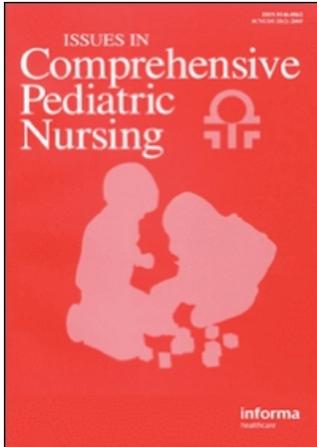


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SEXUALITY AND THE ADOLESCENT WITH A PHYSICAL DISABILITY: *Understandings and Misunderstandings*

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The purpose of this descriptive study was to examine the areas of sexual knowledge, sexual behavior, and beliefs about sexuality among adolescents with congenital physical disabilities. The sample consisted of 15 males and 14 females, ranging in age from 12 to 22 years. The Sexual Knowledge Interview Schedule (SKIS) was administered to all participants during face-to-face interviews. In addition, the participants were asked questions regarding their ability to engage in intimate relationships and their future childbearing potential. Overall, the findings suggested that these adolescents are uninformed or misinformed about general sexual knowledge, have many misconceptions about sexuality and their disability, and depend on health care professionals and parents for sex education. Implications of this research are discussed.

During the past 20 years, the number of children and adolescents in North America with chronic, disabling conditions has increased substantially (Hallum, 1995; Wolman & Basco, 1994). According to a 1994 report by the Canadian Institute of Child Health, approximately 530,000 children and youth between birth and 19 years of age have at least one

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physical disability (CICH, 1994). This figure represents 7.2% of all children in Canada. In the United States, it has been estimated that 3.8 million children from the age of birth to 17 years have a physical disability (U.S. Department of Health & Human Services, 1995).

In part, this trend may be attributed to technological developments that have enabled children to survive difficult births, prematurity, previously fatal congenital anomalies and other disease processes. As a result of improved clinical management and greater understanding of the complications associated with childhood chronic illnesses, many afflicted children who once faced certain early death are now living well into adolescence and adulthood. Regardless of where nurses work, whether they are in community settings or hospital settings, the likelihood that they will encounter children and adolescents with disabilities is high.

Even under the best of circumstances, the life stage of adolescence presents young people with a multitude of challenging tasks. For adolescents who have physical disabilities, the challenges are enormous. Extensive research has been conducted with adolescents who have chronic illnesses or physical disabilities. The topic of sexuality among nondisabled adolescents also has been the focus for many investigators. However, few scholars have attempted to bring these areas of inquiry together. In other words, surprisingly little research attention has been devoted to the issue of sex or sexuality among adolescents who are physically challenged.

The lack of research within this population is particularly disturbing because sexuality is a central concern among adolescents and their families, and because it reinforces the myth that young people with physical disabilities are uninterested in sex and sexuality. Furthermore, this gap in current knowledge implies that physically disabled adolescents are incapable of sexual relationships; that they are, in essence, asexual beings. The purpose of this paper is to describe an exploratory study designed to investigate the areas of sexual knowledge, beliefs about sexuality, sexual behavior, and relationships among adolescents with congenital physical disabilities. Implications for nurses and other health and social service professionals also are discussed.

REVIEW OF THE LITERATURE

A search of databases and literature in the disciplines of nursing, medicine, psychology, social work, education, and counselling revealed few published studies addressing the area of sexuality among adolescents with physical disabilities. While early interest in this topic is evident by the appearance of several publications during the 1970s, notably few studies were published throughout the 1980s. During the last decade, there appears to be a renewed interest in this area. In the present review, current

understandings, with particular attention to sexual knowledge, sex education, beliefs, attitudes, and behaviors among adolescents with physical disabilities, are examined.

Sexual Knowledge

Several investigators have reported lack of knowledge about sexuality among adolescents with disabilities (Borjeson & Lagergren, 1990; Hayden, Davenport, & Campbell, 1979; Nelson, 1995; Rothenberg, Franzblau, & Geer, 1979). Because these adolescents are often isolated from others their age, it has been speculated that they may lack opportunities to learn about their sexuality or to engage in social activities or sexual experimentation (Bardach & Anderson, 1979; McAnarney, 1985; Strax, 1988). With respect to knowledge about sex and sexuality, Erickson and Erickson (1992) observed differences between perceived knowledge (questionnaire) and actual knowledge (interview) in the areas of anatomy, sexual function, and sexual physiology among a sample of adolescents with spina bifida. Many of the teenagers in this study were unsure or uninformed about the implications of their disability on sexual functioning.

Similar findings were reported by Cromer et al. (1990). In their study, which was one of the few to include a control group, adolescents with spina bifida demonstrated lower levels of sexual knowledge compared with adolescents without disabilities. These authors also noted that, although most disabled teens expressed a desire to marry and have children, fewer than 20% had sought information regarding their sexual or reproductive function.

Sex Education

The level and relevance of sex education classes for physically disabled adolescents have received attention by several researchers (Blackburn, 1995; Shapland, 1993; Stevens et al., 1996). As these authors have observed, sex education classes are often conducted in conjunction with physical education programs in which many adolescents with physical disabilities do not participate. Thus, these young people are often inadvertently excluded. According to findings reported by Blum, Resnick, Nelson, and Germaine (1991), nearly one-half of all physically disabled adolescents did not receive any type of education related to sex or sexuality in their schools. Among those who did participate in some form of sex education, less than 20% received material about their disability. Similarly, Blackburn (1995) reported that 80% of disabled adolescents had received sex education from a variety of sources, but fewer than 20% of the sample received this information through a school-based sex

education program. Further, the information received was often not relevant or appropriate to the adolescent's specific disability.

According to Stevens et al. (1996), physically disabled adolescents do not typically receive information on important topics such as marriage, parenthood, contraception, sexually transmitted diseases, and sexual abuse. As Shapland (1993) noted, educators often place an emphasis on fears about the disability, pregnancy, and inappropriate behaviors, while the need for intimacy and human touch as a part of sexual expression is overlooked. According to Blackburn (1995), many young adolescents with physical disabilities inquire about other methods they may use to fulfill sexual needs and desires without necessarily having intercourse.

Goodman, Budner, and Lesh (1971) reported that although many parents teach the facts of reproduction, they are often reluctant to discuss other aspects of sexuality with their physically challenged adolescents. Although this study was conducted more than 20 years ago, there are some indications that the conclusions are equally valid today. Specifically, parents have been reported to fear that sex education will cause a premature interest in sex and sexual activity (Nelson, 1995). Moreover, parents seem to be frightened that their physically disabled child will never achieve a satisfactory relationship or will get hurt if he or she becomes involved with someone. The moral and value systems of parents also appear to play a role in their anxieties about discussing sexuality with their children.

Sexual Beliefs and Attitudes

The literature concerning attitudes toward sexuality and disability is conflicting. According to Hallum (1995), many parents and health care workers historically have tended to think of disabled adolescents as asexual beings who are either unable to engage in sex or are simply uninterested in sex. Several recent studies suggest that this attitude is changing. For example, Nelson (1995) suggested that many physically disabled adolescents can make adjustments to suit their sexual needs. Depending on the physical disability and sexual interest, adolescents may express themselves sexually or be sexually active in a variety of ways.

In one nursing study, Meeropol (1991) questioned adolescents with spina bifida and cerebral palsy and concluded that the majority feel as if they are attractive to other people and "part of the gang" of their able-bodied peers. Moreover, Stevens et al. (1996) compared disabled adolescents with nondisabled adolescents and reported no significant differences in self-esteem levels or degree of satisfaction with physical appearance between the two groups. In contrast, Rauen and Aubert (1992) and Hallum (1995) noted that many pubescent individuals viewed them-

selves as “different from” and “unattractive to” others. Still, according to Cromer et al. (1990), most do feel that they will be able to develop and maintain a sexual relationship at some point in their lives. Overall, this area remains relatively understudied as few investigators have talked directly with the adolescents themselves about their attitudes toward sex and sexuality.

Sexual Activity and Relationships

The degree to which adolescents with physical disabilities engage in sexual behavior is not clear. Several researchers have noted that physically disabled adolescents have fewer intimate relationships than their nondisabled peers (Borjeson & Lagergren, 1990; Dorner, 1977; Stevens et al., 1996). As Stevens et al. (1996) noted, only 29% of 13- to 16-year old teenagers who had a physical disability reported ever having been on a date.

In contrast to these studies, Suris, Resnick, Cassuto, and Blum (1996) reported no overall difference among male or female physically disabled adolescents as compared with a control group of nondisabled adolescents with respect to the frequency with which they engaged in sexual activity. However, as the researchers note, their sample was taken from a secondary public school, and consequently the participants were at a high functional level and may not be representative of the physically disabled adolescent population.

Overall, the research related to sexuality among adolescents with physical disabilities is limited and inconsistent. By itself, this statement is significant, reflecting the widespread perspective that adolescents with physical disabilities are uninterested in issues related to sexuality. Moreover, among the studies that exist, samples are often comprised of adolescents with both congenital and acquired disability, or with physical as well as cognitive disability, variables that significantly influence the experience of living with a disability.

RESEARCH METHODS

The study was approved through the university's human subjects review process. A nonrandom convenience sample of adolescents with physical disabilities was drawn from several cities throughout southwestern Ontario and included 29 young people, 15 males and 14 females, ranging in age from 12 to 22 years with a mean age of 16.4 years. Adolescents with acquired or cognitive disabilities were excluded from the present study because their experiences related to sexuality are likely quite different from those of the target population.

With respect to the type of disability, 12 (41%) had cerebral palsy, 11

(38%) had spina bifida, 2 (7%) had muscular dystrophy, and 4 (14%) had disabilities that participants classified as "unknown" (Table 1). Because each of these disabilities varies greatly in severity and effect on functional status, the participants were grouped according to their ambulatory ability, a categorization that has proved useful by the authors in their clinical work with this population. Seventeen (65%) were nonambulatory, requiring wheelchairs or other assistive devices; 1 (3%) was partially ambulatory, meaning that this individual had limited ambulatory ability; and 8 (31%) were categorized as community ambulators, which meant that the individuals were fully ambulatory and did not require any assistive devices. Consent and assent were obtained from the parents and adolescents respectively.

The primary instrument was the Sexual Knowledge Interview Schedule (SKIS) (Forchuk & Martin, 1989). This 42-item interview schedule, which uses open ended questions coded into close-ended categories, is comprised of two scales, a Knowledge Scale (34 items) and a Potential for Abuse Scale (8 items). The Knowledge Scale includes four subscales: Feelings (4 items), which inquires about the participants' ability to differentiate common emotions; Body Parts Identification (11 items), which consists of naming body parts from a diagram; Body Parts Function (9

Table 1. Age of participants by type of disability

Type of disability	Age range (years)	Number of participants
Cerebral palsy		12 (41%)
	12-15	3
	16-18	8
	19-22	1
Spina bifida		11 (38%)
	12-15	3
	16-18	7
	19-22	1
Muscular dystrophy		2 (7%)
	12-15	0
	16-18	1
	19-22	1
Unknown		4 (14%)
	12-15	3
	16-18	1
	19-22	0

items), which includes simple items related to reproduction, menstruation, urination, and defecation; and General Sexual Knowledge (10 items), which elicits participants' knowledge about contraception, intercourse, sexually transmitted disease, and masturbation. Inter-rater reliability has been reported at $r = .95.3$, while test-retest reliability was $r = .70.1$. The internal consistency, using Cronbach's Alpha, for the Knowledge Scale was $\alpha = .90$; for the Potential for Abuse Scale, $\alpha = .96$ (Forchuk, Martin, & Griffiths, 1995).

In addition to the information elicited from the SKIS, the researchers designed a Relationship Questionnaire to elicit adolescents' understanding of the impact of their disability on sexuality; thoughts about their ability to engage in sexual relationships; expectations for future sexual relationships; and understanding of sexual behavior. This questionnaire also asked where adolescents obtained information about sexuality.

RESULTS AND DISCUSSION

The scores from the SKIS are presented first, followed by findings from the Relationship Questionnaire, related to sources of information, sexual behavior, and the adolescents' beliefs about their ability to engage in sexual relationships. Descriptive statistics are presented.

Sexual Knowledge Interview Schedule: Knowledge Scale

The summed scores from the four subscales resulted in an overall total score for the Knowledge Scale. The Potential for Abuse Scale is not included in this calculation. Participants' mean score on the Knowledge Scale was 23.93 out of a possible score of 43. In other words, adolescents answered questions about Feelings, Body Parts Identification, Body Parts Function, and General Sexual Knowledge with only 56% accuracy. No noteworthy differences were observed on the basis of gender or ambulatory status. However, there were some slight differences in scores according to type of disability. The participants with muscular dystrophy, who were also the oldest participants, achieved the highest Knowledge Total scores ($M = 37.00$; Table 2). Scores for each of the subscales are described below.

Feelings Subscale

In general, respondents recognized basic emotions and differentiated appropriately between different types of emotions. The mean score for the entire sample was 3.79 out of a possible score of 4 (95% accuracy). No differences were observed on the basis of gender, age, type of disability, or functional status. Because the study population did not include indi-

Table 2. Average scores on knowledge scale by type of disability

Type of disability	Average score (out of 43)
Cerebral palsy	20.50
Spina bifida	26.63
Muscular dystrophy	37.00
Unknown	20.25

viduals with cognitive impairments, the high scores on this subscale were not surprising.

Body Parts Identification Subscale

The scores on this subscale reflect the ability of participants to accurately name parts of the reproductive system from diagrams presented to them. The pattern of responses on this scale was similar to the pattern observed in the total Knowledge Scale. Overall, the scores were quite low. Specifically, the mean score for the entire sample was 5.41 out of a possible score of 11 (49% accuracy). The highest scores were again attained by the older children with muscular dystrophy (Table 3). However, one observation not seen in the total Knowledge Scale scores was that the adolescents classified as "community ambulators" had mean Body Parts Identification scores that were higher ($M = 7.38$) than either the nonambulatory ($M = 4.88$) or the partially ambulatory ($M = 4.00$) participants.

Body Parts Function Subscale

Despite the present sample's limited knowledge regarding the anatomical location of various body parts, the participants demonstrated greater knowl-

Table 3. Average scores on body parts identification subscale by type of disability

Type of disability	Average score (out of 11)
Cerebral palsy	4.08
Spina bifida	6.55
Muscular dystrophy	9.50
Unknown	4.25

edge concerning the function of these structures. The mean score for the entire sample was 6.48 out of a possible score of 9 (72% accuracy). No differences in responses were observed on the basis of age group, gender, type of disability, or ambulatory status.

General Sexual Knowledge Subscale

With respect to General Sexual Knowledge, the mean score was 8.24 out of a possible score of 19 (43% accuracy). Based on the authors' collective clinical experience, this score was lower than expected, raising some important questions and implications for education of this population. No differences were noted in this subscale on the basis of gender or ambulatory status. Regarding type of disability, the pattern was similar to that observed for the other scales: adolescents with muscular dystrophy, who were also the oldest participants, had the highest scores, followed by adolescents with spina bifida (Table 4). The lowest scores were consistently seen in the participants with cerebral palsy.

Sexual Knowledge Interview Schedule: Potential for Abuse Scale

The scores on the Potential for Abuse Scale suggested there is little likelihood of abuse among the study sample. The mean score for the entire sample was 0.24 out of a possible score of 3 (8% Potential for Abuse). However, there are several explanations for the low scores on this scale, and it would be misleading to conclude solely on the basis of this finding that abuse is not a problem among this population. For example, the scale included questions such as, "Who other than yourself has touched your sex organs?" For children with spina bifida who require catheterizations, this question may yield a different response than that which might be obtained in a sample of adolescents who do not have physical disabilities. In other words, there may be difficulty distinguishing between appropriate and inappropriate forms of touching.

Table 4. Average scores on general sexual knowledge subscale by type of disability

Type of disability	Average score (out of 19)
Cerebral palsy	6.83
Spina bifida	9.27
Muscular dystrophy	15.00
Unknown	6.25

Relationship Questionnaire

Sources of information

Findings from the literature, as well as from the authors' collective experiences, indicate that among the study population, many adolescents may be excluded from sex education classes. In this study, 55% of the participants between 12 to 15 years of age, and 18% of the participants between 16 to 18 years of age reported they had not attended sex education classes in their schools.

Fully 90% of the participants stated that they received sexuality information by professionals, including nurses, doctors, social workers, teachers, and assistants. Other sources were identified as family (79%), school (76%), the media (69%), and friends (45%). It is noteworthy that only 13 participants out of 29 identified their peer group as a primary source of information.

There were some interesting differences noted among participants' perceptions of the relevance of sex education classes. Among the 72% who had attended classes, a disturbingly high proportion (24%) reported that the classes were either "not useful" to them or that they did not know how useful the classes were. Looking at these responses on the basis of functional status, our finding that 38% of the nonambulators and partial ambulators found their sex education classes not helpful or did not know how helpful they were is not surprising. In contrast, 100% of the community ambulatory participants indicated that sex education classes were helpful to them. Thus, it would seem that the classes were geared to the needs and concerns of ambulatory adolescents, while little attention was paid to the unique concerns of those with more limiting disabilities.

When asked if they would like to know more about sexuality and disability, 14% responded that they were uncertain. However, variation in responses was noted according to age. All older participants, aged 19 to 22, wanted more information, whereas only 44% of the younger participants, aged 12 to 15, were interested in additional information. Among the 16 to 18 year olds, 88% indicated a desire for more information on this topic.

The adolescents also were asked what they thought would be the best way to teach sex education. Most (79%) indicated that they would want information presented to them on an individual basis, rather than in a group setting or in writing. Although this finding does seem to reflect their embarrassment around the topic of sexuality, it does not appear to be borne out in practice. According to two of the investigators of this research (a social worker and a nurse clinician who work closely with adolescents with physical disabilities), the disturbing reality is that few referrals are made for the purpose of obtaining information about sexuality.

Sexual Behavior and Beliefs about Ability to Engage in Sexual Relationships

Of the sample, 87% thought they are able to have a sexual relationship and 79% responded that they expect to have a sexual relationship in the future; 17% responded that they do not; and 4% stated that they did not know. The responses showed no variation by gender.

With respect to their expectations about the physical status of future sexual relationship partners, 45% of participants stated that they did not know. Interestingly, 24% and 28% of participants expected to have “able-bodied” or “either able-bodied or disabled” future partners respectively. Only 3% (one respondent) expected to have a “disabled” future partner. Finally, none of the seventeen 16–18 year olds in this study reported that they had ever had a sexual relationship.

IMPLICATIONS FOR PRACTICE

The findings of this research have several important implications for nurses and other health and social service professionals who interact with adolescents with physical disabilities. Although few study participants reported that they have engaged in intimate sexual relationships, the majority expressed a desire to do so. Consistent with previous study findings, however, they have little knowledge about sexuality in general and about the effects of their own disability on sexuality and reproductive function in particular; they have few ideas as to how they can obtain this knowledge; and they are ambivalent about whether they would even like to receive information regarding sexuality and disability. While they stated that they rely on health care professionals for sex education, they typically do not access these individuals or their peers as a source of learning.

In an era when discussions about sex and sexuality have become commonplace, it is difficult to comprehend that for those with disabilities, the topic remains shrouded in so much secrecy. The systematic exclusion of this group from sex education programs appears to be a significant barrier. When adolescents do attend such programs, the discussions are often irrelevant to their unique needs and concerns, making it difficult for these teens to be active participants. The problem is further complicated by the fact that no single group of health or social service providers has come forth to respond to the concerns of this population. It is possible that nurses and educators feel they do not have sufficient expertise to offer sex education designed to meet the unique needs of this group, although this cannot be stated with certainty. Regardless of the reasons, it is clear that, whether intentional or not, the needs for sex education among adolescents with physical disabilities are being overlooked, thereby reinforcing the myth that these individuals are asexual beings. Further, the prevailing

taboos preclude the possibility for these adolescents to engage in open and frank discussion and information-sharing on this important issue.

The lack of agreement regarding whose responsibility it is to provide sex education to teens with physical disabilities has resulted in a situation where imparting this knowledge simply does not occur. Clearly, education is not the exclusive domain of any single profession but should be viewed as an interdisciplinary imperative. Educational initiatives should include, but not be limited to, knowledge of general anatomy and physiology, specifics about sexual functioning with particular reference to participants' unique disabilities, feelings and emotions related to sexuality, information about family planning, and concerns about sexually transmitted diseases. Such information could be incorporated into a school health program under the auspices of a public health school nurse. As well, it is critical that educators anticipate potential concerns of this population: whether the condition is hereditary and can be passed on to offspring; questions about their ability to parent; worries about attractiveness to others.

Students with disabilities who do participate in sex education programs should be given an opportunity to ask questions both in and out of the group. By including some discussion about common sexual dysfunction as part of a regular program, all members are granted permission to raise issues that otherwise might be avoided. This approach is useful in that it enables the teens with disabilities to see that even those without disability also confront problems with sexuality. Whatever format is selected, deliberate efforts must be made to incorporate content relevant to adolescents with physical disabilities.

Although the occurrence of abuse in this population was not a primary focus of this study, the findings from the SKIS Potential for Abuse Scale suggest that there was a low incidence of abuse among this study sample. However, it would be misleading to conclude that abuse does not exist. Rather, it means that abuse may exist, but we don't know about it yet. The dependency of children on their caregivers makes the process of reporting abuse extremely complex; this is an area that warrants further investigation.

CONCLUSION

The present findings suggest that the sexual knowledge and behavior of adolescents with physical disabilities is an important area of study. Clear trends have been identified, suggesting that these adolescents generally lack adequate understanding of their sexuality. However, the current study's relatively small sample size makes it difficult to draw firm conclusions or to make comparisons based on gender, age, or type of disability. Although many adolescents were invited to participate, only a small num-

ber chose to do so. Whether comparable numbers of able-bodied teens would have refused can only be a matter of speculation, but it is unlikely. In view of the small sample size, the trends found should be further explored in future research with larger samples. In addition, the inclusion of a control group of adolescents without disabilities would allow researchers to more clearly compare the sexual knowledge and behavior of adolescents with and without disabilities.

Nurses, physicians, social workers, psychologists, occupational and physical therapists, parents, and teachers have a collective responsibility to view adolescents with physical disabilities in a holistic manner, acknowledging that they are human beings with sexual needs and desires, not unlike those of teenagers without disability. We cannot pass their concerns on to "the experts" as they simply don't exist. Reluctance by professionals to respond to the needs of this group only reinforces their doubts. While it is true that unless we have a disability ourselves, it is doubtful that we have expertise related to sexual problems associated with disability. Even individuals with the same disability may lack that expertise because each disability typically manifests itself in many ways. However, what we have in common is our humanity, and therefore our sexuality, and this is far more relevant than our differences. It is not necessary for us to have all the answers, nor is that what adolescents want. Rather, they want us to be honest about what we know, and what we don't know, and to demonstrate a willingness to help them find answers, strategies by which they can achieve solutions, and acknowledgment and recognition that their concerns regarding sexuality are valid.

The apparent difficulties faced by adolescents with physical disabilities to discuss sexuality issues reflect the societal attitude that sex belongs to those who are able-bodied. Only when this perspective is challenged will there be fairness for people with cerebral palsy, muscular dystrophy, spina bifida, and so many other disabilities. Adolescents with disabilities have to plan sexual activity in a realistic way, adjustments may need to be made, and there is likely to be considerable trial and error. Ultimately, however, bodily contact is pleasurable, regardless of whether or not one has a disability. Efforts are needed that go beyond education of the adolescent that include education of the public as well. Too often, society's attitudes toward those with disabilities are more of a hindrance to an adolescent's sexual development than any limitation of the condition itself.

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