

Sexual Self-esteem and Body Image of South African Spinal Cord Injured Adolescents

Cheryl-Ann Potgieter, Ph.D.^{1,3} and Gadija Khan²

Although adolescents sustain a large portion of spinal cord injuries, the area of spinal cord injured adolescents and the issues surrounding their sexuality are under-researched. This is the first South African study on the sexuality of spinal cord injured adolescents and attempts to address this paucity. It is generally postulated that the sexuality of adolescents who have sustained SCI will be detrimentally affected by the consequences of having a physical disability, resulting in developmental lags relative to non-disabled peers. The focus of this article is to explore the impact of spinal cord injury on adolescent's sexual self-esteem and body image. A qualitative study was conducted, with data being collected via in-depth individual interviews, which were subsequently analyzed thematically. A disparity was found between dominant ableist discourses of the SCI adolescent as a sexually immature and passive spectator, and the lived experiences of the participants involved in the study. The study concluded that entrenched socially constructed attitudes appear to limit the opportunities for spinal cord injured adolescents to express their sexuality more than the limitations by their disabilities.

KEY WORDS: spinal cord injury; sexuality; self-esteem; body image; adolescence.

INTRODUCTION

The physically disabled adolescent is perceived as a passive, sexually inactive 'child', who lacks both the sexual interest and skills to explore his

¹Department of Psychology, University of Pretoria and Chief Research Specialist/Head Gender Unit, Human Sciences Research Council, Pretoria, South Africa.

²Gadija Khan does holistic mind & body work in private practice, Cape Town, South Africa.

³Address correspondence to: Professor Cheryl Potgieter HSRC/CYFD, 134 Pretorius Street, Pretoria, 0001, South Africa; e-mail: cpotgieter@hsrc.ac.za, cherylp@postino.ac.za.

or her sexuality (1). This is in sharp contrast to society's historical conceptualisation of adolescent sexuality as a rampant uncontrollable force, which needs to be regulated and managed.

One could argue that the silence surrounding the sexuality of the disabled is nowhere more deafening than in the area of the sexuality of adolescents with spinal cord injuries (SCI). The marginalization of SCI adolescent sexuality is reflected in the paucity of research in the area. Prior to the 1970s a combination of erroneous assumptions about the impact of SCI on sexual functioning, and narrow, motoric, genital definitions of sexuality, resulted in an abundance of research focused on male sexual dysfunction (2). More recent studies have focused on psychosexual aspects of sexuality and the post-injury sexuality of women (3–5). Research into the sexuality of SCI adolescents, however, remains shrouded in silence. This omission is difficult to comprehend given that a large proportion of spinal cord injuries are sustained during adolescence (2,6,7). Dewis (6) points out that 67% of new spinal cord injuries occur at age 30 or younger, the most frequent age group being 15–20, which has 27% of the cases.

The paucity of research relating to the sexuality of adolescents with SCI is partly a consequence of the ways in which their sexuality has been constructed within academic discourse. Developmental psychology textbooks, for example, generally devote much space to adolescent sexual development, stressing the importance of physical changes and body image. However, in reviewing a range of these texts, hardly anywhere in any of its copious delineations of 'appropriate gender roles' and sexual activity of adolescents was reference made to sexuality of the physically disabled adolescent Khan (2000, unpublished thesis). Khan (2000, unpublished thesis) points out that Rogers (8), while indeed recognizing that the SCI adolescent has sexual needs, he nevertheless maintains a negative outlook on their "ability to date...". Rogers (8, p. 102) states: "... neither the handicapped boy nor girl especially the latter, can expect many dates". Despite its brevity, the paragraph by Rogers creates the idea that disability most likely precludes regular sexual interactions. Certain writers attribute the SCI adolescent's lack of sexual interaction to factors such as "incomplete personality development" (9). Theorists who adhere to the latter type of arguments tend to ignore the role of negative societal messages which parents and other socialization agents pass to the adolescent. Goldberg (10) noted that many parents of children with physical disabilities consider their children as asexual, and these children are likely to learn from parental reactions that their bodies are ugly and sexually unattractive. In addition, socialization experiences communicate unequivocally, for example, that disabled persons are 'sexual neuters' whose prime identity is that of being disabled, which precludes having a sexual identity and access to

normal sexual and relationship experiences in the future (11). Within the educational arena SCI are excluded from sex education classes, and this reinforces the notion that they are asexual, unattractive, and incapable of regular sexual relations (10).

It has also been suggested that the social isolation imposed by a physical disability may result in early sexual urges being primarily expressed through fantasy instead of through active exploration (12). The adolescent with a disability is thus constructed as a spectator with no active engagement in sexual exploration (13). This arrested development paradigm endorses views such as those of Strax and Wolfson (1), who claim that it is most likely that disabled individuals, on entering adulthood, do not know how to relate to others of the same sex let alone someone of the opposite sex. It is thus generally assumed or implied that physical disability would impact negatively on the sexual self-esteem of developing adolescents thereby compromising their ability to successfully accomplish developmental tasks, especially in the area of sexuality (11).

In addition to sexual self-esteem, literature emphasizes the centrality of body image for sexual development during adolescence. The SCI adolescent does not conform to society's ideal physical image and the physically disabled adolescent may believe that their peers will find their flawed bodies unacceptable and therefore may shy away from contact with them (14). It has been pointed out that rejection by both able-bodied peers and disabled peers, and self-rejection, could constrict and constrain sexual development and expression of the SCI adolescent (1,9,15,16). Lonsdale's (5) study also suggested self-images shadowed by shame and embarrassment, as a result of loss of bowel and bladder function, which may interfere significantly with sexual self-esteem.

Both age and gender may have an impact on the sexuality of SCI adolescents. Trieschmann (2) hypothesizes that individuals who become disabled at an early age when they have limited sexual experience, will have more difficulty initiating relationships and becoming sexually involved. The researchers, could however, not locate any SCI adolescent studies relating to gender and body image. Research focusing on adult women has pointed out the adult women with SCI are stigmatized and excluded from mainstream activities and roles because of their disabilities, and at the same time they are denied access to traditional feminine roles as they are perceived to be asexual and undesirable lovers as well as unsuitable or unfit for maternal roles (17).

SCI leads to some individuals not being able to manage intimate body functions as well as personal grooming. The inability to manage their own intimate functions for example has the potential to so undermine the adolescent's self worth, and cause such self-consciousness about their bodies, that it can lead to the avoidance of sexual contact altogether (6).

It needs to be noted that apart from the largely speculative descriptions about the disabled adolescent's psychosexual development, research about sexual expression such as dating patterns, sexual behavior, and relationships is extremely limited (14). The general consensus, despite the paucity of supporting information, is that the 'normal' sexuality milestones are delayed in the case of adolescents with physical disabilities (Khan (2000, unpublished thesis), 13,18).

Interestingly, in the few studies exploring the self-perceptions of SCI youth, the predicted negative post-injury self-concepts were not confirmed. Results of the Kennedy et al. (19) study did not support the hypothesis that individuals injured during youth had lower self-esteem, greater negative self-perceptions and more depression. SCI did not appear to have long-term effects on psychological well-being. While being cautious about the generalizability of these findings, they speculate that this could indicate that developing a self concept with a pre-existing knowledge of physical limitations, could result in a more accurate assessment of success and independence as an adult and less idealization of the imagined "non-injured" self. However, self-perception was lowered in the presence of depression and low self-esteem, with both the self and the "ideal self" being affected (19). This suggests that in addition to lowering self-opinion, low self-esteem and high depression could lower future aspirations as well.

Gorman et al. (7) found that participant's self-perceptions of their injured and uninjured selves were found to be significantly different on only nine out of twenty adjectives. Participants perceived themselves to be more popular and understanding since injury, suggesting that they obtained something positive from the experience. In both studies level of injury was not significant, contradicting the widely held assumptions that greater functional loss carried a greater risk of poor adjustment. It was concluded that the quality of self-perceptions after SCI, is associated with psychological variables rather than organic ones such as age and level of injury (7). In light of this research it could be argued that while physical disability could play a role in the development of feelings of inferiority, the objective presence of a disability is a poor criterion for judging whether an individual is beset by self-depreciation or not. However, a variable that has been linked to SCI adolescents is depression. A South African study by Van Niekerk (1995, unpublished master thesis) exploring the relative levels of depression between youth with and without SCI found significantly more depressive symptomatology in the SCI sample than in the comparative able-bodied group. Van Niekerk found that while just over half of his sample reported no depression or mild or borderline symptoms, a disturbingly high percentage (45.5%) of participants presented with more severe levels of depressive symptoms, which did not appear to decrease with time after injury. These findings are disturbing, especially in the context of

some of the findings regarding SCI females and body image, and the positive link between negative body image and suicide (4).

The conclusion on reviewing the literature is that while adolescents sustain a large proportion of spinal cord injuries, the area of spinal cord injured adolescents and their sexuality is under-researched. The limited research, which does exist, does not challenge the traditional notions of SCI adolescent's sexuality. The current research attempts to make a contribution to addressing the issue.

Research Objectives

The primary aim of the broader study was to explore the impact of the SCI on the adolescent's discourses regarding their sexuality. For the purposes of this article the impact of SCI on adolescents sexual self-esteem and body image is explored.

METHODOLOGY

The fact that the literature base in the area of adolescent SCI sexuality is practically non-existent, in itself suggested the suitability of a qualitative methodology. Where scant information exists on a topic, variables are unknown, and the literature base is limited, underdeveloped or non-existent, the qualitative design can provide space for flexibility and freedom to explore in order for important variables to be identified (20). It has also been pointed out that the voices and experiences of the disabled are still disturbingly silent politically and academically, with medical professional, psychologists and sexologists speaking for them on the topics of love and sex (21,22). A qualitative design ensures that the richness of their personal experiences is communicated, and their voices heard (23).

SAMPLING PROCEDURES

Prior to conducting the research permission was gained from the relevant educational authorities. In the area where the research was to be conducted there are very few schools for children with spinal cord injuries. The researcher thus selected schools where she was of the understanding that an information rich sample would be available. However, there were schools where headmasters gave permission, but parents were reluctant to give consent for their children to be part of the study. Reluctance stemmed from parents not knowing the researcher, which implied that she did not have their "trust". Teachers at the schools were also not willing

to facilitate the interviews. A second plan then had to be operationalized. The second author of this article had worked at a school for SCI adolescents for 6 years and understood the reluctance of the parents and she was also aware that the potential participants were highly unlikely to speak to an outsider. This raises the issue that the topic might be under-researched, because parents resist granting permission for research dealing with their disabled child's sexuality.

At the school where she was involved, the second author requested the head physiotherapist (after parents had given permission) to invite SCI adolescents between the ages of 15 and 20 to participate in the research project. This approach was adopted because she felt that her physical presence during this part of the process (given that the students knew her) could undermine the students' right to decline participation in the study. The students were informed broadly about the subject area to be researched, and informed that willingness to participate in the study would not guarantee automatic inclusion.

The physiotherapist forwarded a list of potential participants. Preference was given to adolescents in the secondary school phase of education as there is evidence that those adolescents younger than 15 tend to mirror parental attitudes (24). The participants were also required to have been disabled for at least 2 years to minimize the effect of adjustment factors (25).

A sample of seven SCI adolescents eventually took part in the research. All the participants are adolescents of color. The researchers who made contact with the school are also South African women of color. Interestingly, certain parents indicated that their permission was given as the researchers were woman of color, and it was their belief this would lead to their children feeling more comfortable with the research process. Participants were given the choice of three possible venues where interviews could be held. Most felt that they would be inhibited discussing sexuality at home and opted for the interview to be conducted at the researcher's home. In two cases where distance and time were of issue, the interviews were conducted in a quiet, private area in the school residences.

Description of the Sample

The demographic details of the participants are summarized in Table 1 and discussed below.

INSTRUMENTS AND PROCEDURE

Data was collected by means of a biographical questionnaire, and an in-depth interview with a vignette to facilitate discussion.

Table 1. Demographic Details

Demographic variables	Number	Percentage (%)
Gender		
Male	4	57
Female	3	43
Age		
15–16	2	29
17–18	2	29
19–20	3	42
Educational level		
Grade nine	1	14
Grade ten	3	43
Grade eleven	1	14
Grade twelve	2	29

Biographical Questionnaire

Prior to being interviewed, participants were required to complete a questionnaire eliciting biographical and specific SCI information. The questionnaire also served as a means of building rapport and gently easing the participants into the interview process. As none of the quadriplegics were able to do this independently, the researcher recorded their information a few days prior to the interview (Table 2).

Interview Using Vignette

Following the successful utilization of a vignette to facilitate discussion in South African sexuality research by Potgieter (1997, unpublished doctoral Thesis) and Strebel (1993a, unpublished doctoral Thesis), a vignette was devised and used as a prompt in the interview. The vignette, while not strictly conforming to the format of a projective device, which is normally vaguely defined and unstructured (26), could be regarded as similar in some respects. The use of a vignette as regards the present research was seen to have the following advantages: it would foreground and objectify the subject of adolescent sexuality which could be relatively difficult to approach ‘cold’, given the highly personal nature of the topic. It would also give the participants something tangible to start discussing in the third person, thereby allowing them to distance themselves, to some extent, from discussing highly threatening and exposing, personal sexual issues.

The characters in the vignette were demographically similar to the participants, and included one person who was physically disabled. The

Table 2. Levels of Physical Impairment

Type of SCI (<i>n</i> = 7)		
Complete paraplegia	1	14%
Incomplete paraplegia	3	43%
Incomplete quadriplegia	3	43%
Age at onset of injury	Time Since Injury	
18 months	15 years 1 month	
2 years 9 months	14 years	
7 years 7 months	11 years	
8 years 5 months	8 years	
9 years 2 months	9 years	
15 years 11 months	3 years 2 months	
16 years 1 month	4 years	
Bladder control	Number	Percentage (%)
Yes	0	0
No	7	100
Bowel control		
Yes	1	14
No	6	86
Sexual impairment		
Yes	0	0
No	5	71
Don't know	2	28

Five (71%) of the participants indicated an absence of sexual problems, with two (28%) responding, "don't know". Since the information was obtained via the information sheet, and none of the respondents inquired exactly what the term "sexual problem" meant, it is uncertain whether respondents interpreted the question narrowly as referring to organic erotic capability, or broadly as referring to problems relating to sexuality. Either way, it is interesting that 71% did not acknowledge any difficulty in this sphere, which is in contradiction to the automatic assumption that SCI equals sexual dysfunction.

theme of the scenario was a meeting between male and female adolescents, with apparent mutual attraction. In order to answer the questions, participants were expected to identify with the physically disabled characters and in so doing reveal their own inner dispositions, conflicts and experiences in the comfort of speaking in the third person (26).

The vignette also served as a question-framing device. Six open-ended questions constituting an interview guideline were based on it. The questions were designed to act as stimuli to facilitate discussion around the issues of how SCI adolescents perceived and expressed themselves sexually. Certain of the guiding questions raised the issue of this paper viz. body image and sexual self-esteem. The structure provided by the basic questions of the interview ensured that all the participants were asked the same question, thereby making comparisons of responses possible. It also allowed the interviewer to bring into focus areas that may have been avoided consciously or unconsciously by the participant.

Analysis

All the interviews were tape recorded and transcribed verbatim onto computer. In order to produce as “true” a representation of the actual interview as possible, all details such as pauses, hesitations, unclear speech intonations, non-verbal communication as well as the researchers’ comments and questions were indicated.

The “immersion in the data” process started with the transcription process, in that it facilitated a general, intuitive, understanding of the data. It was followed by a more overt process of becoming familiar with the material through several close readings of the transcribed text on a manifest and latent level. The transcribed text was scrutinized for themes and patterns of both consistency and variance (27). The selection of themes was inclusive as suggested by Potter and Wetherall (28) so as not to exclude relevant material. After a protracted process of refocusing on the aims of the study and research questions, and through a process of sifting and sorting, certain themes were merged into related semantic fields. Two of the themes that emerged related to issues of sexual self-esteem and body image and are discussed in the following section.

RESULTS AND DISCUSSION

Sexual Self-esteem: Are we Attractive Sexual Beings?

Participants’ interpretations of the non-disabled girl/boy’s glances in the vignette and their speculations as to whether he/she would contact the disabled adolescent for the purposes of getting better acquainted, was expected to give some indication of the participants’ self-concept and sexual self-esteem; that is, whether they perceived themselves as sexual objects, capable of inspiring active interest in the opposite sex. The majority of participant responses reflected the dilemma of trying to interpret if the glances were inspired by romantic interest, or by pity and curiosity about the ‘protagonist’s physical condition. There was a greater tendency to assume that it was the disability rather than the individual that had generated the interest:

Ah! I think maybe they think now ok she’s only looking at me because I’m in a wheelchair, and she’s not like interested in me.

... I always think people always look at my disability first, like if I like a cute guy, now hey, and then I first think he won’t take me because I’m in a wheelchair...

The first thing that goes to my head is: “what does she think of me”? It depends what her facial expression has to say... if she’s now feeling sorry for me or something like that.

A number of studies reflect the above scenario to be typical of first meetings (29, Kunzmann (2002, unpublished thesis),30). Researchers argue that first impressions carry the lion's share of weight in initial encounters (2,30). Consequently, disabled people fear that they will be rejected before the first "hello". Participants in the Anderson and Clarke (29) study concurred that non-disabled people made devaluing judgments based on physical appearances, which excluded disabled adolescents from being seen as potential partners.

Despite this, five out of the seven participants (71%) were convinced that the disabled adolescent would be contacted, suggesting that their self-concepts included the notion of being sexually attractive enough to elicit interest despite disablement. They thus experience themselves as sexually attractive and have the potential to date which negates dominant discourses (8,9).

... I think she'll phone yes. To find out more about him, to get to know him better and maybe, she is maybe interested in him. Maybe a cute guy or something like that...

I think she will phone, because they had a good evening and he had lots of guts. Because there are some guys that can walk and then they eye you, but they won't make an effort ... And they enjoyed each other and laughed and he made her happy and she made him happy...

However, a close inspection of the text suggested that the issue of attractiveness is complex and that participants' conscious responses should perhaps not be taken entirely at face value. One response, for example, started off strongly positive but petered out tamely, suggesting perhaps the participant's uncertainty about his ability to arouse romantic interest, despite a strong wish to be capable thereof:

I think he will call, because... probably because she came to him and ... because they talked all the time ... I also don't know

Another tentatively positive response implied something negative about people with disabilities and their perceived level of attractiveness. It entrenches the notion that persons with SCI are marginalized because of physical appearances.

Miss, It just depends what kind of girl Judy is. If she's now a person who doesn't worry about people, about how you look, who you are, then she will call

On the whole, the responses of participants in the study were contradictory and difficult to interpret. With the exception of one, the majority of participants in the study appeared unsure and unconfident about their attractiveness as potential love interests. This is in line with a study (29) involving adolescents with cerebral palsy and spina bifida, which documented similar concerns and responses to those emerging from this study. The adolescents identified as their main worry the question as to whether

they would ever find partners because their disabilities made them unattractive to others (29). Doubts about one's attractiveness as a partner are also well documented in the adult SCI population (22,30–32) with SCI induced physical alterations being regarded as obstacles to interpersonal contact. However, the fact that nearly all the participants were convinced that a relationship could develop between the vignette characters suggests that they still perceive themselves as attractive, loving and lovable human beings.

This feeling of their inherent worth, juxtaposed with confusions arising from initial contacts may more accurately reflect a history of negative experiences at the hands of the able-bodied majority, who do not reinforce their positive self perceptions. The majority of adolescents interviewed contended vociferously that able-bodied members of the opposite sex held negative, rejecting attitudes towards them because of their disabilities and consequently avoided contact and romantic involvements with them. There was a strong feeling that they were perceived as sexually unattractive and so persona non grata that in the event of attraction, the individuals concerned would actively resist acting on their feelings.

Watching me but still he didn't... he... he... It's probably because I'm disabled or something. If it was anyone else, then I believe he would have said or made a move, maybe told the person.

Because if I'm with a girl, girls are for me, I'm just good enough to be their friend. They won't ... more... I can... be more serious, that's how I'm experiencing the experience.

One bitter participant pointed out that she had learnt from painful experience that able bodied people not only regarded themselves as more attractive, but as inherently "better" and having more worth on account of their physical integrity.

Like in my own experience too, the guy told me he liked me, and all those things, but his family asked what he plans to do with a disabled girl. There are many other prettier girls; there are many better girls ... not prettier, better girls than me. I'm in a wheelchair, what does he want to do with me?

Respondents felt that potential partners, both able-bodied and disabled willingness to become involved were closely related to participants functional level, for example, whether they had the use of their hands.

Then they start talking. Say, that guy, he looks ok, but he can't feel, cannot use his hands. It's... like that.

While an individual might feel that prevailing societal evaluations are discriminatory and unjustifiable, consistent experiences of societal devaluations undermine self-confidence and can challenge positive self-perceptions. However, this is not always the case. Disabled persons with positive pre-injury self-images in particular would not automatically introject negative evaluations, as differential weight would unconsciously be assigned

to them in order to support a more adequate self-concept (2,18, Kunzmann (2002, unpublished thesis)). Thus, if the ability to continue perceiving oneself as sexually attractive and “happening” depends on pre-injury self-perceptions, the wholesale acceptance of the societal evaluations about spinal sexuality could indicate that the pre-injury self-image and sexual self-esteem of the participants concerned may have been tenuous to start with. Alternatively, it is possible that the impact of trauma had so devastated the individual’s sense of self as to cause major revision of the self-concept, with the likelihood of introjecting prevailing social constructions around disability and sexuality. The latter held true for some of the participants. In speculating about the vignette character’s decision to explore a relationship with a disabled adolescent they predicted that a decision to proceed would result in demeaning, hurtful remarks and active discouragement by peers and family:

They will make fun of her and so on, make fun of her and maybe her father will, her parents will tell her, “What are you doing with the person?” and so forth... because lots of people are very negative about disabled people...

She will maybe think what will my friends say about me if I become serious with someone who’s in a wheelchair ... No, you have bad taste... Couldn’t you get someone better?

Rejecting attitudes on the part of able-bodied peers also has an impact on sexual self-esteem. In expounding on the difficulties of getting around in environments that that made little or no provision for people with disabilities the unhelpfulness of the peer group is highlighted. What is also clearly spelt out is the covert pressure that is put on ‘errant’ peers to return to the fold and preserve the status quo in terms of partner choice:

... Yes, if you go out, I have experienced it already, ... and there are steps, then it’s a whole hassle. In most cases when his (able-bodied) friends are with, then he alone had to pick me up at the stairs and they didn’t even help. But he eventually lifted me and then asked one of them to help, and then they said: “No, why? It’s not our girlfriend”.

These rejecting attitudes on the part of able-bodied peers underline the loss of status of disabled adolescents who find themselves deficient of many of the competencies enjoyed by peers. Lack of mobility, dependence on assistance for activities of daily living and limitations on sexual function result in their being avoided on account of their requiring extra effort and sacrifice (15,16,23).

Such stigmatization and ostracism may impact on self-esteem kunzmann (2002, unpublished thesis). Following Eriksonian theory (34), exclusion from the group could compromise the SCI adolescent’s ability to acquire a stable ego identity which would affect all areas of human functioning. The SCI adolescent’s vulnerability in this regard may be compounded by the fact that his or her body and functional status may have

been significantly altered by SCI, and the fact that this has to be integrated along with normal developmental changes. There may therefore be a disruption from 'how one was before' as well as a disruption from 'how everyone else is', accompanied by an aversive social response to these physical changes. On the other hand, the underlying statements that participants seemed to be making during interviews was that, if people were willing to look beyond the idolized images of physique, everyone would be liberated from the stranglehold of conformity, and learn to celebrate the infinite variety of the human condition.

Mirror, Mirror on the Wall: The Question of Body Image

Contrary to Teal and Athelstan's (35) contention that there is considerable resistance to altering an existing body image, especially when these alterations are perceived as negative and diminishing of self-esteem, the majority of the participants in this study did not appear to cling to unrealistic pre-injury body images. All the participants had realistic perceptions of the permanence of their functional losses but subjective experiences of having a disabled body differed quite significantly across the sample.

The participants' feelings about and relationships with their bodies ranged from a happy celebration thereof on the one hand, to feelings of disgust on the other.

No, when I look at the mirror then I say, "Damn, but you're beautiful!"
 ... the way I feel now I don't even want to look in the mirror. I don't know, I get nauseous, not really nauseous, but a feeling that rises up in me that "No, see what you look like." I feel like that ... look what I look like.

Most of the responses fell somewhere between these two unequivocal states of body love and self-revulsion. One of the participants, while expressing positive sentiments, appeared through the choice of words and defensive tone to have underlying negative feelings, suggesting a lack of resolution:

I feel nothing. I am quite fine. There is nothing wrong with me.

Another participant's non-verbal response spoke volumes about the difficulty of articulating one's feelings about a body radically altered by disability.

How do you feel about your body? (Int)
 Sigh
Is that difficult?
 Yes

There was a noticeable pattern of participants making positive statements about their bodies only to have later utterances detract from the

feelings they conveyed. Later responses suggested that these ambivalent feelings related to the complexity of having to integrate and relate to a body that was partially whole and functioning and partially paralyzed and non-feeling:

I really love my body

I think, then I say to myself, "I'm not exactly ugly. I'm actually a good-looking guy"

later became:

I make sure I never look at my body, just at my face...

Why do you think there is such a difference between the way you feel about your body and your face? (Int).

Uhm... maybe because my face is not disabled...

I can still smile, I can still hear, I can still see...

The theme of ambivalence about body image was further reflected in terse statements like:

I don't think anything; I just watch my face.

I feel, I just feel nah you just so and that's how it is. It's just, you must accept the way you are, you can't do anything about it.

One participant claimed that his feelings towards his body had been unaltered by disability:

The same feeling I've always had...

The majority of participants appeared to be in the process of integrating non-functioning or altered body parts into their body images.

The experience of having positive feelings about unaffected body parts, while suppressing or denying feelings about impaired body parts, has been reported (36,37). This dissociative process, producing the tendency to perceive and experience the body as a dual entity, results from the perception of the body as the 'enemy' (36). It is thought to be the culmination of chronic handling of the individual's body in a non-nurturing invasive way, perceiving one's body as an endless source of trouble and difficulty with holding on to a whole-body body image, when one does not feel one's body.

The tendency to split face from body can be perceived as an example of 'disowning' the defective part which is believed to impede self-acceptance (18). The fact that participants expressed positive sentiments about themselves when referring to their faces is consistent with the idea that from a perceptual point of view, one's face is very closely connected with one's self-essence or sense of self (6,18). Therefore, the wholeness of the individuals' faces enable them to feel a sense of continuity in that their core identities appear not to have been changed by SCI.

A number of participants focused on acceptance of SCI induced-body changes and their resignation to the permanence of the condition. Acceptance was spoken about in philosophical tones and in some instances was preceded by great emotional turmoil:

How did I feel? Then I wished I could die, because it didn't matter to me. What am I doing here? But I can't understand what I'm still doing here.

No um we used to have little discussions in the class and say like what we feel like and stuff like that um and most of the time... and then he used to say like, "Man, I could have ma died"... Or I'm stupid, "Why did I go and dive that day?" Stuff like that...

Some participants stated that with the passage of time a healthier relationship with the body emerged, suggesting coping and acceptance:

Ya, Ok. But did he ever make particular reference to his body and what it looked like or feels like for him. (Int)

No, they'd usually make jokes about it. Now I'd recently make jokes about it... "check out, check the muscle". There's really like no muscle but "check the muscle".

A small number of participants appeared to have positive body images. One participant appears to have incorporated her wheelchair in her body image and the practices she exposes her body to suggest acceptance and body love.

My legs are my wheelchair just like her legs are her legs. I must just imagine I'm a person that walks. (Yes, yes) My wheelchair is my body, see.

It actually doesn't affect me at all. I still look, I go on diet, I do what everyone else does. I go for massages and all those way-out things.

Another celebrated her looks and sporting ability that she felt many able-bodied people would not be able to compete with:

I'm not fat. I'm not fat. Um... I've got legs, which other people don't have really. I can use my arms, which other people can't. Um, there are many things, which I can do, which other people can't do, can't even think of doing. [*Like?*] Swimming for instance. Some people can't swim. Sport, some people have no idea what to do, and stuff like that.

The above examples illustrate various stages at which SCI adolescents may be in their integration of a new body image, and their acceptance of it. Integration involves not only the incorporation of non- or malfunctioning and deformed body parts into one's body image, but also the successful assimilation of any number of orthotic and/or orthopaedic appliances and devices into the new body image (9). The participant, who from an early age regarded her wheelchair as her legs and nurtured her body with therapies such as massage, appears to embody views on successful body image integration and adjustment (18).

As indicated previously, acceptance of one's physically disabled body was not experienced by the entire sample. One adolescent, who had been injured in infancy, traced her negative feelings back to the time that she first felt attracted to the opposite sex. Her burgeoning sexual feelings were accompanied by comparing herself with screen heroines and models in terms of physical attractiveness. Not only, does she have to contend with

being disabled, but also she battles with not conforming to conventional standards of beauty. She therefore perceives herself to be doubly disabled, in the sense that she is disabled and unattractive:

... sometimes I think I can be disabled but couldn't I be so, couldn't my legs be so my hands like this or like that ... I always think about it.

Say from the time I've been interested in guys, since about last year I first became interested in guys, since last year, then maybe I look at people on TV and I think gosh why can't my legs at least look like that or that. I also read about a disabled girl who is a model, and I check, I think "gee" my legs could at least have looked like that. Then I could at least do something. I don't wear skirts, when I wear a skirt it's a long one that hangs over my feet, so...

She regards these feelings as stemming from society's discriminatory attitudes towards disabled people and its preoccupation with physical appearance, attitudes that have resulted in her being ignored and sidelined:

It's probably because people see me this way... they see your exterior, they now judge on you that ... then I think if I was perhaps prettier, then they wouldn't have been like that, then perhaps they would have spoken to me more.

These feelings of being unattractive run so deep that she is unable to accept positive feedback from others:

If, say maybe I had, I had, I've come from the hairdresser and I've got on some make-up and all that, and someone says I look pretty. I don't know, I'll just get angry. I say "don't lie" and all that, and I just tie up my hair or something ...

This female participant's feelings of self-loathing can be explained in terms of socialization and the centrality of body image during adolescence. Studies have suggested that SCI is likely to impact more negatively on females' body image. It is argued that females are socialized to strive for prettiness and are judged according to how well they approximate media images of beauty (5,36). They are consequently more at risk for having poor body images, as they would have internalized dominant values about attractiveness and the idea that disability precludes beauty and excludes sexuality. Being disabled and wheelchair bound is the antithesis of the media sex symbol of modern times (36). Furthermore, middle adolescents, like the female referred to above, found deviations from the peer group norms intolerable, and changes to body image are accompanied by powerful negative affects, including the inability to accept positive reinforcement and feelings of self-loathing (14).

The latter female was acutely aware of being regarded as unattractive because of her disability, and further loathed her body for not being beautiful enough by feminine standards. Interestingly, the fact that her self-loathing coincided with her becoming sexually aware of the opposite sex reflects the destructive power of social messages linking sex and beauty in the case of women.

Concern with physical appearance was not only relegated to orthopedic appliances, and the loss of body function, but also included an awareness of weight. Some respondents, generally quadriplegics, were disconcerted by their extreme thinness, which one attributed to post-trauma depression:

Since I've been in the chair I've lost a lot of weight. I wasn't as thin as I am now. Maybe it's all the worries and the depression that made a person thin, and everything that happened.

Uhm, I always think what do people think of my body, how does it look. It must always look right to me. Because I want the people ... what can I say... they mustn't look at my wheelchair. They must watch me. Then I will feel good. I must always look good.

In the latter instance, thinness was a source of great concern as it detracted from the participant's subjective feelings of attractiveness, which he felt drew attention away from his wheelchair and onto himself. The majority of SCI adolescents shared this perception of the wheelchair. Lonsdale (5), and Stewart and Rossier (9), highlighted the "love-hate" relationships that some disabled people have with their wheelchairs in particular, because wheelchairs so unequivocally communicate the message of impairment and reduce their occupants to a "one-down" position.

Besides the explanations for poor body image discussed thus far, lack of resolution in this area may also be explained psychodynamically. It has been suggested (in terms of males) that the sight of distorted or dysfunctional limbs arouse archaic, unconscious castration fears as they overtly 'portray' the consequences of parental abuse or revenge for real or imagined transgressions (38). This would explain aversive reactions to disability as well as the splitting off of defective body parts in various ways.

Alternatively, the loss of bodily functions creates multiple emotional impacts that have to be defended against as they evoke painful unconscious childhood memories around the issues of trust, autonomy and shame (9). The dysfunctional body parts render the adolescent 'small', relative to all 'walking people' who gaze down at them, triggering unconscious regressive responses. The presence of paralyzed body parts may be experienced as threatening to the adolescent's sense of self, and in an attempt to preserve self-structure; some adolescents may unconsciously split off the feelings relating to their bodies to contain their anxiety. Those with less rigid defenses, on the other hand, may experience significant negative affect in relation to the 'alien' body parts that cause identity confusion and social devaluation. However, body image ambivalences notwithstanding, the hypotheses around deviations from attractiveness norms leading to self-rejection were reflected in only one of the participants in this study. Most participants, while keenly aware of societal ideals and their deviations there from, were able in most cases to reject the inflexible, discriminatory conventions rather than themselves.

CONCLUDING REMARKS

Dominant discourses and social constructions assert that physical disability precludes sexuality and that the disabled are asexual (13,22,38). It is also purported that they are unattractive and inappropriate partners, and that they lag behind developmentally (8,9). The experiences of the participants in this study run contrary to these discourses. These adolescents are clearly sexually aware human beings. They are interested in sex and are sexually expressive, and most of the participants consider themselves attractive enough for romantic relationships. Clearly SCI adolescents are not the sexual neuters they are constructed to be.

Negative social evaluations and dominant able-bodied norms of beauty and adequacy cause SCI adolescents to feel uncertain about their ability to secure a date, and to maintain a relationship with both able-bodied and disabled partners. They are hesitant to initiate an encounter, feel that first impressions count against them, and fear rejection. Although a SCI has serious physical implications, it seems that these negative social constructions affect their self-confidence more than the injury itself, which corresponds studies by Gorman (7) and Wright (18).

Integration of the body image can be facilitated; the various subtleties of sexual expression and communication can be learned; and valuable skills to resist social stigmatization can be mastered. Education and information dissemination is invaluable to disabled adolescents. SCI adolescents should have access to information which empowers them to overcome marginalization. Social networks can also lend a great deal of support to these teenagers at a time when peer group norms can be overpowering. A South African study by Kunzmann (2002, unpublished thesis) has shown that access to online information can boost self-confidence in SCI users, and that internet social networks can lessen the isolation SCI persons feel and open up avenues for sexual expression in a social context without a disability influencing the interaction.

Entrenched pathologizing, able-bodied, discourses put the onus on SCI adolescents to make a litany of adjustments, both physically and in terms of their sense of self, while disabling social and structural barriers remain exempt from change. These negative social constructions should be challenged. Breaking the silence surrounding the socio-sexual lives of SCI people is a beginning (39). Basson et al. (40) assert that treatment and rehabilitation should move away from an emphasis on the physical elements of SCI persons' sexuality. Other aspects of intimacy like independence and mutual respect between partners should also be incorporated into rehabilitation programs (40). Tepper's (41) outline for a sexual education program for youth with disabilities, which focuses on their needs as well as abilities, is a good beginning, because it accepts the disabled youth

as a sexual being. The real work, however, lies in disseminating positive and affirming research that dispels the prevailing myths about the sexuality of adolescents with SCI.

ACKNOWLEDGEMENT

The authors would like to thank and acknowledge Richard Kunzmann for editing, the concluding remarks, and general remarks.

REFERENCES

1. Strax TE, Wolfson S: Life cycle crises of the disabled adolescent and young adult implications for public policy. *In* Chronic Illness and Disabilities in Childhood and Adolescence, RW Blum (ed.) New York: Grune & Stratton, 1984, pp 47–57.
2. Trieschmann RB: Spinal Cord Injuries: Psychological, Social and Vocational Rehabilitation (2nd ed). New York: Demos publications, 1988.
3. Berard EJ: The sexuality of spinal cord injured women: Physiology and pathology: a review. *Paraplegia* 27:99–112.
4. Kettl P, Zarefross S, Jacoby K, et al.: Female sexuality after spinal cord injury. *Sexuality and Disability* 9(4):287–295, 1991.
5. Lonsdale S: Women and Disability: Experience of Physical Disability Among Women. London: Macmillan Education, 1990.
6. Dewis M: Spinal cord injured adolescents and young adults: meanings of body changes. *J Adv Nursing* 14:389–396, 1989.
7. Gorman C, Kennedy P, Hamilton L: Alterations in self-perceptions following childhood onset of spinal cord injury. *Spinal Cord* 36:181–185, 1998.
8. Rogers D: The Psychology of Adolescence. New York: Appleton Century Crofts, 1972.
9. Stewart TD, Rossier MD: Psychological considerations in the adjustment to spinal cord injury. *Rehabilitation Literature* 39(3):75–80, 1978.
10. Goldberg RT: Toward an understanding of the rehabilitation of the disabled adolescent. *Rehabilitation Literature* 42(3–4):66–73, 1981.
11. Nigro G: Sexuality in the handicapped: Some observations on human needs and attitudes. *Rehabilitation Literature* 36(7):202–205, 1975.
12. McAnarney ER: Dating issues for women with physical disabilities. *In* Sexuality and Disability Rintala D, Howland C, Nosek M, et al. (eds.) 15(4):219–242, 1997.
13. Cole S, Cole T: Sexuality, disability, and reproductive issues through the lifespan. *Sexuality and Disability* 11(3):189–205, 1993
14. Rutledge DN, Dick G: Spinal cord injury in adolescence. *Rehabilitation Nursing* Nov/Dec: 18–21, 1983.
15. Mulcahey MJ: Returning to school after spinal cord injury: Perspectives from four adolescents. *American J Occupational Therapy* 46(4):305–312, 1991.
16. Kashani JH: Self-esteem in handicapped children and adolescents. *Developmental Medicine & Child Neurology* 28: 77–83, 1986.
17. Oliver M: A sociology of disability or a disablist society? *In* Disability and Society, L Barton (ed.) New York: Longman Publishing, 1984, pp 18–42.
18. Wright, B: Physical Disability: A Psychosocial Approach (2nd edition). New York, Harper Row, 1983.
19. Kennedy P, Gorsuch N, Marsh N: Childhood onset of spinal cord injury: Self esteem and self perception. *British J Clin Psychol* 34:581–588, 1995.
20. Leedy PD: Practical Research: Planning and Design (6th edition). New Jersey, Prentice Hall, 1997.

21. Makas E: Positive Attitudes toward disabled: Disabled and Non-disabled Persons' Perspectives. *J Social issues* 44(1):49–61, 1988.
22. Shakespeare T: Power and prejudice: Issues of gender, sexuality and disability. *In Disability and Society*, L Barton (ed.) New York: Longman Publishing, 1996, pp 191–214.
23. Stiles WB: Quality control in qualitative research. *Clin Psychol Review* 13:593–618, 1993.
24. Fisher TD: An exploratory study of parent-child communication about sex attitudes of early, middle, and late adolescents. *The J Genetic Psychol* 147(4):543–557, 1985.
25. Lundqvist C, Siosteen A, Blomstrand C, et al.: Spinal cord injuries: Clinical, functional, and emotional status. *Spine* 16:78–83, 1991.
26. Sundberg N, Taplin J, Tyler L: *Introduction to Clinical Psychology*. New Jersey, Prentice-Hall, 1983.
27. Miles MB, Huberman AM: *Qualitative Data Analysis: A Source Book of New Methods*. Beverly Hills, California: Sage Publications, 1984.
28. Potter J, Wetherell M: *Discourse and Social Psychology*. London: Sage Publications, 1987.
29. Anderson EM, Clarke L: *Disability in Adolescence*. New York: Methuen, 1982.
30. Rintala D, Howland C, Nosek M, Bennett J, Young M, Foley C, Rossi C, Changpong G: Dating issues for women with physical disabilities. *Sexuality and Disability* 15(4):219–242, 1997.
31. Ray C, West J: Social, sexual and personal implications of paraplegia. *Paraplegia* 22:75–86, 1984
32. Richards E, Tepper M, Whipple B, Komissaruk B: Women with complete spinal cord injury: A phenomenological study of sexuality and relationship experiences. *Sexuality and Disability* 15(4):271–282, 1997.
33. Kent J, Cartwright D, Ossorio P: Attitudes of peer groups toward paraplegic individuals. *In Perspectives on Disability*, M Nagler (ed.) Palo Alto, CA: Market Health Research, 1990.
34. Erikson EH: *Childhood and Society*. New York: W.W. Norton & Company, 1950.
35. Teal JC, Athelstan GT: Sexuality in spinal cord injury: Some social implications. *Archives of Phys Rehabilitation Med* 56:264–268, 1975.
36. Bogle JE, Shaul SL: Body image and women. *In Sexuality and Disability: Personal Perspectives*, D Bullard, S Knight (eds.) St. Louis: Mosby Publishers, 1981.
37. Woertmann L: Body image of women. Presentation at 'The International Seminar on Women and Disability' in Israel, 1995.
38. Thurer S: Disability and monstrosity: Looking at literary distortions of handicapping conditions. *Rehabilitation Lit* 41(1–2):12–15, 1980.
39. Davies D: Sharing our stories, empowering our lives: Don't dis me! *Sexuality and disability* 18(3):179–186, 2000.
40. Basson PJ, Walter S, Stuart AD: A phenomenological study into the experience of their sexuality by males with spinal cord injury. *Health SA Gesondheid* 8(4):3–11, 2003.
41. Tepper MS: *Becoming sexually able: Education to help youth with disabilities*. SCIE-CUS report 29(3):3–5, New York, 2001.