

SEXUALITY AND PARAPLEGIA: MYTHS AND MISCONCEPTIONS AMONG COLLEGE STUDENTS

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ABSTRACT

Individuals with disabilities are often seen exclusively in terms of their disabilities, resulting in the perception that they possess limitations in all areas of life. This has led to a myth of nonsexuality for individuals with disabilities. This paper reports an exploratory study of the knowledge college students have of sexuality among individuals with spinal cord injuries. Over 120 students at a small southwestern university participated in an in-class exercise in which a male and female student volunteered, alternately, to sit in a wheelchair and portray an individual with a serious spinal cord injury. Students wrote two papers, anonymously, on what the issues would be if the disabled male, and then the disabled female, were establishing an intimate relationship with the able-bodied person standing next to him or her. The student responses were then analyzed for recurrent themes, stereotypes, and attitudes concerning sexuality. Results indicate that students consistently believe that sex would be a major problem, or that sex would be impossible, for a couple in which one partner had a physical disability. Other issues inextricably linked with being disabled were also prominent themes (stigma, pity, relationship and childbearing problems). Stereotypical gender roles and norms were also promoted, especially in the realm of sexuality. Responses evidenced an overwhelming concern for the male's sexual enjoyment.

INTRODUCTION

Sexual expression is a crucial aspect of one's identity and self-concept. Yet, in the last three or four decades the sexuality of individuals with disabilities has witnessed fewer shifts in attitudes than has the sexuality of other groups such as women, the aged, and homosexuals. According to Knight (1989) we have made great strides since the 1970s in eroding the myths concerning the sexuality of individuals with disabilities. While this may have occurred for those individuals possessing a physical disability as well as for those professionals and health officials caring for them, our findings suggest that myths and stereotypes are thriving within the college environment and thus we argue most likely within the society at large.

The most recent comprehensive survey on sexual behavior, conducted at the University of Chicago and led by Edward Laumann, John Gagnon, Robert Michael and Stuart Michaels (1994), ignored the sexual behavior of individuals with disabilities. This denial or oversight is most surprising given the explicit theoretical premise guiding this study of the "social organization of sexuality" (Laumann et al 1994). The major theoretical premise of the Chicago study is that culture, the constraints imposed by culture, and one's interaction with others determines or affects one's sexual behavior.

In the United States, individuals with disabilities number somewhere between 35 and 43 million, depending on what disabilities are included (Shapiro 1993). To exclude such a large group from a major national scientific research project might be evidence enough

that our society does not quite see individuals with physical disabilities as sexual beings. In fact, this oversight lends further support to Goffman's (1963) contention, that we see individuals who possess a physical disability stigma as not quite human. This oversight becomes more apparent when one acknowledges that sexuality permeates everything we are as human beings. In other words, it is crucial to one's self-concept and self-esteem. Further, it might be argued that the myth of nonsexuality for individuals with disabilities is part of the larger purview of a general stigmatization for these individuals (Longmore 1985). Much of the literature suggests that belonging to a stigmatized group leads to strained interaction, misunderstanding, discrimination and negative responses from others (Davis 1961; Elliott, Ziegler, Altman, Scott 1982; Jones, Farina, Hastorf, Markus, Miller, Scott 1984; Makas 1988). Indeed, to deny the sexuality of individuals with disabilities is itself discriminating and evidence of misunderstanding.

However, to say that our society has totally denied the sexuality of individuals with disabilities is somewhat misleading. Literature and films are available regarding sexual issues for individuals with disabilities, but there is some question as to the extent or consistency of that which is provided to these individuals, especially to those who acquire a disability through trauma. For example, one 26-year-old male quadriplegic who participated in an earlier research project on disability indicated that his sexual counseling consisted of a ten minute presentation by a female nurse and a bound handout containing diagrams of stick figures in wheelchairs (Ifcic

1991). Furthermore, if knowledge is not presented in a systematic manner through education, it does little good for the individual with the disability to know that he or she is sexual if others do not know.

This paper reports an exploratory study of the knowledge college students have of sexuality among individuals with spinal cord injuries. Spinal cord injury was chosen as a means to emphasize a high-cost disability that makes disability visually explicit because it places the individual in a wheelchair. In addition, "Spinal cord injury is a low-incidence but high-cost disability that imposes tremendous changes on a person's lifestyle" (Trieschmann 1989). This research emphasizes the stereotypes and assumptions held as well as their implications. Also discussed are the benefits of incorporating a scholarly understanding of the sexuality of individuals with physical disabilities into the classroom, as well as into the larger culture.

METHODOLOGY

Over 120 students in a human sexuality class at a small southwestern university participated in this study in the fall of 1994. The sex composition of the class was two-thirds female and one-third male. We devised an in-class exercise in which a male and female student volunteered, alternately, to sit in a wheelchair and portray an individual with a serious spinal cord injury. The students were told that the person in the wheelchair had no feeling below the chest, but no other information was given. The exercise occurred early in the semester prior to any discussion of disability and sexuality.

We asked students to write two papers, anonymously, on what the issues would be if the disabled male, and then the disabled female, were establishing an intimate relationship with the able-bodied person standing next to him or her. The responses were then analyzed for recurrent themes, stereotypes, and attitudes concerning sexuality.

There were 117 usable responses of which 74 were from females and 43 were from males. Three prominent themes became apparent almost immediately from the data. Two other themes emerged with less frequency, but still merit comment. The following sections discuss the themes in context of whether the male or female is disabled.

DISABLED MALE WITH NONDISABLED FEMALE PARTNER

Sex as a Major Problem

According to McKown (1986) the belief that individuals with disabilities are asexual is a common myth. It is perpetuated by the generalization that having a physical disability permeates all aspects of one's life and that all other areas of the individual's life also have limitations. The students' papers strongly reflected this myth of asexuality.

We were not surprised, since this was a sexuality class, that issues of sexuality were mentioned the most frequently even though we did not specifically mention sex in our instructions. Most informants mentioned sex, but more importantly viewed sex as a problem for the two. Sixty-four of 74 females and 37 of 43 males mentioned sex as a problem. The following is representative of the comments suggesting sex would be problematic:

If he has no physical feelings in his lower body, will he be able to participate and/or enjoy sexual activity? (32 year-old female)

She may feel kinda sad about a lack of intimacy although they can still hold each other, kiss, snuggle, and so on. (19 year-old female)

They probably would have trouble with the sexual part of the relationship and eventually the strain might break them apart. (21 year-old male)

Will she feel inadequate because she can't make him feel anything. Is their relationship strong enough to withstand a potentially limited sex life? (32 year-old female)

While a number of informants made similar comments, many of them simply wrote, "sexual problems." They tended to use negative terms such as dysfunctional sex, incomplete sex, lack of satisfaction for the woman, lack of sexual capability, and even a comment from some that a sexual relationship would be impossible.

This is indicative of a narrow definition of sexual behavior and fulfillment. It also reflects lack of knowledge concerning alternatives in the spectrum of sexual activity and pleasure.

Very few males or females spoke positively to the issue of exploring or experimenting with alternatives to penile-vaginal sex. The feelings of those few are conveyed by the following statement:

Sex will definitely be an issue, if the relationship progressed to a more serious level. There are many ways to have a healthy sexual relationship within their means. It's just an issue of their comfort with each other and themselves as they are. (19 year-old female)

Unfortunately this level of understanding was quite rare.

Issues of Stigma

The stigma of possessing a disability was reflected in many of the students responses. This response was more prevalent for females than for males as 30 of 74 females included comments related to the stigma of disability and only 8 of 43 males mentioned such issues. The issue of prejudice toward disabilities emerged in a Goffman-esque way with comments such as "What would people think?" (particularly friends and family). Some took the broadest approach and asked, "How will society react?" The following are representative comments:

Probably both will be discriminated against... society might treat them bad. (20 year-old female)

They may take flack from society why would a pretty young girl want to date someone in a wheelchair? (19 year-old female)

Comments from males tended also to focus on societal discrimination:

The couple should expect ridicule and lack of support from the community...and would probably spend a lot of time focusing on the concerns of others. (33 year-old male)

Males also mentioned the issue of the reaction of friends and family, and commented on the frustration that the couple would probably feel. As one stated:

What would normally be seen to be dating like holding hands and hugging would be different and not normal. (21 year-old male)

Interestingly, although seventeen percent of the sample had a friend or family member with a physical disability, they had the same percentage and type of responses as those who did not have a friend or family member with a physical disability. Thus, we find

evidence to support other research indicating that even though the potential exists to overcome stereotypes, anxieties, and false perceptions toward those we know on a personal, or intimate basis, this does not necessarily generalize to others in the same situation (Desforges, Lord, Ramsey, Mason, Van Leeuwen, West 1991; Wilder 1984). Thus, our findings provide evidence that intimate or close contact with an individual possessing a disability may not reduce the stereotype of non-sexuality for others. The stereotype of non-sexuality for individuals with disabilities is pervasive within society and is resistant to change.

Having Children

Another emerging theme focused on the issue of having children. More females (37%, 28 of 74 females) than males (30%, 13 of 43 males) discussed the question of having children or mentioned it as a problem. Many simply listed children as a issue without elaborating further. Others raised questions:

Would they be able to have children should they become more serious, and would she want to adopt or try an alternate method of having kids if he cannot have kids? (21 year-old female)

Another female questioned whether the male with a disability would be able to help care for children were they to become a reality.

One 41-year-old male combined not only the issue of childbearing, but also stigma when he wrote:

There would be the stress of childbearing and the image of a disabled father with which to contend.

Relationship as a Whole

As might be expected, there were many comments on the nature of the relationship itself. These responses are separate from the other responses as these go beyond sex and children to encompass the entire relationship. For example, one 19-year-old female indicated that "his handicap might have an overbearing effect and could cause great stress for the relationship." Other quotes indicative of relationship concerns are the following statements:

...What all would you have to give up if your relationship turned serious? (32 year-old female)

His ability to be an equal partner in the relationship if it develops. (40 year-old male)

The following quote is indicative of the larger issue pertaining to feeling trapped in the relationship because of the handicap present in the partner. As one 20-year-old female commented:

She could feel pressured into the relationship feeling that if she rejects him it will hurt him so bad he will no longer want to be her friend.

He might become dependent on her help and then if they have troubles in the relationship, she might feel guilty or sad to leave him alone. She starts to think that she is all he has. (19 year-old male)

It is apparent that this disability is such a strong master status that it literally colors every aspect of the couples relationship. Often students mentioned the issue of felt obligation resulting from the disability. One student summed up this issue in the following way:

She may feel guilty if she gets angry at him because of his handicap and if it didn't work out she would feel obligated to stay in the relationship anyway. (26 year-old female)

The Theme of Pity

As mentioned above, some students fear that a woman may get into a relationship and then feel trapped in that relationship. This issue is inextricably bound up in feelings of pity and obligation. These are powerful forces which often will unite and lead to the initiation of a relationship. However, because of the constancy and the unchanging nature of the disability itself, the woman becomes bound to the relationship. Therefore the question emerges as to whether she is feeling obligated because of his dependency or pity for his disability. These issues are evident in the following statements:

Does she really love him or does she just feel sorry for him? (26 year-old female respondent)

She might take pity on him, feeling as if he needs someone to help him...she wants to fix all of his problems. (19 year-old female)

He's basically helpless and dependent on others. (21 year-old male)

Will he feel like she only accepted the date to be nice or does she really care about him and will accept him for what he really is? (23 year-old male)

Also, he may be concerned with how she feels about his disability wanting her to care for him without pity. (37 year-old female)

DISABLED FEMALE WITH NONDISABLED MALE PARTNER

Of the 117 respondents, 30 recognized no differences between the couple in which the male was disabled and the couple in which the female was disabled. Of the 30, thirteen were male and seventeen were female. Most of the 30 simply stated that there were no differences in issues for either situation. An additional eleven (six females and five males) stated that the issues were essentially the same, but then provided some important qualifying statements. For example, several noted that the issues would be the same in both situations except that the nondisabled male might need other sexual outlets.

Sex as a Major Problem

As in the former situation (male disabled), sex was often considered problematic. Thirty-seven of 74 females and 26 of 43 males mentioned sex as problematic. Although these numbers indicate less concern for, or view of, sex as problematic for the female in the disabled condition, this is somewhat misleading as problems of sexuality in this situation reveal more gender-based stereotypes. First, whether the individual with a disability was male or female, the focus remains primarily on the issues of male sexuality. That is, in the male-disabled condition, issues of problematic sex, although sometimes recognizing a lack of satisfaction for the female, overwhelmingly addressed concerns for the male's ability to perform and to "enjoy" sexual activity. In the female disabled situation only four respondents indicated a concern for the female's "enjoyment" of sex. The focus on male sexuality continued to emphasize concern for the male's sexuality in two ways. First, there remains concern for the male's enjoyment of sex, or lack thereof, with a clear emphasis on the disabled female's inability to satisfy her man.

If sex does come up, she might do it to please him even though she can't feel anything. She

might be apprehensive to tell him she can't feel so as not to make him feel bad if they do have sex. Anyway, she could always fake it so as not to let him find out. (23 year-old male)

Another 22 year-old male suggested that the male's sexual enjoyment would be hindered due to the disabled female's condition. He merely wrote "Dead Sex. (No Movement)." Another 20 year-old male stated "She will always wonder if she makes him happy." Another 41 year-old female recognized the disabled female's feelings, but from the perspective of how this affects the man's enjoyment: "Feelings of not being as feminine sexually unresponsive (man must have his sex)."

Second, the following comments are indicative of the focus on the male's sexuality. They address his questionable sexual attraction to a female with a disability:

She may fear he will not be sexually attracted to her due to her disability. (37 year-old female)

Possible aversion of male to sex with paraplegic. (33 year-old male)

So prominent is the issue of a lack of sexual fulfillment for the male with a female partner who has a disability that many respondents, both male and female, concluded that the able-bodied male would be less likely to be faithful and would need other sexual outlets:

He may be more likely to become frustrated with her, a man may be more likely to cheat on her. (20 year-old female)

Will she be able to cope if he needs and/or seeks alternative sexual partners? (32 year-old female)

Several just stated that the man would be "less likely to be faithful" to a woman who is disabled. These statements are significant when one considers that this was mentioned only once as a probability or option for the female in the disabled condition.

As before, we found that many respondents either questioned the possibility of sex or assumed that it would undoubtedly be impossible:

... He would have trouble dealing with the fact that it could only be a nonphysical relationship.

(21 year-old male)

He must resign to no sex life if they marry. (46 year-old female)

Lack of physical contact. (24 year-old female)

Issues of Stigma

Stigma was again the most common theme after sexuality. Eleven males mentioned stigma while 27 females mentioned it, reflecting proportions quite similar to those in the previous scenario. Concerns ranged across the spectrum from societal stigma to stigma from family and friends. Comments concerning societal reaction included the following:

Society would seem to say that the female is undesirable like a widow or a single woman... even probably if the woman was very attractive. Terrible, but seemingly true. (21 year-old male)

The following comments are indicative of those who expressed general concerns from the public:

She might be afraid of the public's acceptance. (25 year-old female)

He (the male) might have a problem with people staring at them. (19 year-old female)

Many comments were made concerning the reaction of family members. For example, one 21 year-old female simply wrote, "major family problem." Another 21 year-old female discussed the problem of "overcoming the stigma from ignorant family members." The general concern here was the potential embarrassment and nonacceptance on the part of family members, which of course does not portend well for the relationship in general.

Some of the more revealing comments came in reference to the imagined reaction of friends and peers:

He might be embarrassed by being seen with her in front of his friends. (24 year old)

The guy may be chastised by his friends for having a disabled girlfriend. (23 year-old)

But guys would make fun of him for dating a girl that was handicapped. They would probably say something like can't you get a real girl? Guys would expect another guy to do better than that.

(20 year-old female)

Having Children

The issue of children remained as important, but no more so, than in the previous section. Twenty-seven females and ten males mentioned children. Typical of their comments were: "can she carry to term and have children?" However, there was a concern on the part of seven females and two males with the ability of the woman to prominently participate in the role of caregiver and rearer of children. This is somewhat mystifying in that men who are not typically socialized as caregivers have little to say on this potential issue. It is possible that the male respondents are not likely to view the disabled woman as a marital partner and future mother.

Relationship as a Whole

A major sex difference was evident in remarks concerning the relationship as a whole. Twenty-one of the females, but only three males mentioned issues in the relationship that did not relate directly to sex or children. Women were obviously more cognizant of potential relationship issues. Typical statements included the following:

Guys are not mature at this age and they are not going to be willing to be tied down with a relationship, let alone with a handicapp(ed) female. (22 year-old female)

Concerns also addressed recreational/social concerns:

Where will they go and what will they do? (21 year-old female)

There were also concerns with the issue of nurturing responsibility. Fourteen females commented specifically on this issue. They tended to use terms such as "caregiver" or "dependency," and they often worried about the inability of the woman to take care of traditional female obligations:

They might end up resenting each other, he'll have to help her out a lot. (20 year-old female)

I don't see him in a caregiver role. Would he think of her as being fragile? (31 year-old female)

He might be too overprotective and treat her like a doll that can't do anything for herself. (19 year-

old female)

The comments from males were not only few in number but few in words.

The Theme of Pity

While the theme of pity was mentioned by nine males and twelve females in the previous scenario involving the disabled male, only five males and five females mentioned pity concerning the disabled female scenario. Clearly the students worried more about the problem of pity and self-pity regarding the male. The implication is that men have a more difficult time with disability and are more likely to be "pitiful," whereas it would be less difficult for the woman to be dependent and confined to a wheelchair. One 26 year-old male student wrote that the disabled female scenario would be "more easily adapted to." A number of the students used the word "burden" more often with the disabled male. Still, there seems to be some ambivalence as to how sympathetic an able-bodied male could be toward a female partner who was disabled:

Women might have more sympathy for a paralyzed man and could understand, but a man may have a hard time dealing with a paralyzed woman. (21 year-old male)

The male (would) feel sorry for her. (26 year-old male)

Will he feel sorry for her? (39 year-old female)

GENDER STEREOTYPING

This research supports most major studies on gender. Gender distinctions, in terms of appropriate role expectations, were so prominent within the data that we believe this topic should be addressed in a separate section.

While it is recognized that gender is a salient status characteristic and as such not only orders society, but is ordered by it, it was surprising to discover the extent to which stereotypical gender roles and norms were promoted. Perhaps naively we thought that disability would be the more prominent issue rather than gender. Instead we found gender to confound the issue of disability.

Responses were most stereotypical and sex biased in the realm of sexuality. As previously discussed, a male partnered to a disabled female was considered likely to seek alternative sexual partners. Only once was this

mentioned as an option for a female partnered to a disabled male. Thus, there is clear evidence of a double standard. The emphasis or prominence of the male's option to seek other partners outside of the relationship is greater evidence of a stereotypical gender bias when one considers that the respondents reasoning for this seems to imply that the male is more in "need" of sex than is the female. Thus, we see bias in two ways: first, sexual promiscuity is an option for the able-bodied male while not typically so for the able-bodied female; second, there is the implication that the male "needs" sex more than the female.

Congruent with the bias that men "need" sex and females do not is, as previously discussed, the gender bias is represented by the salience of a male centered sexuality in the data. That is, there was an overwhelming concern for the male's sexual enjoyment.

Traditional gender stereotypes were apparent in that there was recognition by both males and females of "normal" role expectations for both sexes. The following response is representative of traditional gendered stereotypes:

A woman's and man's feelings are different a woman might have more sympathy for a paralyzed man and could understand, but a man may have a harder time dealing with a paralyzed woman. (21 year-old male)

Traditional stereotypical gender role expectations were expressed as women were regarded as the nurturers and men were regarded in need of nurturance. Thus, many respondents expressed concern that the disabled female would be incapable of fulfilling her role as nurturer:

Will she be able to work or take care of home and children? (21 year-old female)

The [disabled] male would be more temperamental. He needs someone to take care of him. (20 year-old female)

In addition to promoting the sole nurturing ability as embodied by the female, these comments once again support the myth that a physical limitation results in limitations (i.e. the ability to nurture) in all other areas of life (McKown 1986). It seems most problematic that a woman would be considered incapable of being nurturing due to possessing a

physical disability.

Also apparent was that role reversal was a prominent concern for both males and females. This is evident in that it was considered more difficult for the male to be with a disabled female than vice versa because he would have to care for her. One 20 year-old male stated that a problem would be the fact that "He [the able-bodied male] would have to take care of her [the disabled female] all the time." This is a role that is not, in the traditional sense, a normative expectation for males. It is a role that the male is considered ill prepared for, even in contemporary society. While in the first scenario there was recognition that the able-bodied female would have to care for the disabled male, and that it would be difficult, this was often considered problematic as it was thought that the male may find it difficult to be in a dependent position, one in which he could not work to support a family. Thus, the primary concern was often not that the female would have a great deal of responsibility caring for her disabled partner, as being caring and nurturing is considered a gender appropriate role for a female. Thus, we conclude that there is gender stereotyping, evident in a perceived lack of ability to engage in reciprocal role responsibilities.

DISCUSSION AND CONCLUSION

These findings have serious implications for individuals with disabilities as well as for the larger society. First, the confounding effects of traditional gender expectations within this study has implications for the status of gender relations within society. Gender inequality is a prevalent issue and one in which much effort has been spent attempting to reach some resolution. We speculate that because respondents probably did not perceive gender to be relevant to this assignment, we were able to tap into strongly held, stereotypical, expectations of gender roles. This reminds us that although gender roles within society may have shifted from the extremes, we are far from permitting a full range of behaviors from males and females that would free them from the inequality produced by traditional gender stereotyping.

Second, these findings have serious implications for the self-concepts of individuals with disabilities. A key theoretical premise of self-concept formation is that self-concept is shaped by the reactions of others in social interaction. That is, one acquires images of

oneself through the treatment received from others. Individuals reflect upon the treatment received from others to discern how others perceive them as well as to discern the value-judgment placed upon them. This in turn results in either a sense of pride or shame for who or what one is (Cooley 1983). The impact upon self-identity of the perceived responses from others has been demonstrated in earlier research. That is, self-concepts have been found to move closer over time to the views held by others (Mannheim 1966). Given this knowledge, the present study's findings suggest a major impact upon identity of the reflected appraisals of nonsexuality from others. Furthermore, should an individual be able to overcome these stereotypes, they may still be hindered by social evaluations to the contrary.

McCall (1987), commenting on the evolution of role-identity theory, recognizes the empirical development in the demonstration of the reciprocity between the self and society. In citing Park (1927), McCall recognizes that one's identity is negotiated, not only with oneself, but also with society:

Often enough it happens that [one] is not fitted to the role which [one] chooses to play. In any case, it is an effort for any of us to maintain the attitudes which we assume; all the more difficult when the world refuses to take us at our own estimates of ourselves.

If social evaluations do not place the individual with a disability in the role of a sexual being, it will be difficult for the individual to acquire the adaptive behavioral expectations of that role. That is, if we assume that individuals with disabilities do not have the same needs for physical affection and sexual expression, we will not likely provide them the opportunity or the social acceptance to realize it.

Moreover, stereotypes of nonsexuality are misinformed on two levels. First, studies show that 72 percent of men who are quadriplegic due to spinal cord injury can have intercourse (Madorsky 1983). Second, if society fails to acknowledge that nonambulatory individuals (those in wheelchairs), who may or may not have the capacity for penile vaginal penetration, are sexual beings with the capacity for physical affection and sexual expression, we are essentially reifying the belief that only penile vaginal penetration is real sex. These attitudes deny that individuals with

disabilities have the same sex-related needs and desires as the nondisabled. That is, they need an intimate relationship with another person; they need the same sexual outlets of expression such as touching, caressing, holding and kissing, the soft-gentle expressions of sexuality and perhaps creative solutions within boundaries of individual limitations. We as a society should recognize a multitude of behaviors as sexual activity and evidence of one's sexuality as a human being. We need to recognize other forms of expression other than focusing on penile-vaginal penetration as the only "real" sex. Moreover, we need to acknowledge that sex can be satisfying without either or both partners reaching orgasm.

Thus, the importance of focusing more classroom discussion of the sexual needs and capabilities of individuals with disabilities can broaden the understanding of what it is to be sexual beings. It should be noted that when human sexuality texts for college courses address sexuality and disability, they do so only in a cursory manner. Furthermore, these texts tend to lump all disabilities together which does little to delineate the various social factors affecting sexual behavior. A much more in depth examination of the breakdown of the wide range of disabilities is necessary. Thus, a more comprehensive study of disability and sexuality would encompass the ways in which sexuality is affected by an acquired or traumatic disability versus a congenital disability, a chronic versus short term disability, a conspicuous versus a nonconspicuous disability.

It is important to recognize that, although society has fought hard for the mainstreaming of individuals with disabilities through the removal of physical barriers, we prevent integration on a social psychological level through the denial of sexuality.

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