Sexuality After Spinal Cord Injury: The Greek Male’s Perspective

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OBJECTIVE. This study explored how Greek men with spinal cord injury experience sexuality.

METHODS. Six men with spinal cord injury acted as key informants and data collection consisted of in-depth unstructured interviews, field notes, and a reflective log. The transcribed interviews were analyzed thematically.

RESULTS. The themes that emerged were: Barriers, Metamorphoses, and Enjoying. Sexuality was important in the life of the informants and they were engaged in various patterns of adaptation. Rather than impairment as such, certain social beliefs and values prevalent in Greek society were found to act upon the informants in compromising ways.

CONCLUSION. The results suggest that the process of reclaiming one’s sexuality is a process of meaning-finding. The data support a conclusion that occupational therapists should respect the cultural nature of sexuality. Moreover, the topic of sexuality should be approached in a holistic manner, perceiving it as extending in a continuum, which may be positively or negatively affected as a result of an acquired impairment.


Sexuality is an integral part of human nature and permeates everything people do (Merleau-Ponty, 1962/2002; Weeks, 2003). It encompasses the act of sex but extends beyond it and incorporates physical, sociological, and psychological dimensions (Shakespeare, Gillespie-Sells, & Davies, 1996). Williamson (2000) asserts that sexuality can be expressed through and give meaning to occupations. According to the Occupational Therapy Practice Framework (American Occupational Therapy Association [AOTA], 2002), sexual activity is a part of activities of daily living and thus a legitimate area of concern for occupational therapists. Moreover, several studies (Kreuter, Sullivan, & Siösteen, 1994; Phelps, Albo, Dunn, & Joseph, 2001) have revealed that sexuality is one of the main concerns of men with spinal cord injury (SCI); therefore, it should not be overlooked during rehabilitation.

Occupational therapy has recently returned to a humanitarian scientific paradigm, where the mandates of holism and client-centered practice as well as a wellness model of health assume a primary role in guiding and informing practice (Finlay, 2001; Whiteford, Townsend, & Hocking, 2000). Occupational therapists treat the whole person and direct therapy according to the wishes of the client, who should be at the core of the intervention (Finlay, 2001). This philosophy, combined with occupational therapists’ knowledge of medical as well as social sciences and their focus on enabling engagement in occupation (AOTA, 2002), places them in an ideal position to address sexuality issues during rehabilitation (Couldrick, 1998a).

In the last two decades, a number of studies have explored various issues pertaining to sexuality and the practice of occupational therapy. A review of the literature dealing with sexuality and its relevance to occupational therapy revealed that the majority of occupational therapists believe sexuality to be a legitimate and important area of concern for the profession and consider clients as sexual beings.
(Couldrick, 1998b; Miller, 1984). Novak and Mitchell (1988) examined professional involvement of occupational therapists and rehabilitation nurses in sexual counseling of clients with SCI. More than half of the occupational therapists (58%) reported engaging consistently in sexuality counseling, whereas the reasons for nonengagement included different allocation of responsibilities within the team (70%) and, to a much lesser extent, perceived lack of knowledge (22%). Compared to similar research by Conine, Christie, Hammond, and Smith (1979), the percentage of occupational therapists in the 1988 study reporting lack of knowledge is considerably lower, which may be attributed to changes in the educational curricula. Indeed, a study by Payne, Greer, and Corbin (1988) revealed that the topic of sexuality was addressed in 82% of the educational programs that were researched (all of them in the United States).

A study by Couldrick (1998b) rendered different results, with many professionals reporting lack of education as a main concern, highlighting perhaps the inadequacy of educational curricula in the United Kingdom (Couldrick, 1998b). Moreover, many occupational therapists share concerns regarding the sensitivity of the issue and, although they agree that the therapist should deal with it in a delicate way (Summerville & McKenna, 1998), it is believed that occupational therapists project their own values when dealing with sexuality issues (Yallop & Fitzgerald, 1997).

Summerville and McKenna (1998) proposed a four-level model for service delivery, P-LI-SS-IT, which was originally described by Annon (cited in Summerville & McKenna, 1998). P stands for permission, LI for limited information, SS for specific suggestions, and IT for intensive therapy. Occupational therapists can use this model up to the third level, whereas only a specialized therapist can carry out the fourth level. Initially, the occupational therapist establishes an accepting atmosphere and gives permission to the client to talk about issues regarding sexuality that may be of concern. The therapist provides general education and counseling that may involve assertiveness training to help the client deal with societal attitudes and beliefs, and then he or she may move on to the third level of intervention and provide specific suggestions to address the client's concerns.

When researching issues regarding sexuality, it is important to acknowledge its cultural nature. Sexuality is shaped and influenced by the cultural context (Gagnon & Parker, 1995), within which it assumes its meaning (Foucault, 1978/1990). In Greek society, male sexuality is closely connected with masculinity and is primarily expressed through physical action and by the pursuit of sexual encounters (Lazos, 1997). Greek men are expected to be active, strong, and physically independent, which may explain why sexuality of people with disabilities is still a taboo in Greece.

Several studies have shown that attitudes of the general Greek population toward sexuality of people with disabilities are generally negative (Karellou, 2003; Mavreas et al., 2001; Stasinos, 1994). This negativity may be due to the collectivist nature of Greek society, which emphasizes duty and conformity (Zaromatidis, 1999).

Sexuality remains a topic usually avoided or underdiscussed by occupational therapists (Couldrick, 1998b; Novak & Mitchell, 1998). It is telling that many people with disabilities report dissatisfaction with the sexual rehabilitation services provided by occupational therapists (McAlonan, 1996) and believe that occupational therapists are not appropriately qualified to address sexuality issues (Northcott & Chard, 2000). Possible reasons for this could be health professionals' limited knowledge with regard to sexuality and, perhaps more importantly, the widely held perception that people with SCI are devoid of sexuality. It is believed that gaining an understanding of how these men experience sexuality will make occupational therapists more attentive to the sexuality rehabilitation needs of their clients and will enable therapists to provide more effective rehabilitation experiences. The purpose of this study was to explore how men from one country (Greece) who have SCI experience sexuality. The cultural dimension of the research question was very important, because sexuality is a cultural construct and may vary greatly across cultures (Caplan, 1987; Mandi & Agrafiotis, 1993).

**Study Design**

A heuristic phenomenological approach was deemed to be the most appropriate methodology for this study, because its aim was to provide an account of lived experiences without being colored by any external factors, such as existing literature or social beliefs (Merleau-Ponty, 1962/2002). According to van Manen (1990), phenomenology is the method of choice to explore meanings from the individual's perspective.

**Ethical Issues**

Before commencement of the study, approval was granted from the Ethics Committee of Sapporo Medical University in Japan, which was the affiliating institution of both authors at the time of the study. The informants received full information regarding the research project and use of the data, and only after having read the explanatory statement did they sign the consent form. To ensure anonymity,
the informants were free to choose a pseudonym for themselves and all potentially identifying data were removed or altered.

It was acknowledged that talking about sexuality could be emotionally challenging (Johnson & Clarke, 2003). The researcher (first author) made every effort not to subject the informants to distress or discomfort, and he reminded them of their right to not answer a question or to even terminate the interview. A distinct debriefing stage was not necessary because the conversational structure of data collection facilitated the clarification of any issues as they arose.

Informants

Six men who met the following selection criteria participated in this study: males with SCI; in their 20s up to their 50s; living in Greece; and at least 3 years postinjury. All participants were Greek and had been socialized within a Greek cultural context. The researcher contacted the Greek Association of People with Paraplegia and explanatory statements were forwarded through the association to potential participants. The persons who were willing to take part in the study gave permission to the association to disclose their phone number to the researcher. Table 1 provides background information on the informants.

Data collection took place in Greece for reasons relating to a convenience sample. A more important reason for collecting data in Greece was the first author's own cultural background (Greek), which enabled him to recognize and understand the culturally laden notions of sexuality and masculinity expressed by the informants.

Data Collection

The main collection tool was the unstructured, in-depth interview. The researcher met each of the informants twice and the interviews were conducted within the privacy of the informants' houses. Each interview lasted from 1 to 2 hours and was preceded by a short warm-up period (10 to 15 min) to help the informant relax.

In acknowledgment of the interactive nature of phenomenological inquiry, it was deemed necessary to make use of a reflective log. In this, the researcher put into words his reflections on the research process and on the ways he exerted influence on it. Finally, field notes were also taken.

Data Analysis

Thematic analysis was used to illustrate the experiences of the participants (van Manen, 1990). Transcribed interviews were read many times and the researcher immersed himself in the data before identifying themes. These themes were intra-participant and inter-participant (found in one or in more interviews respectively). The stages of the data analysis process are outlined in Table 2. It should be noted here that the transcription was performed in the original language (Greek) and the analysis was based on these original transcripts, as proposed by MacLean, Meyer, and Estable (2004). The analysis was performed directly in the English language and, once it was completed, the transcripts were also translated into English.

Credibility

To ensure credibility, findings were subjected to peer review by two occupational therapists. Moreover, once themes had been identified, rival themes were sought—as proposed by Gliner (1994)—but could not be located. Reflexivity was another strategy that was used. This strategy, achieved by keeping a personal reflective log, included acknowledging the researcher's own thoughts, feelings, and experiences. It helped the researcher identify his personal thoughts and feelings, and distinguish them from those of the participants.

Verification of the findings was achieved by asking the informants if they really meant what the researcher thought they meant. This questioning was done very carefully so as not to lead informants to one or the other response (Morse & Field, 1995). Moreover, verification with related literature was sought. Because the study did not explore a total terra incognita, other investigators were bound to have reached similar conclusions and, indeed, findings similar to ours were found in previous studies (Cole, 2004;
adapted from Moustakas, C. (1994). Traditionally, Greek men perceive
from which three key themes emerged. These themes were:
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Having to ask for help in order to get ready
One of the main traits for men in Greece is independence
Social reality around them quite often acted on them in dis-
ic impairment as an obstacle to a fulfilling sexual life, the
All of the men who took part in this research found that
Although the informants did not experience their phys-
with some even saying that impairment improved their sexual
The first time after the injury, I kind of resisted sexual rela-
Moreover, requiring personal assistance in order to
Social disapproval was also perceived as an obstacle;
My attitude changed when I got my own car, got myself a job,
Metamorphoses consist of two sub-themes: redefining sexuality and redefining oneself.
Redefining sexuality. All of the men who took part in this research found that
for sex was experienced by the informants of this study as
Coming from a society that views sex as the privilege of
the way they viewed sexuality and themselves had changed. Some of them felt “effectively emasculated” (Murphy, 1990, p. 96), whereas others assumed a facet of overtly aggressive behavior. To reflect the different patterns of behavior adopted by the participants, Metamorphoses consist of two sub-themes: redefining sexuality and redefining oneself.
Redefining sexuality. Traditionally, Greek men perceive sex in a patriarchal way, assuming an active role and focusing on its physical aspects. Sexual acts are not a proper arena for expression of feelings or intimacy, but rather the venue where men can prove they are up to their role (Lazos, 1997).
Most of the participants of this study reported that after the injury they approached the concept of sexuality as a new territory and they ultimately redefined it in a more inclusive way. An erection, while in many ways useful and desirable, was not perceived as a prerequisite to expression of sexuality. Characteristically, Pavlos said: “It’s just like a newborn getting to know the world; that’s how a disabled [term used by the informant] is getting to know his sexuality.” This relearning process usually resulted in an inclusive notion of sexuality, where intimacy and feelings as well as partner satisfaction were the focal points. Alexandros talked about the meaning of sexuality before and after his injury:

To me, before my accident, sexuality had only to do with the sexual urge...after my accident and with the subsequent loss of sensation and motion in my lower limbs sexuality is all about a need to get intimate with another human body rather than having anything to do with your own body.

Spontaneity—or, rather, its loss—was central to the way men experienced sexuality after the accident. If they wanted to go dining, for example, they had to make sure the restaurant was genuinely accessible and that parking was available. Advanced managerial skills may be necessary if the person does not own a car. And of course, the issue “what about my personal assistant?” remains. Although a personal assistant may be necessary for transportation to and from the restaurant, his or her presence may not be always needed or even welcome during dinner, especially if it is a romantic candlelit dinner. As Nick said, “It’s definitely different, the way I experience a sexual relationship, because I have to plan before I do anything, think about where I will go and whether it’s accessible.”

Redefining oneself. The altered relationship with one’s body can also lead to the formulation of a new identity in which disability becomes the inescapable defining characteristic. Some of the participants were not willing or able to change their views on sexuality and consciously or not modified themselves, whereas others started to doubt whether they were the same persons as before the accident. John described how his inability to express his sexuality led to feelings of alienation from other people: “You are being excluded...or maybe you exclude yourself...you can’t express your sexuality, you can’t jerk off, for instance, or hug a girl...you feel less human. You are self-excluded from the human race.” For Alexandros, his changed physical body had an effect on his self-esteem:

In the beginning it was tough...to begin with, your own body is changing, you feel changing, it may not be really changing but you do feel it does and that’s a major blow to your self-esteem.

Initially, Alexandros’ loss of sensation to his genitalia led him feel less than male, something that can be easily understood if we think of the emphasis Greek society places on erection and the focal role erection has in the construction of male identity:

I started thinking about my sexuality from the first moments after my accident. I felt like being castrated, emasculated...I was trying to figure out what it meant, come to terms with the fact that I’ll never feel my penis again, that I’ll never again get the pleasure that I used to take by, say, stroking it.

Some other participants confessed that they had adopted a macho facade so that nobody would challenge their masculinity. Participants who, instead of rejecting, adhered to a hegemonic model of sexuality—that is, sexuality embodied in dominance and physical assertiveness (Lazos, 1997)—were especially prone to view impairment as an obstacle and to develop a negative self-image. They favored a model that bore little resemblance to who they now were, which subsequently led to lowered self-esteem. Dimitris reported that he adopted overcompensation techniques and became aggressive. Tepper (1999) believed that feelings such as anger can be acceptable within the frames of dominant masculinity as opposed to expression of pain or fear. It seems that the impairment becomes the focal point of existence and the disability the main identity constituent, or rather an identity in itself. On describing his sense of disability, Murphy (1990) stated:

A serious disability inundates all other claims to social standing, relegating to secondary status all the attainments of life, all other social roles, even sexuality. It is not a role, it is an identity, a dominant characteristic to which all social roles must be adjusted (p. 106).

Although a conscious and positive disability identity is desirable and helpful, an identity that reflects societal expectations of what a person with an impairment should be like can be detrimental. According to Shakespeare et al. (1996), the social image of people with disabilities can range from infantilized, dependent, and asexual to malignant and guilty about his or her condition.

Enjoying

Most of the informants reported that although they could still get sexual satisfaction after the accident, the ways they were getting it were altered. Before acquiring the impairment they had a self-central motif of getting satisfaction, whereas after the accident they turned to a more interactive pattern, in which they would get satisfaction through giving. Moreover, some of the participants found quite beneficial the fact that their erection was externally controlled, so they did not need to worry about a potential failure. As Pavlos said:

We [Greek men] grow up believing that he who finishes faster is the most effective lover...this is wrong though. My current
Dimitris brought up the issue of the penis: “I don’t take as much satisfaction as I used to...it has to do with the function of the specific organ.” This experience, however, was not shared by the other informants. They were able to get over a genitalia-centered notion of sex and re-map erogenous zones in their bodies. Learning once again how to use their bodies in order to give and receive satisfaction took some improvising from the men, because they had to learn to function sexually in a different physical manner than in the past.

The informants of this study talked about being more willing to explore their full sexual potential than they were before acquiring their impairment. The fact that they had to modify their previous patterns of engagement in sexual activity had a liberating effect, freeing them from inhibitions and preconceptions of what sexuality and sex should be about. The data suggest that the informants could experiment and find what was appropriate and satisfying for them, instead of trying to conform to a conventional model of sex. Nick said:

The satisfaction I get now is of a different kind and it can sometimes be more intense than the one I had before...if I have to give numbers, I’d say it’s five to ten times more intense...sometimes I feel completely drained out, totally exhausted after sex, and I just need to stay for a quarter [of an hour] or so before I can actually get up. This is something I had never experienced before.

Discussion

According to Husserl (1913/2002) our bodies are the basic means through which we experience the world around us. Most of the time, however, we are totally unaware of our physicality—the weight of our feet, the movements of our bladder, penile erection, or even functions like coughing or sneezing, all either go unattended or happen effortlessly. Acquiring paraplegia or tetraplegia forces one back to his body and to constant awareness of its existence. From the background where it was quietly located, the body abruptly emerges into the foreground of consciousness and the way it is experienced is forever changed. By this, however, we do not imply a qualitative change to the better or worse; the new situation assumes status of normality. Murphy, a social anthropologist who became paralyzed as a result of a tumor wrapped around his vertebrae, stated that, “Disability is not simply a physical affair for us; it is our ontology, a condition of our being in the world” (1990, p. 90).

Hence, the informants of this study did not experience SCI as exerting a negative influence on their sexual per se. Most of the barriers experienced by the informants stemmed from the prevailing notions within Greek society of patriarchal sexuality, dominant masculinity, and asexuality of persons with impairments. It appears that all of these assumptions work together to potentially annihilate the sexuality of persons with impairments in general and men with SCI in particular (Sakalleriou & Simó Algado, 2006).

However, men with SCI are not victims and they can actively fight those barriers. Most of the informants of this study managed to overcome those barriers and enjoy a satisfying sexual life. Experimenting and reinventing the meaning of sexuality were basic in this process of reclaiming sexuality. This is also what Seaman (cited in Cole, 2004) believes to be the key to a satisfying sexual life—leave everything behind and start from scratch. This attitude may be problematic, of course, because not all are ready or willing to discard their past experiences.

According to Gerschick and Miller (1997), men with a physical disability can opt for any of the following three adaptive responses with regard to their masculinity: (a) redefine it, (b) double their efforts to meet the commonly held standards of masculinity, or (c) reject the notion of a normative masculinity. What they cannot do is ignore it. These responses match well with the broader adaptive patterns of behavior that humans engage in, in order to reconnect to a disrupted occupational life trajectory, as described by Urbanowski (2003). These patterns are reflective action, endurance, and resilience. People who follow the first pattern (reflective action) engage in a constant search for meaning; people who follow the second pattern (endurance) conform to the given situation; and people who follow the last adaptive pattern (resilience) try to achieve a positive outcome.

Some of the informants of this study chose to reject the notion of hegemonic sexuality and to redefine it in a personally acceptable and satisfying way. They viewed SCI as a chance to become better and to advance toward maturity and selflessness, and were able to reconnect to themselves and to their occupational life’s trajectory as well as to other people through engagement as leading actors in the sexual drama. They were able to find meaning in sexuality and feel sexual once again.

Some other participants, however, tried to meet the commonly held standard of sexuality for Greek men. Greek men with SCI were brought up and socialized in a society that closely connects physical prowess to male masculinity and ability to have an erection to being a man (Loizos & Papataxiarchis, 1991). Within the Greek social context, male sexuality is sometimes perceived in an exclusive and phallocentric way, which can lead men with physical disabilities to experience feelings of emasculation and inadequacy.
(Drench, 1992; Shakespeare, 1999). The fact that manhood in Greece is conditional on performative excellence means that manhood is precarious and may be lost. This poses a threat to the self-identity of men with physical impairments who cannot live up to the widely held ideal of a hegemonic masculinity. Some men may even equate loss of independence (another social construct) or loss of sexual prowess with loss of manhood and have a disrupted gender identity (Tepper, 1999). Feelings of inadequacy are not uncommon, because they can no longer perform as “real” men.

Implications for Occupational Therapy

Therapy does not take place in a vacuum but within a certain cultural context. Occupational therapists, apart from being professionals, are also members of that certain cultural context, sharing common beliefs and practices as well as prejudices (Hagedorn, 1995). Therefore, along with the greater society, therapists do not always view persons who are physically challenged as sexual beings. The results of this study imply that occupational therapists should deal with the topic of sexuality in a holistic manner, perceiving it as extending in a continuum that may be affected positively, negatively, or not at all as a result of an acquired impairment. Instead of treating their clients as asexual, occupational therapists should acknowledge the inherent sexual nature of the human being and help the client reconnect to this important part of life.

The results of this study suggest that the process of reclaiming one’s sexuality is a process of finding meaning again. As occupational therapists it is our responsibility to help our clients achieve this transition and develop a resilient sexual life. To do so, we need to be aware of the inherent meaning that sexuality holds for our clients and integrate it as a legitimate concern in the intervention. The ultimate role of occupational therapy is to empower clients to reconstruct a personally satisfying, resilient, and meaningful occupational life. Urbanowski (2003) suggests that clients should not be viewed one-dimensionally as they appear in our usual work settings, but as occupational beings moving along their occupational life trajectory. It is easy then to envision the role of occupational therapy as one of empowering the clients and enabling them to get reconnected to their chosen occupational life trajectory.

It is vital that occupational therapists appreciate the cultural nature of sexuality and understand the clients’ beliefs toward it. In modern Greece, sexuality and gender are usually indiscernible; a man is acknowledged as a person who is a biological male and who assumes sexual practices and displays sexuality manifestations congruent with the norm for men in Greece (Yannakopoulos, 2001). The body

per se and its functions are vital in the constitution of masculinity as experienced by the majority of men; the penis represents masculinity, and bodily performance is a basic constituent of being a man. The occupational therapist should respect the male client’s beliefs and help him reconnect to his sexuality through a way that is meaningful to him. The therapist could, for example, inform the client about ways to actively use his body during the sexual act (e.g., provide tactile stimulation to his partner).

Occupational therapists should recognize the sexual needs of their clients and actively try to give solutions to potential problems and concerns. The focus should be mainly on dispelling myths and stereotypes and encouraging the client to be explorative rather than trying to find ways to imitate practices performed before the injury. Thus, the client will be able to reconnect to himself and other people and find meaning in sexuality. The need for further education on the topic is great. In a study of occupational therapists’ comfort with clients’ sexuality issues, Yallop and Fitzgerald (1997) found that therapists feel uncomfortable when dealing with situations that challenge their values (e.g., masturbation or homosexuality). Weerakoon, Jones, Pynor, and Kilburn-Watt (2004) reached similar conclusions when they examined allied health professional students’ (including occupational therapy students’) perceived level of comfort with sexuality issues. It is suggested that educational curricula should address the topic of sexuality and present it as a natural phenomenon, part of the activities of daily living. It is vital that occupational therapists feel comfortable with this issue, because otherwise they will not be able to offer effective services.

Conclusion

Persons with disabilities often find that their sexual needs are not taken into account or are not respected; in other words, they are denied one aspect of their personal identity. This study illuminated the processes through which the sexuality of men with SCI is disabled, but it also showed that many men with SCI have managed to overcome those barriers and have a satisfying and fulfilling sexual life. The findings provide insight into possible experiences for the majority of men with SCI. This is certainly not an exhaustive description of experiences, and probably many areas are missing; however, this is a much needed beginning to better understand a much neglected issue. ▲

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