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

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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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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

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