Sexuality Issues in Adolescents with a Chronic Neurological Condition

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Abstract

Substantial progress in the medical treatment of individuals with spina bifida (SB) has increased the numbers who survive into adolescence and adulthood. However, sexual health in this population has not received much attention. This study explored the knowledge (SB Sexuality Knowledge Scale), worries (SB Worries Scale), romantic appeal (from Harter's Self-Perception Scale), and access to sexuality information of a sample of 60 adolescents from a midwestern state. Study participants reported having sexual feelings like their peers, and they knew they could contract sexually transmitted diseases (STDs) if they were sexually active. However, only a moderate percentage was aware that women with SB are fertile, that adolescent women with SB should take a multivitamin with folic acid, and that latex-free condoms should be used by most adolescents with SB. They did not worry about their ability to make friends; however, these adolescents reported low levels of perceived romantic appeal and they worried about sexuality issues. These sexuality issues were not correlated to measures of SB neurological severity. Although over 50% reported having discussed sexuality with a health professional, 29% reported no one discussed sexuality and SB with them. Data from this study can affect the way health care providers and educators conduct sexuality education in health care and school settings.

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Perinatal educators need to have a broad knowledge-base regarding sexuality issues. A population often ignored is adolescents with neurological disabilities,

particularly those with spina bifida (SB). SB is a congenital condition caused by incomplete neural tube closure and protrusion of spinal membranes in the early days of a pregnancy. It is the second most common cause of disability among children and adolescents today (Nassau & Drotar, 1997). Advances in medical/surgical therapies have resulted in an increased number of individuals with SB who survive into adolescence and adulthood. Today, if the medical aspects of SB are well managed (especially care of the urological system), adolescents with this condition can look forward to a life expectancy similar to their nondisabled peers. While health care has generated many efforts to manage the condition and foster independence, little attention has been directed toward reproductive issues and sexual function in this population (Joyner, McLorie, & Khoury, 1998).

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Historically, society has viewed adolescents and adults with disabilities as asexual beings. This myth has been dispelled (Blum, Resnick, Nelson, & St. Germaine, 1991; Cromer et al., 1990) as adolescents with SB report the same sexual and marital desires as their nondisabled peers (Blum, 1997). Yet, societal prejudices continue. Several large studies have compared adolescents with a chronic health condition to groups of healthy adolescents and generated several themes: a comparable, if not higher, percentage of chronically ill adolescents reported frequent sexual encounters, pregnancy involvement, and use of contraception (Choquet, du Pasquier, & Manfredi, 1997; Suris, Resnick, Cassuto, & Blum, 1996). However, because these studies did not have a substantial population of adolescents with severe physical disabilities, it is difficult to be sure if the results are representative of adolescents with SB.

Few studies focus on adolescents with SB. The most recent studies are surveys of adolescents in Australia and The Netherlands (Sawyer & Roberts, 1999; Verhoef et al., 2000). Both of these studies used a semi-structured interview and had samples of 69–83 subjects. Both identified a considerable number of adolescents with SB as

sexually active (60% having relationships, 25% having intercourse) and in need of health education. However, these studies had an older adolescent population (16–25 years old) and did not address issues of folic acid supplementation, the impact of latex allergy, or the relationship of knowledge to behavior. The few studies that have been conducted with adolescents who have SB used different measures and, thus, were difficult to synthesize. We continue to know little about sexuality issues for these adolescents, particularly adolescents in the United States.

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Thus, the purpose of this study was to address the following questions for a sample of adolescents in a midwestern state:

1. What do adolescents with SB know about sexuality and SB?
2. What are their attitudes or worries about sexuality and SB?
3. How do adolescents with SB rate their romantic appeal?
4. What sources of information on sexuality do adolescents identify as most useful?

Methods

This report is part of a larger study evaluating adaptation in adolescents with spina bifida (Sawin, Brei, Buran, & Fastenau, 2001). The larger study was reviewed and approved by the institutional review board of the associated university.

Sample

A convenience sample of 60 adolescents with spina bifida was recruited from a specialty clinic in a large midwestern medical center. After the study was initiated, the SB Knowledge Scale was added to the instruments described below and data were collected on all subsequently enrolled adolescents ($n = 50$). Eligible adolescents and their

parents were contacted both by a letter of invitation and by personal invitation from study and clinic staff during a clinic visit. To participate in the study, adolescents with SB needed to be (1) 12–21 years old, (2) living at home with parents or caregivers at least part of the year, (3) functioning at approximately grade level in school, (4) not previously identified as moderately or severely mentally handicapped, and (5) having no other major medical condition unrelated to SB (i.e., life threatening, progressive, or incapacitating disability).

After the referral of a potential participant, staff initiated contact to explain the study, obtain written informed consent from both the adolescent and parent, and schedule the interviews. The structured interviews took place in the home and by telephone or, if the family preferred, at another site. If conducted in the home, separate confidential interviews took place with the parent and the adolescent. Additionally, select questionnaires were subsequently mailed to the adolescent and parent.

The adolescents in this study were 12–21 years old, with a mean age of 16.2 years. Sixty percent of the sample were female, 40% were male. Fifty-seven percent had meningomyelocele lesions in the lumbar or thoracic region, and 41% had lumboacral or sacral lesions. According to their parents, 80% had a shunt and 60% had a latex allergy.

Instruments

Three instruments and three interview questions were used to collect data on sexuality issues. Two of the sexu-

ality scales were created for this study; one was a scale with established reliability and validity. Our project advisory committee established content validity for our new scale items. The committee included mostly young adults with SB or parents of adolescents with SB, as well as a physician, nurse, and psychologist with many years of experience in working with individuals who have SB.

Three questionnaires were used in the study: the SB Sexuality Knowledge Questionnaire, the SB Worries Scale, and the Romantic Appeal Scale—all described below.

SB Sexuality Knowledge Questionnaire. This questionnaire consisted of two scales:

1) General SB Knowledge Scale. This 7-item, 5-point Likert-type questionnaire addressed general knowledge aspects of SB. The scale included items 1–7 delineated on Table 1. The Cronbach alpha reliability for this 7-item scale was .80. The factor loading of the items on this scale ranged from .58 to .80.

2) SB Fertility Scale. The two-item fertility items (Items 11 and 12) had a Cronbach alpha reliability of .68.

Three additional questions (Items 8–10 in Table 1) did not correlate with the rest of the knowledge scale. For the current report we will include these three items and report them as unrelated knowledge questions. The item on sexually transmitted diseases (STDs) may be unique because it is the only item with a restricted range (1–3) where 96% of the participants strongly agreed or agreed. It is clearly an area where all subjects in our pilot were knowledgeable.

Table 1 Spina Bifida (SB) Sexuality Knowledge Questionnaire

Item	Mean	SD	Percent SA or A
1. Teens with SB have sexual feelings just like other teens their age.	4.3	.95	84%
2. It is easy for teens with SB to get information about sexuality.	3.8	1.3	62%
3. If individuals with SB use a condom for sex, they should use a latex-free condom.	4.1	.98	72%
4. Women with SB need to take folic acid supplements (a multivitamin with folic acid).	3.9	1.1	62%
5. Both men and women with SB who are sexually active need to use some method of birth control.	4.4	.90	82%
6. Teens with SB are attractive and appealing to others.	4.0	1.1	66%
7. Men with SB can have erections.	3.8	1.1	58%
8. Teens with SB who are sexually active can get sexually transmitted diseases.	4.6	.57	96%
9. Women with SB have menstrual periods.	4.2	1.0	68%
10. If you have a child, do you think the child would have an increased chance of having SB?	2.35	1.4	65%
11. Women with SB can become pregnant.	4.3	.88	70%
12. Men with SB can get a woman pregnant.	4.1	1.1	70%

SB Worries Scale. This 7-item scale asked subjects to respond to questions on a 0–5 scale (0 = *no worry at all* and 5 = *worry a lot*) (see Table 2). Five of the seven items (Items 1, 2, and 4–6) addressed sexuality. The other two items reflected a larger perspective (Items 3 and 7). The Cronbach alpha reliability for this scale was .83.

Romantic Appeal Scale. The Adolescent Self-Perception Profile (Harter, 1988) consists of a 45-item instrument that measures an adolescent's perception of self-worth (Overall Self-Worth Scale) and eight domain-specific scales (physical, athletic, job, scholastic competence, romantic appeal, close friendships, behavioral

conduct, and social acceptance). For this analysis, subjects chose one of the bipolar statements and then indicated whether that statement was *really true* or *sort of true* for them. The most positive statement was scored 4 if *really true* or 3 if *sort of true*; the negative statement was scored 2 if *sort of false* and 1 if *really false*. The instrument has been widely used in hundreds of studies of adolescents and has extensive support for reliability and validity of all subscales (Harter, 1988, 1990). We used the romantic appeal scale for this study (see Table 3). Although this scale has been used extensively by others and in our own work with acceptable reliabilities of .72–.84 (Sawin & Marshall, 1992; Sawin, Metzger, & Pellock, 1996; Sawin, Metzger, Pellock, & Guendel,

Table 2 Spina Bifida (SB) Worries Scale

How much do you worry about the following:	Mean	SD	Percent Some/A Lot of Worry 3–5
1. Will I have difficulty making friends due to SB?	1.0	1.6	22%
2. Will others be hesitant to date me due to SB?	1.7	1.8	40%
3. Will I have good health as a young adult?	2.1	1.8	45%
4. When ready to be sexually active, will I have difficulty due to SB?	1.7	1.9	39%
5. Can I have a baby/father a child?	2.4	2.0	54%
6. If I have a baby, will it be normal?	2.7	2.1	53%
7. Will I be able to live independently?	1.2	1.8	27%

Range: 0 = *no worry at all*; 5 = *worry a lot*. Mode for all items is 0.

Table 3 Harter Romantic Appeal Scale

Item	Mean	SD	Range 1–4 4 = <i>really true for me</i> 3 = <i>sort of true for me</i> 2 = <i>sort of false for me</i> 1 = <i>really false for me</i>
1. Some teenagers feel that if they are romantically interested in someone, that person will like them back.*	2.4	1.6	1–4 53% 1 and 2
2. Some teenagers are not dating the people they are really attracted to.**	2.6	1.3	1–4 43% 1 and 2
3. Some teenagers feel that people their age will be romantically attracted to them.*	2.4	1.1	1–4 58% 1 or 2
4. Some teenagers feel that they are fun and interesting on a date.*	2.3	1.2	1–4 54% 1 or 2
5. Some teenagers usually don't go out with people they would really like to date.**	2.6	1.3	1–4 47% 1 or 2

* Items retained in the 3-item scale with Cronbach alpha of .70

** Reversed scoring

2000), the original Cronbach alpha reliability for this scale was .56 for this study. When the reliability statistics were examined, it became evident that eliminating two items that both related to dating behavior (Items 2 and 5) resulted in a Cronbach alpha of .70.

Other Scales Used for Construct Validity

In addition, two other scales from the larger study were used to evaluate the validity of the sexuality scales. Structured interviews were used to collect data for the WeeFIM™ (an 18-item functional assessment instrument) and the Adolescent Self-Management and Independence Scale (AMIS). The WeeFIM™ is currently the most frequently used functional assessment outcomes measure in pediatric rehabilitation settings. Study personnel established inter-rater reliability with the instrument according to the established protocol. The AMIS is a tool developed for our larger study. Both scales use a 7-point rating system (7 = *totally independent*; 1 = *totally dependent*). The WeeFIM™ measures function in areas such as eating, dressing, transfers, mobility, and bowel and bladder function. The AMIS measures abilities such

as knowing medical treatment, ordering supplies and medications, and making appointments. Cronbach alpha reliabilities in our study were .80 for the WeeFIM™ and .90 for the AMIS.

Sources of Information

Three interview questions were used to evaluate the adolescents' sources of sexuality information: (1) Where have you received the most useful information on sexuality? (2) Where have you received the most useful information about sexuality and SB? and (3) Have you ever talked to a health care professional about sexuality? Content analysis of the first two questions was conducted and frequencies were summarized using the categories outlined in Table 4. Participants responded either *yes* or *no* to the last question.

Results

Adolescents with SB reported a fairly high level of knowledge of SB-related sexuality issues, a fairly moderate worry level, and a fairly low perception of themselves as having romantic appeal (see Table 5). No difference

Table 4 Sources of Sexuality Information Most Useful to Adolescents

Source	Most Useful General Sexuality Information	Most Useful SB Sexuality Information
Family	24% (most often the mother)	8%
School	36%	6%
Health Professional	22% (generally, SB clinic/hospital)	42% (almost always SB clinic)
No One	14%	29%
Experience	4%	0%
World Wide Web	0%	8%
Other (did not know)	0%	5%
Total	100%	98% (not 100% due to rounding)

Table 5 Study Variables, Measures, Frequencies, and Reliabilities

Construct	Measure	Mean	Range	SD	Reliability Alpha
Knowledge	SB Sexuality Knowledge Scale				
	a. General Sexuality Knowledge Subscale	4.1	1–5	.56	.80
	b. Fertility Knowledge Subscale	4.2	1–4	.85	.68
	(1 = <i>strongly disagree</i> ; 5 = <i>strongly agree</i>)				
Worry	SB Worries Scale	1.9	0–5	1.3	.83
	(0 = <i>no worry at all</i> ; 5 = <i>worry a lot</i>)				
Romantic Appeal	Harter's Romantic Appeal	2.4	1–4	.91	.56 (.70 when revised to 3 items)
	(1 = <i>really false for me</i> ; 4 = <i>really true for me</i>)				

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by gender or age occurred on each of these scales. However, two SB variables—shunt status and level of lesion—approached significant differences in relationships with romantic appeal ($p = .09$ and $.08$, respectively). Thus, these may be important variables to examine in future studies.

Question 1: What Do Adolescents with SB Know about Sexuality and SB?

The mean score on the General SB Sexuality Knowledge Subscale was 4.1; the mean score on the SB Fertility Knowledge Subscale was 4.2. When the SB sexuality knowledge items were examined individually (see Table 1), adolescents with SB clearly demonstrated that they know the following: they have sexual feelings just like others their age (84%), those with SB who are sexually active need to use some method of birth control (82%), and those with SB who are sexually active can get STDs (96%). They were less aware that women with SB have menstrual periods (68%), can get pregnant (70%), should be on a daily multivitamin with folic acid supplementation (62%), and, if used, condoms need to be latex-free (72%). Generally, the adolescents reported only moderate agreement with the items “It is easy for teens with SB to get information about sexuality” (62%) and “Teens with SB are attractive and appealing to others” (66%). In addition, their reports varied about whether or not having SB gets in the way of being close to a boyfriend/girlfriend: 44% agreed, 39% disagreed, and 16% were unsure.

Question 2: What are Adolescents’ Attitudes or Worries about Sexuality and SB?

Five of the seven SB Worries Scale items related to sexuality. The means for items in this scale ranged from 1.0 to 2.7 (see Table 2). Over half of the subjects in this

study worried *some to a lot* about the scale items “Can I have a baby/father a child?” and “If I have a baby, will it be normal?” Approximately 40% of the subjects reported *some to a lot* of worry about the scale items “Will others be hesitant to date me due to SB?” or “When ready to be sexually active, will I have difficulty due to SB?” In contrast, fewer than 25% reported worries about the scale item “Will I have difficulty making friends due to SB?” In the larger picture, few (about 27%) worried that they will be able to live independently, but almost half worried about “Will I have good health as a young adult?”

Question 3: How Do Adolescents with SB Rate Their Romantic Appeal?

Study participants reported a fairly low perception of their romantic appeal (see Table 3). The three items in the scale with acceptable reliabilities were the following: Some teenagers feel that if they are romantically interested in someone, that person will like them back; some teenagers feel that people their age will be romantically attracted to them; and some teenagers feel that they are fun and interesting on a date. On a scale of 1–4, these adolescents rated themselves 2.4, which generally indicated that the positive statements were *not true* for them. Instead, they endorsed the opposite statements (e.g., “Other teenagers wonder about how fun and interesting they are on a date”). The scale score indicates adolescents in the study found the negative statement *sort of true* more applicable to them.

Construct Validity

Three scales—SB Knowledge, SB Worries, and Romantic Appeal—each had a significant relationship with the overall Harter Self-Worth Scale that we used as a measure for mental health, thus giving support for their validity. Controlling for the two SB characteristics (shunt status and level of neurological lesion), the SB Sexuality Knowledge Scale had the lowest significant correlations ($r = .37$), followed by SB Worries ($r = -.49$) and Romantic Appeal ($r = .62$). Furthermore, both the SB Worries and the Romantic Appeal scales also had moderate to strong correlations with the Harter subscales of Physical Appearance and Social Acceptance ($r = -.41$ and $.61$ for physical; $r = -.44$ and $r = .54$ for social). Actual dating frequency did not correlate with sexuality knowledge,

worries, or romantic appeal. Further evidence of validity for the sexuality knowledge scale was its correlation with the WeeFIM™ (Anonymous, 1998; Ottenbacher et al., 1996) ($r = .42$) and the AMIS (.43) used in our larger study.

Question 4: What Sources of Information on Sexuality Do Adolescents Identify as Most Useful?

Participants responded to three interview questions ("Sources of Information" section on page 26). Adolescents in this study reported school, parents, and health care providers, in that order, as the primary sources of general sexuality information (see Table 4). In contrast, health care providers at the SB clinics were identified as the primary source of information regarding SB and sexuality. Overall, 52% of the sample indicated that they had discussed sexuality with a health care professional. It is interesting to note that 29% of the sample (the second largest group) reported that no one had discussed SB and sexuality with them. Several of the subjects used the World Wide Web for information about SB and sexuality. Peers were not a substantial source of information for either general sexuality or SB sexuality. One subject who reported school as a source for information on sexuality and SB indicated that the teacher provided SB-specific information.

Discussion

Knowledge

Like adolescents in other studies (Blum, 1997; Verhoef et al., 2000), adolescents in our study clearly indicated that persons with SB were sexual beings with the same feelings and desires as others. They also seemed to be aware that they were just as much at-risk for STDs as their peers. The teens' lack of knowledge about folic acid is disconcerting because adolescents with SB are the highest at-risk population for a pregnancy complicated by a neural tube defect (NTD). All adolescents with SB can benefit from a referral for genetic counseling and all females should take a multivitamin with folic acid. Generally, if one partner has SB, there is a 3%–5% chance of having a child with SB (a slight increase from the 2%–3% chance in the general public (Anonymous, 1991). Data are scarce on pregnancy outcomes for women with SB who take folic acid; however, information on women who have had a pregnancy with NTD

indicates a dramatic reduction of NTD incidence in a second pregnancy when folic acid has been used (Brouwer et al., 2000). Like all other women of childbearing age, adolescent women with SB need to take 400 micrograms (0.4 milligrams) of folic acid daily, even when they are not planning on getting pregnant. However, if adolescent women with SB are thinking about becoming pregnant, they need to take 4000 micrograms (4.0 milligrams) of folic acid by prescription for 1–3 months before becoming pregnant. Women with SB have been shown to have naturally low levels of foliate (Gross, Caufield, Kinsman, & Ireys, 2001), but a normal response to supplementation (Brouwer et al., 2000).

[I]f adolescent women with SB are thinking about becoming pregnant, they need to take 4000 micrograms . . . of folic acid by prescription for 1–3 months before becoming pregnant.

Fertility issues can be confusing for teens. Females with SB start their periods 1–2 years before their peers do because of central nervous system changes that may be caused by hydrocephalus; however, their menstrual periods and fertility are normal. Some women with short stature and a small trunk are unable to sustain a pregnancy and may be cautioned not to become pregnant. Two reasons explain why it is critical for all women with SB to know that they can conceive. First, adolescent women with SB need to use appropriate birth control methods to control timing of pregnancy or to avoid pregnancy for either personal or medical reasons. Second, adolescent women with SB must take folic acid preconceptually for several months. For women with SB, careful planning is critical and unintended pregnancy should be aggressively avoided.

Perinatal nurse educators need to be aware of sexuality issues not only for women who have SB, but also for women whose partners have spina bifida. Fertility issues for males with SB are less clear than for females with SB. The neurological level of lesion and its impact on erections, ejaculations, and quality of sperm influence fertility for males with SB (Sloan, 1995). Generally, those with a lower level of lesion (sacral) are most likely to have

psychogenic erections, ejaculations, and normal fertility (Sandler, Worley, Leroy, Stanley, & Kalman, 1996). An evaluation by an urologist is necessary to determine the status of individual fertility. However, until proven otherwise and for pregnancy prevention, it is important to assume fertility.

According to research (Hultling et al., 2000; Sadovsky, Miller, Moskowitz, & Hackett, 2001), sildenafil (Viagra) has been shown to be very effective in assisting men who have spinal cord injuries (SCI) and impaired sexual function to achieve and sustain erections for intercourse. Although smaller numbers of men with SB have been studied, promising results with sildenafil have also been reported (Palmer, Kaplan, & Firlit, 2000). In addition, this same medication has been shown to increase arousal in women with SCI and other neurologically-based sexual dysfunctions, but no data are currently available on women with SB (Sipski, Rosen, Alexander, & Hamer, 2000). Electro-ejaculation and artificial insemination are techniques used for some men with SB who wish to father a child, if they are not otherwise fertile. It is unclear whether or not adolescents are aware of these options as they grow into adulthood.

Although women with SB have a variety of options for birth control, those who wish to use barrier methods need to consider the status of their latex allergy. Generally, 40%–60% of persons with SB are allergic to latex. This allergy substantially impacts their sexuality. Sixty percent of participants in this study were allergic to latex; however, 80% practiced latex precautions as recommended by those who treat SB. Because latex allergies have developed throughout life for individuals with SB and because added exposure leads to subsequent risk, many people with SB actively avoid contact with latex, especially latex contact with mucus membranes. Thus, nurses who interact with individuals who either have an allergy or are at high-risk must know about nonlatex barrier options (see Table 6). Knowing how to use latex-

Although women with SB have a variety of options for birth control, those who wish to use barrier methods need to consider the status of their latex allergy.

free condoms or a combination of a latex-free condom over a latex condom is an important survival strategy for young women with SB. In addition, because of the lack of neurological enervation, sexually active women with SB or SCI frequently may have decreased or no vaginal lubrication with sexual excitement and need to use a water-soluble lubricant with all activities, except oral sexual activities (Verhoef et al., 2000). Young men with SB, whose partner is not at risk for latex allergy, need to reverse the process: First, they must put on a latex-free condom, followed by a latex condom.

Worries

Study subjects worried most about sexuality-related items, specifically whether or not subjects could have a biological child and whether or not the child would be nondisabled. While the average worry score was not extremely high and did not convey overwhelming worry, the level of worry did vary widely and reflected the underlying concerns for many. In addition, we used a general SB worry question (*will have trouble [with sex] due to SB*). Specific questions regarding incontinence and positioning might be more useful and generate more specific discussions of concerns. Subjects did not volunteer these worries in our “Other Worries” section, but other studies have reported them (Verhoef et al., 2000).

Romantic Appeal

The two items removed from the romantic appeal scale had characterized actual dating. Together, these two items correlated only moderately ($r = .58$) with the measure of dating reported by the subjects. The resulting romantic appeal scale had to do with being attractive to another teen (not actually dating). The correlations with physical appeal (some teenagers were happy with how they looked; others liked their body the way it is; others liked their physical appearance) were high ($r = .61$) and gave support for validity of the scale. Further, the romantic appeal scale—not actual dating activity—was correlated with self-worth, which gives support to the power of the individual’s perception and meaning when predicting mental health.

Source of Information

Interestingly, our study revealed that the family replaced the peer group in some of these adolescents’ lives. Peers were not a substantial source of information for either

Table 6 Sexuality Resources for Perinatal Educators Working with Adolescents Who Have a Disability

GENERAL

- Sawin, K. J. (1999). Women with chronic illness and disability. In E. Q. Youngkin and M. Davis (Eds.), *Women's Health: A Primary Care Clinical Guide* (2nd ed.). Stamford, CT: Appleton Lange.

SBAA WEB SITE (www.sbaa.com)

- Latex Allergy List—A very useful list; updated yearly.
- *Latex Allergy: A video*—A 12-minute video suitable for professional and lay audiences. Available from the Spina Bifida Association of America, 4590 MacArthur Blvd. NW, Suite 250. Washington, DC 20007-4226.

BOOKS – SPECIFIC TO SB

- Lutkenhoff, M., & Oppenheimer, S. G. (Eds.) (1997). *SPINAbilities*. Bethesda, MD: Woodbine House.
- Sloan, S. (1995). *Sexuality and the person with spina bifida*. Washington, DC: Spina Bifida Association of America.

BOOKS—APPROPRIATE TO ANY TEEN WITH A DISABILITY

- Kriegsman, K. H., Zaslow, E. L. D'Zmura-Rechsteiner, M. A. (1992). *Taking charge: Teenagers talk about life and physical disability*. Bethesda, MD: Woodbine House. Available from the American Spina Bifida Association (see above for address). The much acclaimed primer for older school-aged and teenaged patients.
- Kaufman, M. (1995). *Easy for you to say. Questions and answers for teens living with chronic illness or disability*. Toronto, Canada: Key Porter Books, Ltd.

OTHER RESOURCES FOR GENERAL INFORMATION ON WOMEN, MOTHERS WITH DISABILITY

- Center for Research on Women with Disabilities (CROWD)—Provides ongoing research and resources for information on women with disabilities. Department of Physical Medicine and Rehabilitation, School of Medicine, Baylor University, 3440

Richmond Avenue, Suite B, Houston, TX 77046. Phone: 713-960-0505. Toll Free: 800-44-CROWD. Director: Margaret Nosek, PhD. Web site: <http://www.bcm.tmc.edu/crowd/>

- Parents with Disabilities Online! www.disabledparents.net
- Information on accessible GYN exam table: <http://www.disabledparents.net/examtable.html>
- Information on accessible family planning locations: <http://www.ppct.org/centerservices/centers/locations.shtml>
- Breast Health Access for Women with Disabilities – San Francisco area, but a good model. http://www.cancerlynx.com/breast_health.html
- National Clearinghouse on Women and Girls with Disabilities – Educational Equity Concepts, 100 5th Avenue, 2nd Floor, New York, NY 10011. Voice/TT: 212-243-1110 Voice/TT. Fax: 212-627-0407. Web site: <http://www.edequity.org/welcome.htm>
- Through the Looking Glass – An organization that promotes research and information for parents with disabilities. Web site: www.lookingglass.org
- The National Women's Health Information Center, Women with Disabilities. Web site: www.4women.gov/wwd/

BARRIER BIRTH CONTROL OPTIONS FOR LATEX-SENSITIVE WOMEN

- Avanti brand polyurethane condom (Schmidt Laboratories). Has had limited testing that supports the prevention of pregnancies and STDs. A 1995 Consumer Reports article questioned just how much protection is offered. To date, the FDA has not allowed the manufacturer to make any effectiveness claims.
- Reality Female Condom (The Female Health Company)—Made of polyurethane. Laboratory testing showed that Reality was an effective barrier to HIV and to a virus particle that is smaller than the hepatitis B virus, the smallest virus known to cause an STD. May be covered by Medicaid. Call to check on your state. Phone: 1-800-635-0844. Web site: www.femalehealth.com

general sexuality or SB sexuality. Although this finding is not unique to our study (Sawyer & Roberts, 1999), it does reflect the isolation reported by some adolescents and young adults with SB and further complicates the social interaction needed to establish intimate relationships. Compared to other studies conducted in Australia and The Netherlands (Sawyer & Roberts, 1999; Verhoef et al., 2000), our study found lower rates of school as the primary source of general sexuality education (36% versus 84% in the Australian study and 74% in the Dutch study) and slightly lower score rates of “no information on SB and sexuality” (29% in our study versus 84% in the Australian study and 18%–23% in the Dutch study). Also, more of our subjects (just over half) had

discussed sexuality with a provider than the subjects in the other two studies conducted in Australia and The Netherlands (39% and 25%, respectively). However, more subjects in the other studies received sexuality information from their peers (Sawyer & Roberts, 1999) than the subjects in our study. The common thread in all three studies is a need for more SB-specific sexuality information for both sexes.

Implications for Practice

Perinatal nurse educators have a wide variety of opportunities to influence adolescents with disabilities. The PLIS-SIT model is a helpful technique in dealing with sexuality

for all women (Sawin, 1999). This model delineates four levels of intervention regarding sexuality: *Permission-giving, Limited Information, Specific Suggestions, and Intensive Therapy*. Acknowledging adolescents with disabilities as sexual and creating an environment that gives them permission to discuss sexuality concerns are fundamental approaches to all interactions. Conveying permission is powerful and creates a sense of normalcy, especially if the adolescent has previously been treated as an asexual person.

Effective communication is the key to *permission giving*. Health professionals need to use appropriate terminology when communicating with individuals with disabilities. Table 7 offers general guidelines for building effective communication and avoiding “handicapism.” Table 8 provides appropriate terminology. Communicating the expectation that a person with a disability has the same issues and concerns as others do and finding a way to integrate these concerns into interactions with adolescents with a disability will put permission giving into action. Role models with similar experiences are often very helpful. In addition, the use of popular media as sources of information “normalizes” the adolescent’s experience. A survey conducted by *Glamour* magazine underscores the discrimination experienced by women

with disabilities and offers solutions from women who have faced the same challenges (Mairs, 1996).

[T]he use of popular media as sources of information “normalizes” the adolescent’s experience.

Data from the current study offer nurses the basis for assessing an adolescent’s knowledge, worries, and perception of romantic appeal. Folic acid must be discussed with all adolescents. Though many more women know about the advantages of folic acid supplementation, many still do not use folic acid. Fortification of cereals begun in 2001 provides only a portion of the folic acid needed for prevention of NTD. Recent data indicates that women would be more likely to take folic acid if it were recommended by their health care provider (March of Dimes, 2000). All opportunities should be used to discuss this important information with young women, especially those with SB.

Further, all adolescents with chronic conditions must know their fertility status and have direct, open communication about specific birth control options (Blum,

Table 7 Disability Etiquette

After an initial greeting, sit down so that a person using a wheelchair will not have to crane his/her neck to make eye contact.

Shake whatever a person offers in greeting – a hand, prosthesis, or elbow.

When speaking with a person with a hearing loss, try to keep your face out of the shadows and your hands away from your mouth as you speak.

If you are speaking to someone and a sign-language interpreter is present, remember to look at and talk to the person, not the interpreter.

If someone’s ability to read, write, or handle documents is limited, be prepared to provide assistance in completing paperwork.

When someone with a disability enters an establishment, do not assume he/she needs your help. Greet the person and tell them you’re available for assistance.

Always speak directly to a person with a disability. Do not assume a companion is a conversational go-between.

When you offer to assist someone who is visually impaired, allow the person to take your arm so you can guide, rather than propel, him or her.

Act naturally. Do not be afraid to use expressions such as “Would you like to see that?” or “Let me run over there.” On the other hand, do not ask personal questions you would not ask someone without a disability.

Wheelchairs are extensions of the personal space of the people using them. Do not hang or lean on them.

Service animals are working when they are with their owners. Do not touch the animal without the owner’s permission.

When speaking with a person with a speech difficulty, talk normally. Do not pretend to understand when you do not. If necessary, ask the person to repeat. They’ve experienced this before and know problems can arise.

Information provided by the Virginia Department of Rehabilitative Services.

Table 8 Acceptable Terms for Describing Persons with Disabilities

Disabled

*Not Handicapped
Crippled
Deformed*

Nondisabled

*Not Able-Bodied
Normal
Healthy*

Person Uses a Wheelchair

*Not Person is Wheelchair-Bound
Person is Confined to a Wheelchair*

Person Has Cerebral Palsy

Not Cerebral Palsy Victim

Person Had Polio

Not Person Suffers from Polio

Person Has a Specific Learning Disability

Not Person is Learning Disabled

Person Has a Speech Disability; Has Limited Speech; Is without Speech

*Not Person is Mute
Person is Unable to Speak
Person is Speech Impaired*

People Who are Blind; Person is Blind

*Not The Blind
Person Suffers from Blindness*

People Who Are Visually Impaired; Person Has Low Vision or Impaired Vision

*Not The Visually Impaired
Person Who is Partly Blind*

People Who Are Deaf

*Not The Deaf
Deaf Mute*

Person Who is Hard of Hearing or Has a Hearing Loss

Not Person with a Hearing Impairment

People with Mental Illness

*Not The Mentally Ill
Mentally Ill People*

People with Mental Retardation

*Not The Retarded
The Mentally Retarded*

Person with Spasticity

Not Spastic Person (muscles are spastic, people are not)

1997). The number of adolescents (both females and males) that did not know a woman with SB could become pregnant indicates the need for conversations initiated by perinatal nurse educators who work with these youth and their parents.

Information can also be the key to deal with the worries that were expressed by women in this study. Referrals to genetic counseling for *specific suggestions* for both the adolescent and their parents can provide realistic information and individual risk assessment. Although the general risk of having a child with NTD is increased for women who have SB, the risk is still relatively low. Preconceptional counseling and pregnancy management by a health care team that is experienced in high-risk pregnancies most often result in a healthy pregnancy, vaginal delivery, and a healthy baby. The critical message to deliver to adolescents is the need for careful preplanning and, if sexually active, appropriate contraception.

A critical aspect of this journey for women with physical disabilities is finding a provider that is both architecturally and attitudinally accessible. Examination tables may need to be more accessible and pelvic examinations may need to be modified (Sawin, 1999; Welner, 1997; Welner, 2000; Welner, Foley, Nosek, & Holmes, 1999). However, the most critical attribute is a provider who includes the women with disabilities in decision-making regarding the exam and options for care.

Developing a perception of oneself as a person with romantic appeal is based upon both the individual's attributes and society's perceptions. Adolescents' perceptions of romantic appeal are influenced by sexuality information and attitudes portrayed by parents. Perinatal nurse educators have multiple opportunities to convey the normalcy of sexuality to both adolescents and their parents. Even if they are armed with knowledge, individuals with disabilities (especially women) face broad societal discrimination that can negatively influence their perception of romantic appeal. Role models, positive portrayal of individuals with disabilities in the popular media, and sensitive health care providers can lessen the effect of negative messages delivered by society. Low romantic appeal may put adolescents with disabilities at risk for abuse. The high incidence of sexual abuse in adolescents and adults with disabilities (again, especially women) make it imperative to specifically address sexual abuse. Specific suggestions regarding prevention, monitoring, and interventions must be presented to parents through-

out the life of a child growing up with a disability and discussed openly with adolescents and their families.

Intensive therapy is not in the perinatal educator's scope of practice; however, educators must understand when the adolescent and/or the family need these services. Perinatal educators can facilitate the appropriate referral, including obtaining justification for services if the adolescent and his/her family have limited insurance coverage. While they do not provide intensive therapy, support groups or mentorships based on the use of effective role models may meet some of the support needs of adolescents. Networking with independent living centers located in major cities throughout the country can put the educator in touch with both educational and political action resources.

Limitations of the Study

One potential weakness of the current study is the format of the knowledge questions. The stem—"women with SB," "individuals with SB," or "men with SB"—frames the knowledge questions. While attempting to tap general knowledge, the questions may attenuate the individual's report of knowledge and behavior specific to themselves. For example, did individual adolescent women with SB know that they should be on a multivitamin and were they taking it? Did they know their fertility status verses fertility status of women with SB as a whole? The knowledge questions were the only questions that referred to a collective, rather than to the adolescent himself/herself. Collecting data specific to the person may be more useful. It is also clearly an advantage the clinician has, and one future studies should consider.

In addition, the sample was modest and quite homogeneous, coming from one setting, one ethnic background, and one part of the country. Clearly, if we are to generalize findings to adolescents as a whole, we need to include adolescents of various ethnic backgrounds and from different parts of the country. Finally, it is important to study sexuality in the context of other challenges the adolescent and family are facing. Our team's future work will focus in these areas.

Summary

In summary, adolescents with SB may have knowledge deficits, worries, a low level of perceived romantic ap-

The perinatal educator is in an ideal situation to integrate sexuality across the continuum of services where she may encounter adolescents with SB or other chronic illnesses and disabilities.

peal, a lack of access to information regarding SB and sexuality, and behaviors that put them at-risk. The perinatal educator is in an ideal situation to integrate sexuality across the continuum of services where she may encounter adolescents with SB or other chronic illnesses and disabilities. The need for comprehensive sexuality education in this population is high. Also, discussion of sexuality, contraception, and abuse must be part of standard psychosocial assessment and anticipatory guidance for all teenagers, including those with chronic conditions (Suris et al., 1996).

If the perinatal educator is not familiar with conditions such as SB, consulting with a rehabilitation nurse (either pediatric or adult) will offer multiple resources beyond what can be shared here. However, the primary intervention of normalcy and respect for the sexuality issues of adolescents with disabilities is a resource readily available and one that should be used liberally.

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