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Fifty Shades of Stigma: Exploring the Health Care Experiences of Kink-Oriented Patients

Jessica F. Waldura, MD,[1,2] Ishika Arora, BS,[1] Anna M. Randall, DHS,[2] John Paul Farala, MD,[1] and Richard A. Sprott, PhD[2,3]

ABSTRACT

Introduction: The term *kink* describes sexual behaviors and identities encompassing bondage, discipline, domination and submission, and sadism and masochism (collectively known as BDSM) and sexual fetishism. Individuals who engage in kink could be at risk for health complications because of their sexual behaviors, and they could be vulnerable to stigma in the health care setting. However, although previous research has addressed experiences in mental health care, very little research has detailed the medical care experiences of kink-oriented patients.

Aim: To broadly explore the health care experiences of kink-oriented patients using a community-engaged research approach.

Methods: As part of the Kink Health Project, we gathered qualitative data from 115 kink-oriented San Francisco area residents using focus groups and interviews. Interview questions were generated in collaboration with a community advisory board. Data were analyzed using a thematic analysis approach.

Main Outcome Measures: Themes relating to kink-oriented patients' experience with health and healthcare.

Results: Major themes included (i) kink and physical health, (ii) sociocultural aspects of kink orientation, (iii) the role of stigma in shaping health care interactions, (iv) coming out to health care providers, and (v) working toward a vision of kink-aware medical care. The study found that kink-oriented patients have genuine health care needs relating to their kink behaviors and social context. Most patients would prefer to be out to their health care providers so they can receive individualized care. However, fewer than half were out to their current provider, with anticipated stigma being the most common reason for avoiding disclosure. Patients are often concerned that clinicians will confuse their behaviors with intimate partner violence and they emphasized the consensual nature of their kink interactions.

Conclusion: Like other sexual minorities, kink-oriented patients have a desire to engage with their health care providers in meaningful discussions about their health risks, their identities, and their communities without fear of being judged. Additional research is needed to explore the experiences of kink-oriented patients in other areas of the country and internationally.

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Key Words: Kink; BDSM; Fetish; Sexual Minority; Health Care; Stigma; Qualitative Research

INTRODUCTION

An estimated 2% to 10% of the U.S. population engages in non-traditional sexual practices, commonly called *kink* or *BDSM* (bondage, discipline, domination and submission, and sadism and masochism).[1,2] These practices occur between consenting adults and can include activities that create intense sensation, physical restriction (bondage), and/or elements of "power exchange," in which one party takes on the role of the "Dominant" or "Top" and gains temporary and limited power over the "submissive" or "bottom."[3] It also can include erotic role play or sexual fetishism. Although kink, BDSM, and fetish practitioners

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[1]Department of Family and Community Medicine, University of California—San Francisco, San Francisco, CA, USA;

[2]The Alternative Sexualities Health Research Alliance (TASHRA), Berkeley, CA, USA;

[3]Department of Human Development and Women's Studies, California State University, East Bay, CA, USA

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use different terms to describe themselves, we used the term *kink* as the most inclusive term for this heterogeneous population.[4,5] Individuals vary widely in their level of engagement with kink. For some, it can occur solely during a phase of sexual exploration or only with certain partners; for others, it can be a lifelong and immutable aspect of their sexuality, along the lines of a sexual orientation.[6,7] For simplicity, the term *kink oriented* is used to refer to all individuals along this spectrum.

Kink activities are often designed to create powerful physical or psychological experiences and, as such, can pose health risks.[3] For example, kink behaviors such as biting, whipping, or rope bondage can lead to physical injuries.[8] Other activities such as inserting a whole hand into the vagina or anus (fisting) or the use of hypodermic needles to produce temporary piercings can expose individuals to an increased risk of sexually transmitted infections (STIs) or blood-borne pathogens.[9] In addition, individuals whose sense of self is deeply tied to their kink orientation can suffer from minority stress because their sexual behaviors and identities are often socially maligned.[10–12]

The link between kink orientation and social stigma is concerning because studies have documented the negative impact on health care access and usage when patients experience stigmatizing interactions with medical professionals.[13] Delays in seeking medical care, decreased testing for HIV, and lack of disclosure of possibly relevant sexual activity to health care providers are behaviors that are predicted by experiencing stigmatizing interactions.[14] Furthermore, anticipated stigma (the expectation that others will shun, discriminate, or express prejudicial attitudes if a concealable stigmatized identity is revealed) predicts levels of stress and depression.[15] However, the literature has presented mixed results in detecting a connection between anticipated stigma and use of mental health care services and there has been very little research on anticipated stigma and medical health care usage.[16]

One particular area of concern for kink-oriented people is the issue of consensual kink activities being confused with intimate partner violence (IPV) or abuse.[17–19] Distinguishing IPV from consensual kink activities has been a clear point of activism within the organized kink communities, especially for discussing rights within the legal and social services systems.[20] Given that medical institutions and services are a key area for the assessment of IPV and that little training on kink is offered in medical education, this issue can be a specific factor in the connection between stigma and health care services.

Until recently, the health care community tended to malign kink identity and behaviors, with older literature often using case studies to examine links between kink and psychopathology or criminal behavior.[21,22] However, in the mental health field, professionals have begun producing a growing body of literature examining kink from the perspective of the patient and the mental health provider, with prominent themes being the experience of stigma and issues concerning disclosure of kink orientation (otherwise known as *coming out*).[18,23–25] Furthermore, research has begun examining kink in relation to personality functioning.[26–29] These studies have found kink-oriented individuals to be more extraverted and to have larger numbers of sexual partners; however, they have consistently found no association with mental illness, sexual dysfunction, or distress.

In contrast, the medical community has largely ignored the existence of kink orientation, although it is not rare and has the potential to affect health. Medical schools do not routinely include a discussion of kink sexuality in their sexual health curricula,[30] and with rare exceptions, kink sexuality is not included in continuing medical education offerings for clinicians. In addition, a review of the medical literature found no peer-reviewed clinical research describing the physical health of kink-oriented individuals or their use of health care outside of mental health fields. Therefore, in response to this lack of research, we initiated the Kink Health Project, whose aim was to explore the health and health care experiences of kink-oriented people, with a particular emphasis on discovering kink-related health care needs, and on examining the possible role of stigma in shaping interactions with health care providers. This article presents an overview of the major findings of the project.

METHODS

The Kink Health Project was conducted as a community-engaged qualitative study. The core research team consisted of a family physician and clinical researcher, a developmental psychologist and psychosocial researcher, and a clinical sexologist in private practice and community-based researcher, in addition to two research assistants. The core research team partnered with kink community members at all stages of the project.[31] We began by forming a community advisory board (CAB) consisting of 16 kink community members representing a variety of subcommunities within the kink population. Initial members of the CAB were identified by approaching leaders of publicly visible kink organizations, such as the San Francisco Bay Area Leather Alliance and the SF Citadel. Then, we asked to be referred to kink community members who would enrich the group's diversity. Some invitees had considerable experience with the local health care system as patients, advocates, or providers; some were members of distinct subgroups such as gay male, transgender, or lesbian communities. Together we (i) defined the research questions and study methods, (ii) recruited a diverse group of kink-oriented participants, (iii) engaged in data analysis and in the refinement of focus group and interview guides as the study progressed, and (iv) collaborated to disseminate the findings through academic and community channels.

Our target population was adults older than 18 years living in the San Francisco Bay Area and identifying as kink oriented (or a related term) and/or practicing at least one consensual non-traditional sexual behavior or fetish (self-defined). We recruited participants primarily using a snowball approach, beginning with people referred to us by members of the CAB. We also advertised

the study using social media, at exhibitor booths during San Francisco kink-oriented street fairs, and by stocking local kink-friendly businesses with recruitment materials. As the study progressed, we identified sub-communities whose voices remained under-represented (eg, people new to kink, people of color) and directed additional recruitment efforts toward those participants.

Data collection ran from January 2013 through October 2014. We began with two large focus group "town hall" meetings consisting of 25 to 45 kink community members.[32] The town hall meeting were used to solicit broad feedback about the community's concerns regarding kink and health and findings were used to narrow the focus of the project and create the initial set of focus group and interview questions. Then, we conducted four traditional focus groups with four to seven participants each and 23 individual in-depth interviews.[33] The small focus groups and individual interviews used semistructured guides covering three general domains: (i) the impact of kink orientation on physical and mental health, (ii) experiences with the health care system, and (iii) ideas on how health care providers can deliver kink-aware care. The interview guides served as starting points and session leaders were free to diverge from the guide to explore unexpected findings. Interview guides were revised iteratively in tandem with data analysis (Appendix 1 lists examples of interview guide questions). Participants also completed a short survey consisting of demographic information and kink, sexual orientation, and gender descriptors.

Data Analysis

We followed a six-step thematic analysis approach, as described by Braun and Clarke,[34] guided by an epistemology of critical realism, finding patterns while adjusting for differences between candidate quotations as situated from particular viewpoints of the participants. Candidate quotations were coded as examples of proposed generative mechanisms, such as "anticipated stigma" or "centrality of identity," and other codes were created using an inductive open coding technique. Audio recordings were transcribed verbatim by a professional transcriptionist. We convened the CAB at least once per quarter to review findings, suggest new lines of inquiry, and contribute additional insights. Final codes were applied to the data by one author using Atlas.ti 7.1.1. (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) and were double checked by another author. Discrepancies were resolved through discussion with the core team. Next, the core team organized the coded data into a set of candidate themes. Over the course of several meetings, we chose a final set of themes with associated subthemes and generated a schematic map.

Data from the demographic survey were summarized using Excel (2007; Microsoft, Redmond, WA, USA). Questions with write-in answers (ie, race, gender identity, sexual orientation, kink identities or roles) were transcribed verbatim and then assigned a category according to a coding scheme developed after reviewing the range of values (eg, "gay," "homosexual," and "dyke" were assigned gay or lesbian). For the question about kink identities and roles, we categorized the write-in answer based on a commonly used typology in the kink community, in which individuals describe themselves by the power roles they express during sexual encounters or as part of their identity.[3] Those who prefer to be on the dominant side of a power dynamic or the one applying the stimulation are often referred to as "Top," "Dominant," "Master" etc; these were combined under the term *Top*. Those who prefer to be on the submissive side of a power dynamic or to be the one receiving the stimulation can be known as "bottom," "submissive," "slave," etc; these were combined under the term *bottom*. Individuals who participate in the two roles are often known by the term *Switch*.

Protection of Human Subjects

Institutional review board approval was obtained through the committee on human research at the University of California—San Francisco. No personal identifiers were collected and all participants gave verbal informed consent. Focus group and interview participants were compensated $20 for their time.

RESULTS

We collected qualitative data from 115 participants and demographic data from 99 of those participants (Table 1).

A short survey yielded the following information. Participants' ages ranged from 23 to 69 years (mean = 46 years). Most (81%) were white. Most subjects (79%) were non-heterosexually orientated. Almost one fifth (19%) were gender non-conforming and one participant identified as intersex. Participants' kink identities and roles were fairly evenly divided among the main categories of Top, bottom, and Switch (Appendix 2 presents a full list of kink self-identifiers). Almost half had their first self-defined kink experience before 20 years of age, and most described themselves as at least moderately experienced in kink. Most (87%) considered themselves part of a kink community.

Forty-four percent of participants had visited a medical care provider for a kink-related concern. Of those with a current primary care provider, 38% were out about their kink orientation.

Analysis of the qualitative data yielded five major themes (Figure 1):

1. Kink and physical health
2. Sociocultural aspects of kink orientation
3. Impact of stigma on interactions with health care providers
4. Coming out to health care providers
5. A vision of kink-aware medical care: a patient's perspective

The following section includes quotations from participants using the jargon of the community (Table 2 presents a glossary of terms).

Table 1. Characteristics of participants in the Kink Health Project

Demographic characteristic	n	%
Age (y)		
18–29	13	13
30–44	28	29
45–64	52	54
≥65	4	4
Total	97	100
Gender identity		
Male	47	47
Female	34	34
Gender queer or gender fluid	8	8
Transgender female-to-male	4	4
Transgender male-to-female	1	1
Other (including intersex)	5	5
Total	99	100
Race		
White	79	81
Black or African American	7	7
Asian	0	0
Latino or Latina	0	0
Other or mixed race	11	11
Total	97	100
Sexual orientation		
Straight (heterosexual)	21	21
Gay or lesbian (homosexual)	29	30
Bisexual	25	26
Queer	20	20
Other	3	3
Total	98	100
Kink role		
Top, dominant, master	28	29
Bottom, submissive, slave	29	30
Switch	33	34
Other	7	7
Total	97	100
Feels part of a "kink community"	80	87
Level of kink experience		
New to kink	0	0
Fairly inexperienced	10	11
Moderately experienced	23	26
Fairly experienced	24	27
Very experienced	33	37
Total	90	100
Age at first kink experience (y)		
<20	42	48
20–29	24	27
≥30	22	25
Total	88	100

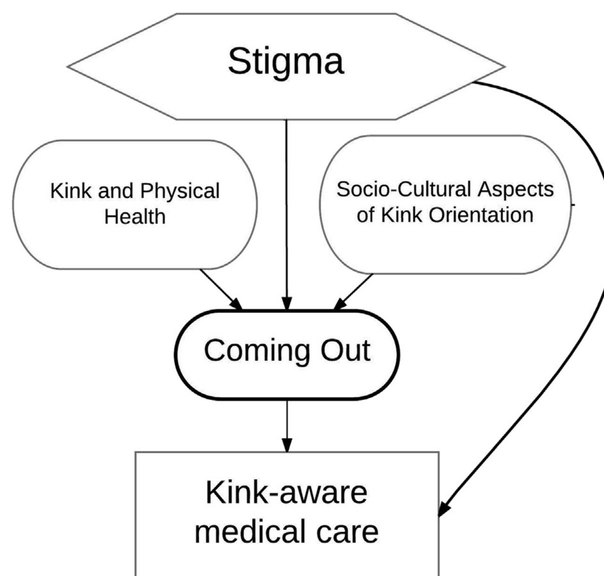

Figure 1. Five major themes of the Kink Health Project. Arrows represent the main paths of interconnectedness and direction of influence between the major themes. "Stigma" directly affects patients' decisions about whether to come out to their health care provider and could influence whether the patient receives kink-aware medical care. "Kink and physical health" (eg, having marks or injuries) and "sociocultural aspects of kink orientation" (eg, the degree to which an individual believes that kink is central to his or her identity) influence patients' decisions about coming out. After a patient comes out, medical providers could deliver kink-aware medical care.

Kink and Physical Health

Participants in this study frequently discussed the possibility of physical health complications from their kink behaviors. Most participants engaged in kink practices that had the potential to lead to physical injury (Table 3), most commonly bruising or open wounds from activities such as whipping, flogging, or sex toy use, etc.

Blood-borne pathogen exposure (HIV and hepatitis B and C) was a particular concern for participants who engaged in practices with a high risk for body fluid exchange. One participant described receiving a needle stick while placing a temporary piercing in the partner and another participant described using a knife to scratch the partner in a way that produced a moderate amount of blood.

A number of participants described themselves as highly sexually active. Twelve participants were currently involved in the practice of consensual non-monogamy or "polyamory," that is, engaging in multiple concurrent sexual relationships with the knowledge and consent of all partners. Participants showed a high level of awareness of the increased risk of STI and HIV exposure with multiple sexual partnerships, and many participants mentioned a desire for more frequent STI testing than would be recommended for the general population. There was an overall sense that health care providers had little awareness of the possibility of non-traditional sexual arrangements and in general would not ask questions to detect these. One married participant stated:

> You know, there's just not even a thought in their [health care provider's] head that we could have had other partners. (42-year-old woman, bottom)

Table 2. Commonly used kink terms

Term	Meaning
BDSM	Acronym For Bondage And Discipline, Domination And Submission, Sadism And Masochism
bottom, submissive (sub), slave	One Who Yields Control (Lower Case Preferred)
Flogger or flogging	Use Of A Multi-Tailed Whip With Long Flat Strips Of Leather Or Other Flexible Material
Impact	Kink Activities That Involve Striking A Part Of The Body (Eg, Spanking, Flogging, Etc)
Play	To Engage in kink or BDSM
Polyamorous	Having more than one sexual or intimate relationship with the knowledge and consent of all parties
Switch	One who switches between Top and Bottom roles
Top, Dominant, Master	One who enjoys assuming control (capitalization preferred)
Toy	Implement used for sexual or kink stimulation

A number of participants felt that their kink orientation had a positive effect on their health because it improved their general sense of well-being and encouraged them to take good care of themselves.

Sociocultural Aspects of Kink Orientation

Many participants felt that their kink orientation placed them in a sociocultural context that affected their health care. For example, those whose kink orientation was more central to their identity often wanted their clinicians to be aware of it, even if kink activities did not affect their physical health directly.

> That's just a part of who I am, you know, my kinky side. And that's actually a huge piece of my identity that I think would help fill the doctor in on just who I am. (49-year-old woman, bottom)

The demographic survey showed that most participants (87%) considered themselves part of a kink community that provided them with support and a place to be open about their identity without fear of judgment or discrimination. This acceptance was tied to an improved sense of health and well-being.

> This community allows me to feel authentic … this community here lets me relax and be who I am and that is just huge for my health, for anyone's health. (49-year-old man, Top)

The kink community, whether in person or online, also served as the most common place for participants to obtain information about kink and health. A number of participants said they would preferentially turn to the kink community for medical information, rather than talk to their health care provider.

Table 3. Examples of physical health complications of kink activities mentioned during interviews

Musculoskeletal injury (eg, from whipping, flogging, etc)
Bruising (from spanking, punching, flogging, caning, etc)
Broken skin leading to infections or poor healing (from whipping, flogging, biting, etc)
Nerve damage (from bondage using ropes, handcuffs, etc)
Anal or vaginal trauma (from rough sex, insertion of toys or fists, etc)
Burns (from hot wax play)
Blood-borne pathogen exposure (from accidental needle sticks after temporary piercings)
Fainting (from vasovagal response to pain or emotional intensity)

> [I had] a lot of bruising and not sure if there was any health issues … I didn't feel comfortable going into the doctor, and so I chose instead to talk to people in the community and have them kind of look at it and see if things were okay. (42-year-old woman, bottom)

Impact of Stigma on Interactions With Health Care Providers

One of the most prominent themes was the fear of encountering stigma in the health care setting—a concern that was mentioned by almost all participants.

> I don't think the general medical field has a good understanding of what we're doing. And, you know, I've been having some medical problems since September and I was so tempted to tell my main doctor. I just do not feel that she would understand. (49-year-old woman, bottom)

Women in particular were concerned about being judged for their sexual activities:

> There's kind of a double standard where women aren't supposed to have freaky sex or a lot of sex or not be monogamous, and I feel if any of those things came up with a provider, they'd probably, even if they didn't say it, just be judgmental towards me for those behaviors. (25-year-old woman, bottom)

However, despite the pervasive anticipation of stigma, few participants reported direct experiences of judgment or discrimination. When these did occur, they mostly took the form of micro-aggressions (defined as subtle verbal or non-verbal messages conveying disapproval or discomfort with kink orientation). Participants most commonly described body language cues from their clinicians, such as frowning, stiffening of the posture, or pushing the chair farther from the patient. Often, participants could sense disapproval but were unable to describe exactly how they knew they were being judged.

Despite their fears, participants often had good experiences interacting with health care providers, even when they were open about their kink orientation. In fact, a few participants who had visited an emergency department for a kink-related concern and had been honest about the mechanism of injury were pleased with the professionalism of their providers. However, participants often reflected that the San Francisco Bay Area might be an outlier, or "bubble," and wondered whether it would be harder to find non-judgmental care in other areas.

> If we were even just across the Bay—certainly in another part of the country—we would likely encounter a lot more sense of need to delay seeking out care and hesitancy disclosing the nature of injuries or conditions that we came in for. (Male town hall participant, age and kink role not mentioned)

Participants used different mechanisms to avoid stigma, with the most common being to hide their kink orientation from their providers. Other mechanisms included prescreening providers for openness before enrolling in care, giving false information about one's identity or activities, attempting to hide physical evidence of kink activities, and avoiding or delaying medical care.

> There is a thread of discussion in [the kink community] about when you talk to medical professionals, about lying to them, but lying to them in a useful way. In terms of like, "oh, I play rugby. That's why I have bruises all over my body." Have a story to tell the doctor, to get past the evidence on your body, because people are afraid. (32-year-old man, Switch)

> I lied about my name because I wanted to remain anonymous. … Why? Because I don't trust them with the information. Even if I trust the health care provider, once they write it down I have no idea where it goes. (55-year-old man, Top)

Coming Out to Health Care Providers

The previously discussed themes converge on the theme of coming out (the decision to reveal one's kink sexuality to a health care provider). Specifically, the degree to which kink activities are likely to cause injury or medical concerns, the level of identification with kink sexuality or involvement in the kink community, and the concern about health care-related stigma influenced participants' decision about whether or not to come out to their providers.

Many kink-oriented participants would prefer to be out to their providers to receive individualized medical care, STI and HIV testing, and counseling to decrease risk.

> I'm definitely in favor of coming out to them [doctors] because it's relevant. For one thing, blood borne diseases can be got by different ways than just sexual intercourse. We might have different risks. We might get a torn rotator cuff from too much flogging. It's good if the doctor is conversant with those things because then, they can give appropriate treatment. Just like it's important that the doctor knows that I'm gay so that he won't continually ask me if I'm pregnant. (53-year-old gender non-conforming person, Switch)

Other reasons to come out included a desire to form a more honest health partnership with a medical provider, to pre-empt questions about intimate partner violence, and to explain unusual relationship configurations.

> I chose to disclose to my health care provider just because I figured one day I might be extensively bruised and I might actually have something wrong with me and I don't want to talk about why I'm bruised. I need to talk about I have appendicitis or something else and I need to deal with that. (Female town hall participant, age and kink role not mentioned)

> I think it was important for [the doctor] to know that it was a kink relationship. She had to be able to hear this. I am monogamous. My "baby girl" [girlfriend] is polyamorous. She has another sub [submissive]. So, those things do come out of my mouth, the different arrangements and things that we do. (49-year-old man, Top)

Although participants acknowledged the many advantages to coming out, the demographic survey showed that only 38% had disclosed their kink orientation to their current primary care clinician. The most common reason for not coming out was fear of stigma. Other reasons included not wanting to spend time during the appointment educating providers or reassuring them of the consensual nature of kink behaviors.

> If I felt it was relevant I would be willing to explain, but it seems like a lot of work. And normally I love explaining to people, but not to people that I'm paying. (28-year-old woman, bottom)

Some participants chose not to come out to their medical providers because their kink behaviors had no direct relevance to their health. This was more common in people who identified as Tops and those whose kink practices were limited to activities not likely to cause injury (such as role play or light bondage).

A Vision of Kink-Aware Medical Care: A Patient's Perspective

A primary concern of participants was the need for clinicians to be able to distinguish between consensual kink behaviors and IPV. Kink, by definition, is a set of activities that have been mutually agreed to by mentally competent adults, whereas abuse is not.

> A lot of what we do is risky, physically and mentally risky. You know, if I'm going to drag somebody across the room

by the hair, that's physically and mentally risky. But if I know that that turns them on, then it's part of our fun. And so we do things that, without consent, are abusive and scary and risky and terrible, and with consent they're hot and sexy. And so the only way you can give consent is to do negotiation. And so it all comes down to that. If somebody says, "I want you to slap me across the face," then I can do that. But I can't do that if they haven't said that. (51-year-old woman, Top)

Numerous participants voiced concern that health care providers' lack of familiarity with kink would cause them to confuse their behaviors with abuse.

I like impact play, so I tend to bruise … I didn't feel confident enough in my health providers that they would not mistake my consensual marks for abuse. … It stopped me from seeking health care a few times. It made me delay. (53-year-old gender non-conforming person, Switch)

The fear that health care providers would confuse kink behaviors with abuse was particularly prominent in women participants.

I know that what I'm doing is safe and consensual, but I worry if I ever went to the doctor and was covered with bruises they would not understand that they were consensual behaviors … I guess they should know that there are other ways people get bruises besides having somebody abuse them. (25-year-old woman, bottom)

For some, the fear of being labeled as a victim or perpetrator of IPV, with its potential social and legal implications, caused patients to delay a medical visit or avoid one altogether.

And now that I'm married and have a kid I'd be even less likely to go into the doctor because I would be worried not only would they haul off my husband assuming he did it … but then they would be calling CPS [Child Protective Services] assuming my child was in a dangerous place. If anything got out to my work place and things like that, it would be even scarier. (42-year-old woman, bottom)

Most participants desired counseling to decrease risk and had questions regarding specific kink activities and their health.

Being pregnant, of course, poses a lot of issues on what is safe and what is not safe. I went through seven OB/GYNs before I found one that I was comfortable with. Some just wouldn't talk about it at all. Some gave me domestic abuse pamphlets. I got that a lot. I got ones who were okay with it, but wouldn't tell me what was okay to do, like nothing was okay. I'm like, well, I know that's not true. People do all kinds of athletic activities, so some of this has to be okay. I finally found a practice that was kink friendly that I really liked and they actually walked me through. I'm like, well, can I do flogging? If I can do flogging, how hard? Where on the body? We walked through all kinds of things and got a pretty good list of what I could do. (27-year-old woman, bottom)

Participants voiced a desire for health care providers to take a sexual history that was open-ended enough to encourage participants to come out about their sexual preferences. Many felt that clinicians did not enquire deeply enough about sexual histories or asked questions in a way that made participants feel reluctant to disclose their sexual preferences.

They have to go through your sexual history and you can tell they try to be as nonjudgmental as possible, but sometimes … when you answer certain questions, seems like they're being a little judgy. Just the way they just kind of don't look at you after you answer something. (25-year-old woman, bottom)

As the study progressed, we began asking participants what providers could do to encourage disclosure. One participant suggested adding a broad open-ended question to the sexual history.

I'm wondering if there's some more open-ended question someone could ask, that didn't necessarily imply that you were into weird shit. (44-year-old woman, Switch)

During the final phase of interviews, we began asking patients how they would respond to a question such as "What else would you like me to know about your sexuality, so I can take best possible care of you" and received positive feedback from participants with whom we tried it.

Some participants voiced a desire for individualized STI and blood-borne pathogen screening reflective of their specific risk profile, rather than depending on population-based guidelines. A number of participants wanted STI and blood-borne pathogen testing more often than current guidelines would indicate for someone with their demographic characteristics, and some participants encountered resistance or confusion on the part of medical providers when they requested the testing.

I get tested for blood borne pathogens every six months because I do sparring kind of play where there's potential for both of us to get scratched up … and yeah, my doctors want to know—you're in a monogamous sexual relationship, why are you getting tested every six months? And, why aren't you getting tested for the sexually transmitted stuff, just the blood borne? (44-year-old woman, Switch)

A few participants insisted on more frequent or complete STI testing because they felt that the community standard for highly sexually active people is to be able to present recent laboratory results to prospective partners.

> Herpes is a big deal in our community and people want to see that on your test results right … but [the doctor] doesn't want to test for herpes … we kept pushing back and forth and I finally said, "look lady I said I am in a community where I go out and people want to see test results and they want to see herpes on there or they're not going to touch me," and she's like "oh, okay." (49-year-old woman, bottom)

Participants requested that providers acknowledge alternative family structures and be willing to ask about and include non-traditional intimate partners in the health care setting. Some participants were engaged in multiple concurrent sexual partnerships, and a few had a primary non-kink sexual partner and an additional significant kink relationship that might or might not be sexual. In one case, a participant had a husband and a Master and felt that she could not make important medical decisions without consulting her Master, although he would not normally be recognized or included in a traditional medical context. Participants indicated that they would like health care providers to acknowledge the important people in their lives, even if they fall outside of expected relationship structures.

DISCUSSION

This study of kink-oriented San Francisco Bay Area residents is the first of its kind to examine the intersection of kink sexuality and medical health care. Our study focused on the patients' perspective and found that kink-oriented individuals have unique behavioral and social characteristics that directly affect their health and their use of health care.

As expected, participants described engaging in activities that carry some risk of physical injury such as bruising or breaking the skin. In general, subjects seemed well informed on how to minimize these risks. Surprisingly, however, 44% had visited a medical provider because of a kink-related concern. Our study did not aim to provide a breakdown of the specific reasons for the visits; however, participants' stories showed a wide range of concerns, from requests for counseling to decrease risk to management of injuries and mental health concerns. These stories confirmed our suspicion that kink-oriented patients have genuine medical concerns because of their unique sexual behaviors. Our findings validated the range of health concerns described by Moser[35] in his book on best practices for clinicians caring for kink-oriented patients, which is based on his extensive experience as an internist and sexual health specialist. Unfortunately, in our sample, fear of judgment often prevented participants from seeking advice from their clinicians and many turned preferentially to resources within the kink community. Although our casual review of popular internet resources showed that advice about kink and health is often sound, it should nevertheless be concerning to the medical establishment that patients do not feel comfortable seeking advice from their clinicians when they need it.

The risk of STI or blood-borne pathogen acquisition might be higher in the kink population, because a significant number of participants described themselves as highly sexually active and some were engaged in activities with a high risk of blood or body fluid contact. This finding parallels that of Moskowitz et al[36] in their study of men who have sex with men engaged in kink behaviors, in which they found a higher valuation of hypersexuality and lower rates of condom use compared with non–kink-engaged men who have sex with men. Participants in our study often expressed a desire for more frequent STI testing; however, many found resistance to these requests because their health care providers identified them as being at low risk based on demographic information or a cursory sexual history. Overly narrow sexual histories can underestimate risk in some kink-oriented patients and we had positive feedback from participants about adding a simple open-ended question when taking a sexual history, such as "What else you would like me to know about your sexuality so I can take the best possible care of you?"

Participants in this study discussed different topics relating to their unique sociocultural context, primarily relating to issues of identity, community, and non-traditional relationship structures. Some participants felt their kink identity was strong enough that it should be acknowledged by health care providers, even if their kink behaviors did not directly affect their health. Participants also discussed their connection to kink communities and the ways in which these benefitted their health through social support and provision of health-related information. Some participants had non-traditional relationship structures, which would generally not be recognized or included in a health care setting (such as polyamory or having significant and concurrent kink and non-kink relationships). All discussions about social context pointed to a critical unmet need: that of an open and honest health partnership between kink-oriented patients and their health care providers, which would allow patients to be openly themselves and to engage in meaningful discussions about their health risks, their identities, their communities, and their families.

Although most participants wanted to reveal their kink orientation to their health care providers, only 38% were out to their current primary care clinician, with anticipated stigma being the greatest barrier. Similar findings have been documented in other fields, such as psychotherapy and health education.[23,37] The patients' fear is not surprising, given the medical establishment's historical view of non-traditional sexualities. In fact, the evolution of the medical stance toward kink can be tracked through changes in the *Diagnostic and Statistical Manual.* As recently as 1987, the *Diagnostic and Statistical Manual, Third Edition, Revised* considered anyone who had acted on their kink urges to have a mental illness. In 1994, the *Diagnostic and Statistical Manual, Fourth Edition* added the requirement that a person be distressed or impaired to classify kink orientation as an illness, and in 2013 the *Diagnostic and Statistical Manual, Fifth Edition* went a step further by differentiating non-pathologic

paraphilias from pathologic paraphilic disorders.[38,39] Although evidence is building that consensual kink practices can be considered normal variations of human sexual expression,[40] health care providers would likely not have received formal sexual education that includes the most recent thinking about sexual minorities.[30]

Although we expected to hear stories of poor health care delivery or overt discrimination owing to stigma, we heard very few. In fact, some participants felt they were treated with kindness and respect once they came out to their providers; and when stigma was experienced, it was mostly in the form of micro-aggressions.[41,42] However, the experience of *anticipated* stigma was almost universal, with its roots possibly in personal experiences of stigma outside the health care setting or in a general sense of societal condemnation of non-traditional sexual preferences.[15] Participants described anticipated stigma as affecting all aspects of their health care, from their willingness to access care in the first place to their decision to reveal their sexual practices to their providers once there. Research by Quinn and Chaudoir[43] showed that anticipated stigma in individuals with a concealable stigmatized identity leads directly to psychological distress and poorer self-reported health outcomes. Although this study was not designed to look at health outcomes, the importance of anticipated stigma in our sample suggests that kink-oriented patients could be at risk for health disparities, whether directly, as suggested by Quinn and Chaudoir, or indirectly through lack of usage of available services or lack of disclosure of health risks, as suggested by our study. Further research is urgently needed to explore this possibility, especially given the known association between sexual minority status and stigma-mediated health disparities seen in lesbian, gay, bisexual, and transgender populations.[44]

Participants in this study were able to paint a coherent picture of kink-aware medical care, which could be broken down into five main concepts, namely differentiating kink from IPV, providing non-judgmental counseling on decreasing risk, taking open-ended sexual histories, offering individualized STI screening, and acknowledging alternative family structures. Of these, one of the greatest challenges is likely to be the task of distinguishing kink behaviors from IPV. With an increasing emphasis on identifying IPV, clinicians are correct to be concerned about any patient presenting with physical or emotional injuries. Participants expressed approval of clinicians' screening for IPV, but they also felt burdened by the need to explain or defend the consensual nature of their kink activities and they feared the legal and social consequences of IPV accusations. Participants repeatedly requested that clinicians become aware of the existence of kink and be open to the possibility that their injuries might have been consensually acquired. It should be noted that kink-related injuries would not be covered under mandatory reporting laws, even in states requiring mandatory reporting of suspected IPV, because they were not acquired as a result of abuse. For a helpful review of health care provider mandatory reporting laws in IPV, see Mandatory Reporting by Health Care Professionals by the Colorado Coalition Against Domestic Violence (available at: http://ccadv.org/wp-content/uploads/2014/02/CCADV-MandatoryReportingIssueBrief.pdf). Further training for clinicians wishing to learn about distinguishing kink from IPV can be found in the endnotes listed here.[45,46]

This study has some limitations. As a qualitative study, conducted in a single urban population, the findings should be generalized with caution. San Francisco is well known for its sexual open-mindedness and we could have encountered different results if we had conducted the study in other parts of the United States or in other nations. Perhaps a more significant limitation might be that we were able to interview only people who openly identified as having an interest in kink and were willing to talk to us about such a personal topic. Thus, our participants might have represented a subset of kink-oriented individuals more heavily involved in kink practices and lifestyle. We imagine that an even larger number of people might practice kink in private and be unconnected to any community; however, we were unable to capture the experiences of those people in our study. Of note, our sample was comprised mostly of non-heterosexually oriented participants (79%); however, the study was not designed to interpret whether, or to what extent, an interaction exists between sexual orientation and kink orientation. Further research would do well to focus on teasing out these variables, especially because stigma and coming out were among the main findings in our study and these are well-documented health care experiences in the lesbian, gay, bisexual, and transgender population.

CONCLUSIONS

Medical providers are increasingly expected to provide evidence-based and culturally competent care to sexual minorities. Pioneers in the world of lesbian, gay, and bisexual health made huge strides during the past 30 years to incorporate care of non-heterosexual patients into the standard scope of general medical practice. More recently, we are beginning to see transgender health being edged into the mainstream, and although there is a long way to go, guidelines on the care of transgender patients are being disseminated by the nation's health care leadership.[47,48] Care of kink-oriented patients should be no different. Kink is not rare and is not limited to sexually progressive urban settings such as San Francisco.[49] For some individuals, it could be restricted to pink furry handcuffs and unlikely to be of medical significance; for others, it can be substantially more involved, encompassing the physical, psychological, and social lives of such patients. Our study shows that kink-oriented individuals could have health care needs directly related to their sexual practices and identities; further, it suggests that their health might suffer without access to informed and non-judgmental health care. Participants in this study have

begun to shape a vision of kink-aware medical care, which includes sexual history-taking that is open-ended enough to include patients with diverse sexual practices, assisting patients in making informed decisions about how to moderate the risk of their specific behaviors, and having an understanding of the consensual nature of kink and how it differs from IPV. There is a need for research that replicates this study in other areas of the country and for studies that measure the impact of kink sexuality on health care needs, particularly as they relate to access to care and the experience of stigma.

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Corresponding Author: Jessica F. Waldura, MD, Family and Community Medicine, University of California—San Francisco, SFGH, Ward 22, 1001 Potrero Avenue, San Francisco, CA 94110, USA; E-mail: jess.waldura@ucsf.edu

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STATEMENT OF AUTHORSHIP

Category 1

(a) Conception and Design
Jessica F. Waldura; Anna M. Randall; Richard A. Sprott

(b) Acquisition of Data
Jessica F. Waldura; Ishika Arora; Anna M. Randall; Richard A. Sprott

(c) Analysis and Interpretation of Data
Jessica F. Waldura; Ishika Arora; Anna M. Randall; John Paul Farala; Richard A. Sprott

Category 2

(a) Drafting the Article
Jessica F. Waldura; Ishika Arora; Anna M. Randall; John Paul Farala; Richard A. Sprott

(b) Revising It for Intellectual Content
Jessica F. Waldura; Ishika Arora; Anna M. Randall; John Paul Farala; Richard A. Sprott

Category 3

(a) Final Approval of the Completed Article
Jessica F. Waldura; Ishika Arora; Anna M. Randall; John Paul Farala; Richard A. Sprott

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Appendix 1. Examples of questions from focus group and interview guide

How does the kind of sex you have affect your health care?
Tell me about experiences using the health care system where your sexual practices were an issue?
Do you think it is important for your health care providers to know about your sexual practices? Why? Why not?
Have you ever discussed your sexual practices with any of your health care providers? What response have you gotten? If you have never discussed your sexual practices, why not?
Have you ever avoided or delayed seeking health care because of your sexual practices or identity?
What should health care providers know about kink, fetish, or BDSM to provide competent care?
What is the major health concerns facing the kink community right now?
What should be the focus of the research for the Kink Health Project?

Appendix 2. Terms used by participants to describe kink identities and roles

Age Play	Dominant	Kink	Pet	Sir
Bottom	Domme	Kinky	Pup	Slave
Bottom Heavy Switch	Feminized Sex Slave	Leatherman	Pushy Bottom	Sub
Boy	Fet	Lil' Girl	S/M	Submissive
Bunny	Fetishist	Little	Sadist	Switch
D/S	Furry	Mamma	Sadistic	Top
D/S	Girl	Masochist	Sadomasochist	Vanilla
Daddy	Handcuffs	Master	Service Poodle	Various
Dom	Hedonist	Mistress	Service Sub	Whip