both the saliva and hair samples, and shared with us they felt comfortable during the process of collecting these samples. When asked about their motivation to provide these biological samples, they mentioned several reasons. Most participants \((n = 7)\) verbalized they felt curious about their health status: “I would do it, not because of the money but to know how healthy or sick I am” (P05) and:

I’m curious of how I am. I would like to know my results regarding my hormone levels, how my neurological system is working and what are the effects of stress on my body. I like studies that really have an impact, you know… (P07)

It’s possible that one could feel weird [providing samples] because I have never participated in a study like that, but there is a first time for everything… and if you don’t take the risk, you won’t know if you have a certain disease or something. You’d never know… (P03)

I would like to know if I really suffer from stress or not. Look, once I lost a lot of my hair… My hair was very long [showing the length on her back] and it started to fall out… I thought then that I was very stressed and depressed. I had to wear a headband to cover the part of my head where I had a bald patch (P02)

Half of them mentioned that they were motivated by the opportunity to contribute to knowledge about the transgender community:

Ehh… I feel motivated mainly because… Oh God, let me express myself well: The main motivation for me is to know the impact of stress on Puerto Rican transsexuals. (P06)

I have always participated in your studies. What motivates me is everything that is related to our wellness as transwomen and to create knowledge on issues that directly affect us. (P08)
Two participants explicitly mentioned their trust of our research team. One of them said: “I support your research because I know you are serious people. I trust your research...” (P01).

Potential Provision of other Biomarkers

We explored participants’ willingness to provide other types of biological samples for further studies related to HIV and chronic stress. Specifically, we explored their opinions about providing saliva for cortisol tests, blood, and cerebrospinal fluid and engage in tests such as MRI and CT scan. Below we describe results for each type of specimen/test.

Saliva. Saliva gathering to measure cortisol levels requires the collection of several samples at specific times of the day (30 minutes after awakening –before breakfast and brushing teeth; before lunch; before dinner; before bed time –preferably at least one hour after dinner) (Labrix, 2015). These specimens need to be stored in a refrigerator. These requirements could entail a complex challenge to transwomen who engage in sex work because their patterns of sleep are not typical. However, most of them (80%) identified that they were willing to participate in a study with such a strict regimen for saliva collection.

Blood. Nine out of the ten participants in our study reported that they were willing to provide blood samples to assess overall health. Eight mentioned that the best time of the day to obtain a blood sample would be during the nighttime to avoid interfering with their rest. Forty percent (n = 4) mentioned that they would need transportation if the sample collection process would take place in a laboratory facility. Half of the sample reported they would require a monetary incentive due to the more invasive nature of the test. One participant mentioned the following:

I’ll be honest and don’t want it to sound like ‘Look, they [transwomen] just want to participate because there is an [monetary] incentive’. It’s not just that. It’s part of it because many times we must be on the streets [working] because we have to pay this or the other thing. And we must decide which thing we are going to pay first. So, for me [the money] is very important, but in addition I love to be part of studies that are related to transgender health. Studies that could help us advance the fight for our rights. In short, I would need transportation and monetary incentives because we are totally broke. (P10)

Cerebrospinal fluid. Cerebrospinal fluid collection is a test to look at the fluid that surrounds the brain and spinal cord. Usually it is used to diagnose medical disorders that affect the central nervous system. In patients with HIV, this kind of test is important to evaluate HIV dementia and the correlation of hormones with oxidative stress (Rozek et al., 2007). It involves a highly invasive test, which understandably can generate anxiety among potential participants. There are different ways to get a sample of cerebrospinal fluid. Lumbar puncture (spinal tap) is the most common method (MedlinePlus, 2017).
Half of participants in our sample (n = 5) were reluctant to consider providing cerebrospinal fluid mainly due to fear of the process. For example, one transwoman stated:

Uy! It scares me. That scares me…One should never say: ‘De esta agua no beberé’ (I won't drink from this water) you know…Maybe you say no and then you face a situation that requires it even though you said you wouldn’t do it. Maybe you ‘estás mala’ (you’re sick) and you end up in a hospital and you have to do it anyways. (P03)

Among those who reported willingness to provide such a sample, one of them mentioned that the monetary incentive should be at least $1,000. The rest mentioned that they needed to be sure that they would feel no pain or discomfort during the process of fluid collection.

MRI and CT scan. A CT Scan is best suited for viewing bone injuries, diagnosing lung and chest problems, and detecting certain types of cancers. An MRI is suited for examining soft tissue in ligament and tendon injuries, spinal cord injuries, brain tumors, etc. In patients with HIV, these techniques are also helpful to identify neurologic manifestations of HIV (e.g., to gauge HIV’s impact on the brain, to examine the body for changes in fat distribution) (John Hopkins Medicine, 2017). CT scans are widely used in emergency rooms because the scan takes fewer than 5 minutes. An MRI, on the other hand, can take up to 30 minutes to complete (Shields Health Care Group, 2013).

All participants were enthusiastic about the possibility of participating in a study that required the use of MRI or CT scans. The reasons were related to their wish of being checked “internally” (n = 4). One participant mentioned: “That would be spectacular! I need to know more about my body because I am completely made of silicon: lips, cheeks, chin, breasts, buttocks, hips…” (P08). Another participant expressed the following:

I’d really be interested in a study like that. An MRI! I’m anxious about knowing what are the side effects of taking hormones for so many years. I’m feeling weird and don’t know if it could be related to the hormones… (P05)

Three transwomen mentioned that they would need transportation. The same amount (3) preferred this procedure during the morning. In terms of incentives, one participant mentioned that she would do it for $50, while another said that she would participate even if there were no monetary incentive at all.

DISCUSSION

It is vital that Health Psychology research with transwomen in Puerto Rico and elsewhere move beyond the documentation of health problems via self-report. Biomarkers for HIV and chronic stress can be powerful tools to better describe and understand the health status and health disparities of transwomen, and to inform the development of health promotion interventions.

All the transwomen that we recruited decided to participate in our study and provide both saliva and hair samples. We did not encounter a potential participant unwilling to engage in our feasibility and acceptability study. It took us two visits to the field to complete recruitment. Initially, we thought that due to the nature of procedures for biomarker collection some would decline to participate. We also believed that transwomen would be reluctant to provide hair samples out of concern for how this procedure might impact their physical appearance, reflecting the great importance of the way their hair looks as part of affirming their gender identity. In our prior work, transwomen in this context emphasized the commitment and hard work to project a
feminized appearance, and their hair is an essential aspect of this process. However, none of our participants mentioned any concern about a potential threat to their aesthetic appearance.

Their overall willingness to engage in a study with biomarker sampling allowed us to explore their motivations behind their willingness; and through the interviews, we learned about the potential limits of such participation. Our results revealed three main motivations for participation that should be considered in future studies: 1) desire to know about their individual health, 2) perceived need to contribute to a better understanding of health in the transgender community, and 3) previous positive experiences with our research team (some of them had participated in prior studies on transgender health implemented by our team). Contrary to what one would expect based on reports in the literature about distrust of the health care system and multiple competing demands, our findings indicated that transwomen may be highly motivated to learn more about their personal health and welcome the available medical technology if the procedures are not too invasive. And even for those that are invasive, given the proper considerations (timing, compensation, reassurance of understandable fears), it seemed that participants were willing to consider it.

Participants were aware of the high levels of stress they were experiencing as well as the potential negative impact of such body modification procedures as hormones and especially silicone injections on their health. These concerns are revealing and reflect the dismal situation in terms of access to transgender-specific as well as general health care for the transgender community in Puerto Rico. Other than governmental or community-based programs that exist sporadically, there is no consistent and ongoing health care tailored to the needs of transwomen in Puerto Rico, and the stigma and lack of cultural and clinical competence among mainstream providers is a major barrier to accessing care (Rodríguez-Madera, Varas-Díaz, Ramos-Piburnus, Neilands, Rivera Segarra, Pérez, & Bockting, in press). Our finding of a strong motivation on the part of Puerto Rican transwomen to learn about their health is inspiring and a call for health providers and policy makers to respond to this enthusiastic demand. It is noteworthy, that even in this small feasibility study, two participants were able to learn about their HIV status and were linked to care, yielding immediate benefits.

Concerns about the health of the transgender community appeared just as important as concerns for their individual health. Participants mentioned repeatedly their motivation to contribute to the health of their community. Future studies should continue to consider and respond to participants’ sense of collective identity and altruism to their peers. This includes the collection of biomarkers, which might seem like an individual level process, but seemed to also have communal meanings for the transwomen in our study. Solidarity with other transwomen was an important aspect of their decision to engage in our study.

Several participants mentioned that they felt comfortable engaging in the provision of biomarkers considering their previous participation in our research studies. Our team has approached the transgender community in Puerto Rico via participatory research strategies such as: implementation of ethnography with the collaboration of key informants, provision with results from our efforts through diverse initiatives and, incorporation of some transwomen as consultants and including them as co-authors in formal presentations and publications (Padilla et al., 2016; Rodríguez-Madera et al., 2016, 2015; Rodríguez-Madera & Toro-Alfonso, 2008). We also have implemented community engagement strategies via provision of condoms during our systematic visits to the field, implementation of psychosocial workshops on topics previously
identified as needs (e.g., family issues, conflict management), and helping them receive funding for community specific agendas. In addition, our project has been consistently conducting advocacy with them on policy issues. This approach has evidently fostered a sense of trust and solidarity between the community and our research team.

Our findings also stress the need to consider the sociocultural context of transwomen in Puerto Rico. Puerto Rican transgender women frequently encounter many economic difficulties -due to lack of employment, as well as challenges accessing basic resources. Therefore, economic incentives and basic accessibility issues (i.e., transportation) are especially important to foster participation in future studies.

Limitations

We understand that because this was a feasibility study, the small sample is an important factor to be considered when interpreting our results. Thus, we cannot generalize that transwomen in San Juan metropolitan area or in other towns of Puerto Rico will be willing to provide biological samples.

Recommendations and Conclusions

We hope that the results from this feasibility and acceptability study shed light on the potential use of biomarkers with marginalized, underserved populations such as transwomen in Puerto Rico. Future studies related to Public Health and Health Psychology need to augment self-report data with biomarkers. Considering the high prevalence of certain health conditions among transwomen (e.g., cardiovascular disease, cancer, depression, anxiety, substance use disorder) (American Medical Student Association, 2016; Bockting et al., 2013; Program for LGBTI Health, 2016), there is a need to identify biomarkers that enhance our understanding of the mechanism underlying the complex interactions between chronic stress and these conditions. There are current initiatives to identify and discuss promising technologies for biomarker discovery and validation (Yuan et al., 2016). Considering the fertile ground for studying biomarkers among the transwomen population, our next step will be to incorporate biomarker collection to assess the impact of chronic stress on multiple bodily systems to help move forward a research agenda on transgender health in Puerto Rico that understand its health from a holistic, integrated perspective.

REFERENCES


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