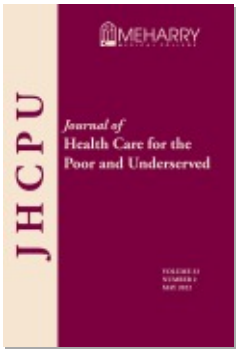
In Our Own Voices: The Lived Experience of Sex Workers in Philadelphia who Identify as Women



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ORIGINAL PAPER

In Our Own Voices: The Lived Experience of Sex Workers in Philadelphia who Identify as Women

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Abstract: Sex workers face many occupation-specific health challenges, including facing stigma in health care settings. There is a lack of both quantitative and qualitative research regarding sex workers in the United States. **Methods**. Hermeneutic phenomenology and Harding's feminist theory guided the qualitative portion of this mixed-methods study that also included a quantitative health needs assessment. Private interviews were conducted with a purposive sample of sex workers recruited from a drop-in support center for cis- and transgender individuals identifying as women. **Results**. Issues of homelessness, food insecurity, and personal safety were among the women's top health-related concerns (n=29). Seven themes emerged from qualitative data after transcripts were reviewed, reflected upon, and validated with a focus group at the center. Extraordinary emphasis was given to the theme, "I am a person." **Conclusion**. This study helps to illuminate the lived experience and health risks of being a woman-identified sex worker in Philadelphia.

Key words: Sex work, lived experience, health promotion, prostitution, health concerns, trauma informed care.

Lack of knowledge among health care providers of the lived experience of sex workers is a public health problem. The lived experiences of sex workers are intertwined with their health. When health care providers and public health officials lack understanding regarding how exactly these lived experiences affect the health, health encounter preferences, and health care utilization of sex workers, then providers are not equipped to adequately address the health care needs of this population. At present, research expanding such knowledge is lacking.

Sex workers who identify as women have multiple health risk factors that include unstable housing, unemployment, incarceration, mental illness, emotional/physical/sexual abuse, substance abuse, and sexually transmitted infections.[1–7] They may be more likely than non-sex workers to undergo reproductive coercion.[8] A 2009 study found that among sex workers surveyed, pressure to have unprotected sex was associated with client

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perpetrated violence.[2] Sex workers are often unrecognized by obstetrician-gynecologists because information about sex work is absent from routine sexual history taking, which inhibits sex workers who identify as women from receiving essential health services.[8] Sex workers often do not seek out health care because of fear of provider judgement.[9] In one 2017 study, sex workers felt unable to discuss sex work and process unresolved trauma while in drug treatment because of stigma, which undermined their treatment outcomes.[10]

The agency of sex workers is frequently not acknowledged by researchers and health professionals.[11] A 2017 study among North American sex workers found that they had the self-awareness and self-efficacy to identify the following resilience-promoting factors: validating sex work and eliminating whorephobic oppression; safety and mobility within work environments; sexual boundary-setting; and social support.[12] Health care providers do not often recognize or acknowledge these factors promoting resiliency and health. A photovoice project among sex workers demonstrated narratives centered within an autonomy, human rights, and self-regulation framework as a means of resisting narratives revolving around discrimination, violence, and trafficking.[13]

Harding's feminist theoretical framework provided the lens through which this project was conducted. This lens prioritizes researching women's experiences from the perspective of the women living those experiences.[14] Feminism stresses that women's experiences and perspectives are authoritative sources of knowledge.[15] Feminism is a useful lens for the qualitative portion of this study because participants identifying as women are considered experts pertaining to their experiences. Feminist theory is compatible with the health needs assessment portion of this study because participants self-identified their health needs for researchers to disseminate to the larger medical and public health community. This study creates new knowledge about women-identified (both cisgender and transgender) participants in their own context, providing a voice to marginalized individuals whose experiences have largely been ignored by researchers.

Objectives. This study's aim is to begin to fill the gaps in our knowledge concerning how the lived experience of being a woman (i.e., a cisgender or transgender woman) sex worker affects her health, health preferences, health needs, and health care utilization. The findings may help clinicians gain insight into best practices for providing comprehensive care for women sex workers within the context of these patients' lived experiences. To our knowledge, a similar study has not been conducted in the United States.

Methods. *Study setting*. Prevention Point, a community-based agency in the city of Philadelphia (that was originally founded for clean needle exchange for intravenous drug users) hosts a program called *Ladies' Night*, an evening drop-in support group for people who identify as women. There are two large community rooms at this agency where a buffet-style dinner is served, there is a bathroom equipped with a shower, and several private medical examination rooms flank the larger rooms. Only people who identify as women (either cis- or transgender) are permitted to attend Ladies Night in order to promote an atmosphere perceived as "safe" without the intrusion of people identified as men. Identifying as a woman is the only requirement to attend Ladies' Night.

Study participants. English-speaking participants at least 18 years of age who identified as women were eligible for this study and were recruited via purposive sampling.

In addition, an affirmative response to the following question was a requirement of the study: *Have you ever had sex in exchange for money, food, or drugs?* Potential participants were recruited for the study by means of study flyers that were posted in the agency community room, as well as periodic announcements by Ladies' Night counselors on the evenings that the researchers were present. Participants were compensated for their participation with gift cards to a national chain pharmacy with a location in the neighborhood. This study was approved by the executive director of the agency as well as the institutional review board (IRB) of our university. Spoken informed consent was obtained prior to entrance into the study. Written consent was waived by the IRB, as the greatest risk to potential participants would be a breach of confidentiality. Participants were identified by number only in order of enrollment, and all information collected was securely stored and de-identified for reporting in order to protect confidentiality.

Interview content. The qualitative, semi-structured interview guide consisted of open-ended questions that were selected to reveal the central characteristics of the phenomenon under study, i.e., the lived experience of the participants in their own words. (Refer to Box 1 for a sample of the interview questions.) In addition to approval by the IRB, interview questions were also approved by agency social workers who had initial concerns about the potentially traumatizing nature of some of the questions. The quantitative survey component was adapted from the previously validated Centers for Disease Control (CDC) Reproductive Health Assessment Questionnaire (Version 04-28-2011).[16]

Box 1.

SEMI-STRUCTURED INTERVIEW QUESTIONS (ORDER AND EXACT PHRASING VARIED ACCORDING TO LEAD OF PARTICIPANT)

- Tell me about a typical day for you.
- Tell me about how you perceive your health.
- What factors in your life have contributed to wellness or to poor health?
- How have you felt about interactions with health care providers? Why?
- What do you consider "good" health care to be and why?
- What do you consider "bad" health care to be and why?
- Where do you get your health care? Why do you choose that (those) institution(s)?
- Tell me about your current housing.
- How, if at all, do you feel housing contributes to your health?
- Do you want health care providers to know you have exchanged sex for money, food, housing, or other things?
- When seeking health care, what is most important for your health care provider to know about you?
- What else is important for a health care provider to know about your experience?
- Is there anything else that is important to you that we didn't cover in the interview?

Study procedures. Once potential participants were identified, they met with the researcher in a private exam room. Once spoken informed consent was obtained from qualified participants, the quantitative survey was administered via paper and pencil. Subsequently, the qualitative semi-structured interview was conducted and recorded with a Zoom (Zoom NA: Hauppauge, NY) audio recorder, with additional field notes taken by the researcher. The audio recording was transcribed verbatim into written transcripts via NVivo (QSR: Australia) transcription services. Transcripts were read repetitively and statements or phrases that seemed particularly revealing about the experience being described were highlighted line-by-line, according to the method of vanManen.[17] Commonalities in the phrases were grouped into themes with further reflection. Data saturation was presumed once no new themes emerged, and study enrollment ceased. The themes (and supporting phrases) were presented to a focus group of Ladies' Night attendees who had not participated in the study, were reviewed and confirmed for validity. Themes were further reviewed in a presentation to agency staff (working with this population on a daily basis) who confirmed the perceived trustworthiness of the data.

Results

Survey data. Thirty-one women agreed to participate, but two were excluded because they answered no to the question, "Have you ever had sex in exchange for money, food, or drugs?" A total of 29 individuals identifying as women (cis- and transgender) completed the study. The age range was 27–59 years, with a mean age of 42 (±9) years. Sixteen (55%) of the women identified as White, non-Hispanic; six (20.7%) identified as Black; four (13.7%) as Hispanic; one (3.4%) as Asian/Pacific Islander; and two (6.8%) as mixed race. Participants were queried about their most important concerns regarding life and health. In response to the question, *What is your biggest health worry?*, concerns varied from sexually transmitted infections to diabetic neuropathy (Table 1). In some instances, the responses were the same for both *biggest life worry* and *biggest health worry*. Twenty-four (82.7%) of the 29 women reported homelessness and were staying in a temporary shelter or living on the street. Many participants revealed that they were suffering from chronic health conditions that required ongoing treatment that was difficult to manage in conjunction with homelessness (Figure 1). Twenty-six (90%) of the women reported food insecurity (having difficulty buying enough food). Twenty-two (76%) of the women reported needing help with substance abuse treatment (most commonly for heroin substance use disorder).

Thematic analysis. Several themes emerged from the qualitative data which were analyzed following the method previously described by vanManen. These seven themes are presented in Box 2.

Discussion

Lived experiences. This study achieved its primary objective of illuminating the lived experience of sex workers who identify as women in Philadelphia, Pennsylvania. The neighborhood of Philadelphia where this study was conducted (Kensington) has been

Table 1.

SELF-IDENTIFIED CONCERNS OF PARTICIPANTS (N=29)

Participant #	Biggest life worry	Biggest health worry
1	Addiction to heroin	Hepatitis C
2	Homelessness	Scripts get stolen
3	Homelessness	Methadone
4	Gonna get killed	Gonna get HIV
5	Homelessness	Blood clot in brain
6	Addiction to heroin and cocaine	Lung cancer, seizures
7	My health	Diabetic neuropathy
8	Living on the streets and dying	None
9	Shelter	Was sober for 2yrs, then started eating as addiction
10	Catching AIDS	Catching AIDS and abscesses from using
11	Overdosing and catching HIV	Overdosing and catching HIV
12	Money and drug addiction	Worried about STIs
13	To get off drugs	To get off drugs
14	Get my life on track	My addiction to heroin, a bunch of things
15	Staying clean	Staying clean
16	Finances	Catching a disease
17	Homelessness	Hepatitis C
18	No income	Getting older
19	My health	Working hard not to use, clean for 2 days
20	Stupid stuff	Anxiety
21	Life, struggles, "getting it together"	Depression, worried about lungs
22	Having disease	Problems with my heart
23	My son, my addiction	Born with HIV (self)
24	On the streets right now, getting kids back	Hep C
25	Medical health	Need medication and can't afford it
26	Living on the street	Liver failure- stage 2 cirrhosis of the liver
27	Money	Getting Hepatitis C healed
28	Kids	COPD
29	Getting Hepatitis or AIDS	Getting Hepatitis or AIDS

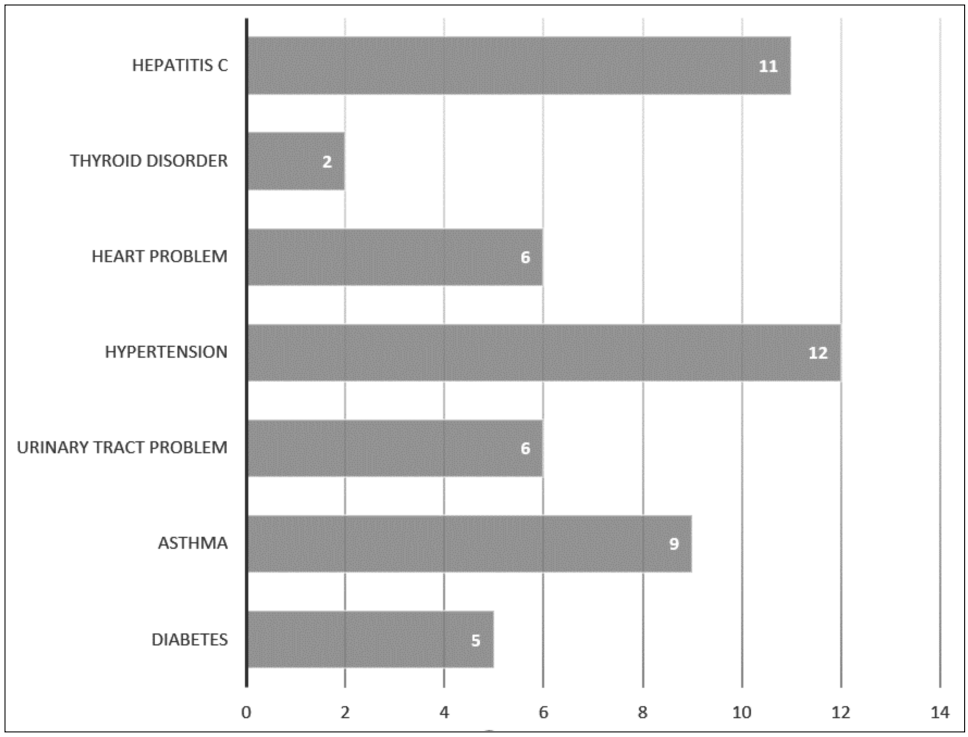

Figure 1. Prevalence of medical co-morbidities found in study participants (n=29).

considered to be the epicenter of the city's opioid crisis.[18] Because of this, the participants in this study may be very different from sex workers who identify as women in other urban or rural environments, thus limiting potential transferability of results. One of the strengths of this study was the trustworthiness of the data, validated by key informants who echoed the veracity of the themes identified. Additionally, we concluded that several of the themes resonate not just with this population of sex workers who identify as women but can be recognized as essential common human needs. To be treated as a whole person (and not just as any type of worker or object) is a fundamental human desire. However, what makes this concern particularly salient for sex workers is that they have *typically* been objectified in the extreme and experienced treatment from others as less than human. The patriarchal White male-dominated society found in the United States exacerbates this objectification.[19] Phenomenological research requires the researcher to set aside preconceived notions about the population under study in order to be able to truly capture the central characteristics of the phenomenon with minimal bias. While the study findings were corroborated by an independent focus group of sex workers who identify as women, it is impossible for the researchers to completely remove their biases in their interpretation of the qualitative data. Specifically, the researchers are clinicians and do not have the experience of being sex workers. Thus, the researchers' perspective may have influenced the analysis of the qualitative data.

Box 2.

THEMES AND REPRESENTATIVE QUOTE(S)

Theme	Representative Quote(s)	Clarifying Notes
I am a person.	"See me as a person, not just a drug addict"	
One day at a time	"I get up. I try to figure out my way to get well. I get high so I'm not sick. Doesn't even get me high though I basically get well so I'm not sick. And um . . . I go around to panhandle. I still um, I try to get by my day"	Participants detailed the chronology of a typical day and underscored that living each day meant functioning from moment to moment without much advance planning.
The system works against me	"I try applying for jobs but you get none. They look at you, you know and then they could tell you know they're homeless or whatever. So it has been really hard trying to get a job. So that's why I'm doing what I'm doing right now"	Most of the women voiced this concern, although one member of the focus group disagreed and voiced that "some people are making excuses—you can come here (to the community agency) to get a shower and clean clothes".
Hustling and surviving	"We do all we have to do for money. Panhandle and go on a date to make money. I have clients so it gets kind of complicated"	Women detailed how they were able to earn money. Sex work was seen as accessible to them as a means to survive. To "go on a date" was a phrase often used; in this population, meaning to have transactional sex.
Good Health Care	"Someone that would have time for me and not rush me" "I have a good doctor, I can be HONEST with him. I feel safe with him"	Participants were clear in describing their expectations of health care, which appeared almost entirely synonymous with descriptions of health care providers (as opposed to institutions).
Bad Health Care	"Being a drug addict, they treat you differently like you're shunned upon. They don't take the TIME" "They don't make you feel comfortable enough to TELL THEM WHAT'S GOING ON WITH YOU"	Participants were clear in describing their expectations of health care, which appeared almost entirely synonymous with descriptions of health care providers (as opposed to institutions).
Thank God I'm Still Alive	"You know I thank God. You know I take one day at a time" "Almost dying from overdosing. Oh, many times. And when I re-evaluated my logic, once I found out methadone can help with pain, I just I finally had an EPIPHANY and got my shit together"	Many of the women expressed spiritual gratitude. Many women also expressed that they were aware of other people (family, friends) praying for them and for the most part, seemed to appreciate that as a demonstration of caring.

Survey data. We had anticipated that the availability of certain reproductive procedures and devices such as pelvic examinations or contraceptive items would be of paramount importance to the women. The women in this study clearly expressed that women's health care is more about care of the whole person beyond reproductive health. In fact, reproductive health was not listed as one of the women's top concerns. Some of this may have been related to the age of the women, many of whom were considerably older than what we had anticipated and beyond their reproductive years. Instead, we encountered participants' desire to be heard fully as human beings, and to be given the respect of time and attention.

Lessons for providers. Multiple participants discussed the importance of being comfortable with and the ability to be honest with a health care provider about their engagement in sex work. Clinicians should ask patients whether or not they engage in sex work as part of routine sexual history taking. This question should be asked in a trauma-informed manner, and clinicians should be trained in how to ask about and how to respectfully listen to patients for whom sex work is a reality. According to the Substance Abuse and Mental Health Services Agency (SAMHSA), some components of trauma-informed care that clinicians can work to adopt are ensuring physical and emotional safety defined by clients; trustworthiness and transparency; collaboration and mutuality to decrease power differentials and promote the healing nature of relationships; empowerment, voice, and choice for clients to make collaborative decisions with providers about treatment; and acknowledgment and integration of cultural, historical, and gender issues.[20] Training in trauma-informed care for providers should take place at health care institutions and health care education entities.

Multiple participants said it was imperative for providers to provide ample time for them to feel comfortable enough to share honestly about their lives. Clinicians should individualize the time needed to see patients. Clinicians should consider expanding the length of visits from 15 minutes to 30 to 60 minutes and/or having multiple visits. This is especially important if the clinician knows the patient is engaged in sex work, experiences housing insecurity, uses drugs, or is involved in any combination of the three. Participants expressed the importance of having a provider who will do more than "throw a pill at you," which underscores the importance of clinicians referring patients to mental health care beyond medication management alone. This care could incorporate psychotherapy and mindfulness-based stress reduction.

Clinicians can learn from the Engage, Motivate, Protect, Organize, Self-Worth, Educate, Respect (EMPOWER) Clinic for Survivors of Sex Trafficking and Sexual Violence. It provides long-term integrated trauma-informed gynecological and psychiatric care for survivors of sexual trafficking and gender-based violence.[21] While these circumstances may not apply to everyone, EMPOWER's non-judgmental, strength-based approach offers many strategies for how clinicians could provide better care for sex workers who identify as women. They incorporate comprehensive psychiatric care including therapy into their practice, which streamlines referral to mental health services. EMPOWER's trauma-informed approach to history taking includes ensuring patients are fully clothed, attentive listening, and avoiding overwhelming and/or rushing the patient. Patients are given the space to describe their life circumstances in a non-linear pattern. Confidentiality is reiterated and, if a referral is being made, the patient is specifically

asked what details about their history and care may be shared with whom. Clinicians regulate their body language by having their arms uncrossed and hands in view, facing the patient, maintaining eye contact, avoiding blocking the door, avoiding typing or appearing distracted, and asking for permission before and thoroughly explaining the reason behind physical contact. Clinicians are trained to believe and validate patients; use non-judgmental, empowering language such as "sex without a condom" instead of "risky sex;" and normalize the experiences of patients.[21]

Policy recommendations. Decriminalization of sex work is a policy initiative that would allow many more women to reveal if they engage in sex work.[20] This would also allow for health care providers to "hear the truth" and better address their health care needs.

Conclusion. This study aimed to learn how the lived experience of being a woman (i.e., a cisgender or transgender woman) sex worker affects her health, health preferences, health needs, and health care utilization. The main themes that arose from participant responses were the desire to be seen as a person; living day by day; hustling and surviving; defining what good and bad health care means; and gratitude for being alive. Participants expressed the importance of feeling comfortable speaking honestly with health care providers about sex work and having mental health services beyond medication management alone. Models that can serve as starting points for clinicians to create safe spaces for sex workers include incorporating some of the themes presented in this study, as well as incorporating the principles of trauma-informed care.

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