The evidence to date regarding self-management in adolescents with chronic health conditions (CHCs), particularly congenital disabling CHCs, is limited. One such population includes adolescents with spina bifida (SB), who have difficulty with self-management, including underachievement in independence, education, and employment (Dise & Lohr, 1998; Shurtleff, 2000). SB is a complex multisystem condition with orthopedic, urologic, gastrointestinal, neurological, immunological, and neuropsychological components that require lifelong management. More than 25 years ago, Hayden, Davenport, and Campbell (1979) documented the need for increased self-management in youths with SB. However, there remains a limited understanding of the experience of self-management and strategies to develop self-management in adolescent women with SB. Clinicians and researchers have proposed that developing self-management skills in youths with CHCs is central to combating this vulnerability, achieving self-sufficiency, and transitioning to young adulthood (Betz, 2004; Nodhuturff et al., 2000). However, data from the Center for Women with Disabilities suggest that the development of self-management skills may be a particular challenge for young adolescent women with a CHC (Nosek, Howland, Rintala, Young, & Chanpong, 2001).

The purpose of this qualitative study (which is part of a larger investigation of adaptation in adolescents with SB; Sawin, Bellin, et al., 2002; Sawin, Buran, et al., 2003), which integrates developmental theory, systems theory, and situational perspectives to explain individual adaptation in adolescents with SB. This study was also influenced by two prominent models in the disability literature: the Independent Living Model (DeJong, 1979) and the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001). The Independent Living Model emphasizes the critical role of the person with a disability and proposes that outcomes are driven by the person with a disability. According to this model, as the individual with a disability advances in skill, the healthcare professional assumes the role of a consultant. Thus, understanding the experience of self-management is central to empowering and improving health outcomes for people living with disabilities. The focus of the ICF is functioning, which is viewed as a complex interaction between the health condition of the individual and the contextual factors of the environment as well as personal factors. The integration of these frameworks prompted us to choose self-management as the outcome of interest and guided the qualitative interview about self-management.

Theoretical Underpinnings

The larger study is grounded in the Ecological Model of Adaptation in SB (Sawin et al., 2002; Sawin, Buran, et al., 2003), which integrates developmental theory, systems theory, and situational perspectives to explain individual adaptation in adolescents with SB. This study was also influenced by two prominent models in the disability literature: the Independent Living Model (DeJong, 1979) and the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001). The Independent Living Model emphasizes the critical role of the person with a disability and proposes that outcomes are driven by the person with a disability. According to this model, as the individual with a disability advances in skill, the healthcare professional assumes the role of a consultant. Thus, understanding the experience of self-management is central to empowering and improving health outcomes for people living with disabilities. The focus of the ICF is functioning, which is viewed as a complex interaction between the health condition of the individual and the contextual factors of the environment as well as personal factors. The integration of these frameworks prompted us to choose self-management as the outcome of interest and guided the qualitative interview about self-management.

Review of the Literature

Adolescent Women with a Disability: A Population at Risk

A growing body of research suggests that young women with CHCs that involve physical disabilities are at risk for a range of negative outcomes. The combined effect of gender and disability place...
these women at greater risk for psychosocial health problems (e.g., depression) compared to their male counterparts with a disability and other women without a disability (Nosek & Hughes, 2003). Furthermore, they are vulnerable to physical and psychological abuse and sexual exploitation (Hassouneh-Phillips & McNeff, 2005; Nosek, Foley, Hughes, & Howland, 2001). Stereotypes that devalue women with disabilities only highlight their vulnerability across these areas of psychosocial health (Collins & Valentine, 2003). One mechanism for offsetting this increased vulnerability is developing self-management skills. Currently, there is a paucity of research exploring experiences with self-management in women with physical disabilities; data regarding self-management experiences among adolescent women with SB is particularly scarce. However, the broader literature on self-management across diverse populations illuminates several key individual and familial factors affecting self-management experiences as well as the efficacy of interventions designed to support these skills.

**Individual Factors Influencing Self-Management**

For youths with a disability, the development of specialized knowledge, opportunities for skill development and testing, and self-efficacy emerge as vital components in the growth of self-management. For some, the development of condition-based knowledge will naturally evolve, whereas others require more hands-on education to become more independent in the monitoring and management of their condition. Regardless of the pathway to achieving this specialized knowledge, the requisite expertise to monitor the symptoms, treatment, and physical and psychosocial consequences of the particular condition forms a critical foundation for self-management (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Sawin et al., 1999).

Experiences in problem-solving tasks, such as decision making about goals and treatment (King, Shultz, Steel, Gilpin, & Cathers, 1993) and learning how to access resources (Hughes, 2004), are other building blocks for self-management. Experiences with these skills may first develop in a protected environment, such as in the presence of a nurse or parent. Success in sheltered settings may foster confidence in these youths about their ability to engage in independent decision making in less controlled settings. Some research suggests that the development of self-management requires both knowledge and a belief that the learned skills will result in desired outcomes (Nodhturft et al., 2000). It makes sense that the more comfortable youths are in their knowledge and skills, the more likely they are to engage in self-management at home, school, and in the broader community. Ideally, the development of specialized knowledge, skills, and self-efficacy would lead to a positive feedback loop whereby youths with a disability continue to expand their self-management activities.

**Family Factors Influencing Self-Management**

Family health literature often discusses the influence of the family environment on self-management. In a retrospective study, Loomis, Javornisky, Monahan, Burke, and Lindsay (1997) found perceived family encouragement of independence and achievement to be positively related to employment, community mobility, and social activity in young adults with SB. Furthermore, in their research with preadolescents with SB, McKernon and colleagues (2001) surmised that a cohesive family environment conveys a sense of security, which, in turn, encourages young adolescents to be more interactive with their environment. In contrast, an overprotective parenting style may hinder self-management in adolescents with CHCs (Holmbeck et al., 2002). Some data also suggest that profound physical and mental health implications are tied to experiences of self-management. Reduced opportunities for decision making have been linked to an increase in behavior problems (Holmbeck et al., 2002) and lower self-image (Resnick & Hutton, 1987) in youths with CHCs. In addition, Howland and Ritala (2001) found that overprotection predicted future abusive relationships for women with physical disabilities. Regardless of whether dependence on parents is initiated by the adolescent or parent, it deters the development of self-management skills in adolescents with CHCs in general and, perhaps, is especially problematic for young women with physical disabilities.

**Self-Management Activities of Youth with Disabilities**

Research about the specific self-management activities in which youths with disabilities participate is limited. Furthermore, the available data are mixed and primarily focus on arthritis, diabetes, and asthma. Select studies have included youths with SB. In a recent study examining the self-care needs and skills of transition-age youths—including adolescents with SB—competence in self-management was noted in some aspects of healthcare needs, such as making choices and developing specialized knowledge about the condition (Betz, Redcay, & Tan, 2003). In contrast, deficits emerged in knowledge of legal rights and protections, environmental modifications and accommodations, and health
insurance issues. Although progress was noted in some dimensions of self-management, other areas were noticeably underdeveloped.

Other research has similarly highlighted limited or restricted experiences with self-management reported by children or youths with SB. For example, Blum, Resnick, Nelson, and St. Germain (1991) observed a pattern of dependence on parents by adolescents with SB in self-care areas such as bowel management and responsibilities at home in general. Monsen (1992) reported reduced decision making and autonomy in adolescents with SB. Using a retrospective chart review, Davis and colleagues (2006) documented delays of 2–5 years in self-care or autonomy skills of adolescents with SB. Finally, a recent study found that although there was an increase in knowledge over several time points in late childhood and early adolescence, many young adolescents still had low-to-moderate knowledge about SB (Greenley, Coakley, Holmbeck, Jandasek, & Willis, 2006). No study was found that addressed self-management in women with SB.

Enhanced self-management is critical to improve the health status and quality of life in adolescent women making the transition to adulthood. Given the broad implications of self-management for the physical and mental health of adolescent women with SB and the limited research on self-management, a more complete understanding is needed. Specifically, gaps exist in understanding the complex experience of self-management for adolescents with SB, the self-management activities these adolescents are currently accomplishing, and the areas of unmet need. This knowledge may ultimately help the development of effective, tailored interventions designed to increase self-management skills and reduce the vulnerability of adolescent women with SB.

Methodology
This qualitative analysis, part of a larger mixed-method investigation that explored adaptation in adolescents with SB (Sawin et al., 2002; Sawin, Buran, et al., 2003), specifically addressed the following research question: “What is the experience of self-management for adolescent women with SB?” Participants in the larger study (n = 66) were 12–21 years of age, English speaking, and functioning at grade level in school. Approval from the university institutional review board was obtained before the study was initiated.

In order to explicate the gender-specific experiences of adolescent women with SB, the 31 transcribed single interviews of adolescent women were analyzed for this report. The integrated ecological model was a sensitizing orientation for the development of the interview guide and was the rationale for conducting a gender-specific analysis. Content analysis was conducted to examine the interview responses for common domains, themes, and subthemes using the techniques of Morse and Field (1995). Analysis of this qualitative data also generated results on two other domains of everyday living—self-concept and family relationships and peer relationships—which are reported elsewhere (Bellin, Sawin, Roux, Buran, & Brei, 2007; Roux, Sawin, Bellin, Buran, & Brei, 2007).

Data were collected through semistructured interviews designed to determine the adolescent women’s experiences of living with SB. Specifically, the interview guide included the self-management activities participants performed, how responsibility for those activities was decided in their family, their satisfaction with current self-management, what they thought they needed to do to become independent, and their goals for the future and thoughts they had on achieving these goals. Interviews were conducted by a trained nurse researcher with knowledge of adolescence and family theory and experience with adolescents with SB. Generally, interviews lasted between 30 and 60 minutes with the average interview lasting 45 minutes. The interviews were audio taped and transcribed verbatim.

Data Analysis Techniques
Initially, the first three authors reviewed four randomly selected transcripts to generate a preliminary coding scheme for the data. Twelve additional transcripts were subsequently analyzed to establish common domains and themes. The remaining 19 transcripts were then examined to confirm classification and determine exemplars. The interviews were examined to ensure saturation was established, and no new data emerged with this analysis. Finally, the last two authors, who have extensive clinical experience with this population, reviewed the domains, themes, and exemplars to confirm classification and placement. The exact words of the adolescents were used to describe the themes. In addition, each exemplar was initially identified with both the level of the SB lesion (LOL) that described the participant and her age. The exemplars were then examined to determine whether there were themes or subthemes predominant in women of specific ages or LOL. As themes and subthemes crosscut adolescents of all ages and LOL, the LOL classification and the actual age were deleted from the report of the exemplars to further ensure confidentiality.

Results
Characteristics of participants are reported in Table 1. Three themes and seven subthemes capturing different dimensions of the adolescents’ experiences...
with self-management emerged in this analysis. The three themes included: (1) opportunities to engage in self-management activities; (2) dance of individuation—parental impact on self-management; and (3) advocacy within self-management—confronting discrimination and stigma (Table 2).

**Theme 1:** Opportunities to Engage in Self-Management Activities—Knowledge, Skills, and Aspirations

This theme reflects participants’ thoughts about the key steps for moving toward increased self-management. Their experiences highlighted the importance of developing a specialized knowledge base and skill set related to SB and the need to become independent in more general areas of self-care, such as money management and dressing and grooming. Their stories revealed great variability in adolescent and family commitment to the development of these life skills. Two subthemes emerged: (a) specialized knowledge and skills related to managing SB and (b) general skill-building tasks to achieve independence.

The first subtheme—specialized knowledge and skills related to managing SB—enunciates the idea: “I feel it should be my responsibility.” Taking ownership of the many and varied tasks associated with SB was a crosscutting theme of participants’ stories. A key component of self-management in SB is developing mobility competence and learning “how to get around, get around in buildings and learn what to do if there’s no like, accessible way to get into a building…how to get up like…bumps, you know, on sidewalks,” explained one participant in early adolescence. Participants who ambulated using braces encountered similar challenges when learning how to put them on. “That took me forever,” admitted one participant. Their stories emphasize the importance of perseverance when trying to accomplish self-management tasks. For example, one young woman who had difficulty passing her driving test proclaimed “I’m going to try it again.”

Part of the unique self-management tasks associated with having SB related to anticipating and managing potential problems. Preparing for bladder or bowel accidents was an accepted part of self-management for SB. A participant shared how she minimized such accidents: “I have to take extra supplies just in case something happens. Like an accident or something. I have a backpack on my chair, so I just put my supplies in it and just go ahead and put in a pair of jeans, underwear, and extra nighttime underwear that I wear to bed, and some pads, and I’ll put them all in there and I’ll stash them in there. That way I have them just in case of an accident.”

Young women with SB also reported taking precautions to avoid secondary conditions such allergic reactions (“There are certain food that I can’t eat because…of my latex allergy.”), urinary tract infections (“My urine will [change] and I’ll start getting really, really tired.”), and other potential complications. Specialized knowledge to manage medications was another common component of self-management specific to SB. A participant in late adolescence reported, “I take ‘xxxx’; it’s for high blood pressure, but it’s to prolong my kidneys.”

Finally, the participants discussed the ever-present issue of catherization and critical decisions about bowel management in daily life. This latter aspect of self-management in SB seemed to be particularly challenging. A participant in middle adolescence shared her struggles with the bowel management decision: “I would like [the bowel program] to be different. I don’t want to have to go through surgery, but I would like it to be different. I don’t want another hole in my body. I had a hole with my surgery. I watched that thing every day of my whole entire life. I don’t want to have to deal with that, with another hole.”

**Table 1. Characteristics of Participants**

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**Table 2. Conceptual Themes and Subthemes**

| Theme 1: Opportunities to Engage in Self-Management Activities—Knowledge, Skills, and Aspirations |
| Subtheme a: Specialized Knowledge and Skills Related to Managing SB—“I feel it should be my responsibility.” |
| Subtheme b: The Journey of Skill-Building Tasks to Achieve Independence—“I need to learn to take care of myself. Yeah, that’s a big step for me.” |

| Theme 2: Dance of Individuation—Parental Impact on Self-Management |
| Subtheme a: Restricted Parenting—Parenting Delays Skill-Building to Achieve Independence—“She’s overprotective.” |
| Subtheme b: Balanced Parenting—Parenting Balances Protection and Promotion of Independence: “Different with certain situations.” |
| Subtheme c: The Process of Shared Decision Making to Enhance Optimal Outcomes—“In case I do need help.” |

| Theme 3: Advocacy within Self-Management—Confronting Discrimination and Stigma |
| Subtheme a: Self-Advocacy—“I want to be treated like I’m a person.” |
| Subtheme b: Peer and Adult Advocacy—“He’ll stick up for me.” |
Spina Bifida

The Experience of Self-Management in Adolescent Women with Spina Bifida

Subtheme b—general skill-building tasks to achieve independence—included participating in typical activities of daily living. Participants’ stories revealed an awareness that skill-building tasks are necessary to achieve independence in areas such as dressing and grooming, money management, laundry, and meal preparation. Young women of all ages identified multiple tasks they need to master to be independent. The level of participation in skill building in the deficit areas varied greatly.

A minority of young women were actively engaged in or pursuing self-management opportunities. Indeed, only a few indicated they were making progress in taking care of themselves. For example, one participant in late adolescence shared “I cook. My mom showed me how to do laundry, so I do laundry.... I try to keep my room clean. Uh, do my homework, you know. Take my own bath. Dress myself, you know. Normal stuff.” Another participant in early adolescence reported, “I brush my teeth. I do wash my face and hands. I do brush my hair sometimes ... sometimes I do it; sometimes I don’t do it by myself.”

However, the majority of the young women with SB were delayed in achieving several key developmental milestones. Remarks made by participants in both the early adolescence stage (“I haven’t learned how to cook. I can do, like, microwave, and I can sometimes sort clothes if my mom tells me.”) and late adolescence (“I don’t yet know how to wash my own clothes, but, um, I’m going to have to learn this year ‘cause if I’m going off to college—which I am—I’m going to have to learn to do that.”) evidenced delay. These young women with SB consistently acknowledged gaps in self-management: “I need to learn to take care of myself. Yeah, that’s a great big step for me”; but most failed to delineate a plan to increase self-management in the home or community environment.

Adolescent women also had varying amounts of experience with money management and employment. Some were restricted and did not have any experiences with earning money through typical adolescent activities like pet care or babysitting. “I get no income whatsoever,” reported one participant in late adolescence. Others lacked basic money management concepts. The philosophy espoused by one young woman was particularly intriguing: “Save half of it. Put half of it on my car, spend half of it.”

A few older adolescents were actively involved in money management or were developing basic career skills through part-time employment. One participant shared, “I’m working 1 day a week for 2-3 hours babysitting for a church school. I love it.” Another described her work as a data entry clerk in the following manner, “I put payroll and stuff in the computer.” Even fewer had concrete plans for stable future earnings. For example, although one woman had been in contact with vocational rehabilitation, she acknowledged, “[Vocational rehabilitation] talked to me about it, about what I want to do, and I don’t know yet.” Others seemed to rely on the security of social security income (SSI): “What I’m planning on doing is dropping SSI after I get a job and seeing—because I can always go back to SSI—if I have to.... So if something happens to where I’m not making as much money, then I could go back on it.” Finally, when asked about a goal that is critical to them, these women described aspirations about school, relationships, or future careers. No response addressed “self-management of their condition.” In addition, in the adolescent women’s stories there were no references to healthcare providers acting as influential partners in the development of these activities.

Theme 2: Parental Impact on Self-Management—Dance of Individuation

The influence of parenting styles on self-management experiences in all aspects of daily life was another comprehensive theme of participants’ stories. One subset depicted situations that increased risk of delayed development in autonomy, personal choice, and self-management. Others, however, described a “blended reality” where parents simultaneously pushed normalcy and created a protective safety net. The difference in the two styles of parenting (restrictive versus balanced) influenced the need for participants to pursue self-management in life skills, including participating in typical adolescent activities and having the autonomy to choose friends and romantic partners. Some participants accepted ongoing parental involvement because it ensured optimal health outcomes. However, others reported the desire to balance parental involvement and independent decision making as they struggled with these developmental processes. Three subthemes capturing the presence and influence of parental involvement in the lives of the adolescent women with SB emerged: (a) restrictive parenting—parenting delays skill-building to achieve independence; (b) balanced parenting—parenting balances protection and promotion of independence; and (c) the process of shared decision making to enhance optimal outcomes.

Subtheme a—restrictive parenting (parenting delays skill building to achieve independence)—is typified by remarks such as “She’s overprotective.” With complex conditions such as SB, parents, especially mothers, are very involved in the personal care of their children. It is easy for parents to forget the
changing needs of their daughters and continue to exhibit behavior more appropriate for dealing with children rather than acknowledging their daughter is moving through adolescence and desires more privacy. Frustrations about a perceived invasion of privacy in self-care activities were expressed by the adolescent women. For example, one participant revealed, “I feel sometimes that [my mom] thinks she knows more than I do about myself, and I feel sometimes that she doesn’t respect me, she doesn’t respect … what I say. One thing that really annoys me about her is she’s always got to get into my catheters … sometimes I’ll come home and they’ll be lying out. I’m a private person; I don’t like my personal stuff laid out.” Another young woman seemed similarly exasperated: “I feel like I don’t have any privacy. It’s like this morning we got into a fight because she just barged right in, and I didn’t have any clothes [on].”

Typical opportunities to promote achievement of adolescent milestones may be altered for many of these women with SB. Participants described stories of feeling overprotected and, perhaps, aggravated by their parents placing restrictions on their pursuit of self-management. Restrictions were evident in opportunities for peer socialization (“When I want to spend the night at a friend’s house or something—my Mom’s always afraid of letting me go over there and stuff.”) and in the development of basic life skills like cooking (“Certain things that [my mom] tells me that drive me insane … it just drives me nuts. The other day I was helping with supper. We were making deviled eggs, and I ask her if I could do it, just ask her how to do it. ‘Well, it’s too hard, you can’t.’ I’m 17. I can do it. It makes me so mad.”). Similarly, these young women reported sharing decision making about everyday living, particularly in choices related to friendships and activities with peers. However, the level of parental involvement in these decisions did not seem to differ from that of typically developing adolescents. For example, one adolescent with SB made choices about “who my friends are” but her parent “usually makes the decision whether I hang out with them after school or not.” A major part of the shared decision making involved open communication in the family unit: “I’ll talk it over with my parents and make sure it’s okay that I ride with a friend.” Inclusion of the parent perspective was accepted and even valued by many participants: “I make the final decision, but if there’s something [my parents] don’t like about [my friends], then I want to hear what it is.” Though participants did not always heed the advice, they seemed to listen to and thoughtfully process the information offered by parents, as illustrated by the comments of one participant in middle adolescence, “Sometimes [my parent’s advice is] dumb, but I listen to it anyway. And sometimes it’s very good advice and all. I’ll take it and I’ll follow it.”
Theme 3: Self-Management Experiences in Advocacy—Confronting Discrimination and Stigma

A final theme of self-management involved experiences of discrimination and challenges that were buffered through self-advocacy and peer or adult advocacy. The ability to adapt to these experiences suggested a firm sense of self and a desire to pursue independence despite encountering various forms of discrimination. The participants who described positive adaptive strategies demonstrated an ability to be accountable for themselves while knowing they could not control the discriminating remarks of others. Two subthemes capturing different responses to discrimination and stigma surfaced: (a) self-advocacy and (b) peer and adult advocacy.

Subtheme a—self-advocacy—is typified by the remark “I want to be treated like I’m a person.” Managing the discriminatory attitudes of others was a common experience of many participants. One middle-adolescent participant indicated that it was important not to be defined by her lack of mobility or the wheelchair she used. “I’ve made that clear, that I don’t want to be treated like I’m in a wheelchair. I want to be treated like I’m a person.” Several self-advocacy activities revolved around others teasing, staring, or making insensitive, negative comments about the teenager. Participants frequently reported using humor or simply ignoring the inappropriate actions of others. “I got used to everybody making fun of me and found a defense that I can use. I like being a smart ass,” shared one participant in early adolescence. Another young woman in late adolescence revealed that in the past, hurtful comments had been difficult to receive, but she had developed effective coping coping mechanisms, “I’ve gotten to the point where I smile at them and go on, because I know that, you know, that that’s going to be there. But when I was little, I would throw a fit and, you know, go and tell and all kinds of stuff. Now I just smile and walk on because I know that, you know, I’m not going to change, obviously.”

Participants’ self-advocacy involved not limiting their expectations because of their CHCs and striving to be treated as emerging adults. One participant in middle adolescence was motivated to rise above the limitations placed on her by others and “prove people wrong” about their limited view of her abilities. Another young woman’s comment about self-advocacy included confronting infantilized communication. She explained, “I babysit for this couple and they have three kids. The guy kept asking me if I had to go potty. Kept asking me, you know, just kept saying ‘go potty,’ and I said ‘Look … I’m a big girl. If I have to go potty, I’ll go. Don’t keep asking.’”

Being treated with respect at school was also a common concern. However, the young women reported encountering attitudinal and architectural barriers to their full participation. A story shared by one participant in early adolescence illustrated these challenges, “I’m in choir and you have to sing in the gym where it’s upstairs. Well, nobody ever said anything to me and I was like, ‘Hey, I am not going, it’s not my job to figure out how to get up there and stuff. They’re the ones that made it up there, they’re the one going to figure it out’. … So I called the principal and I asked if I had to do it since there was no way I could get upstairs, and he’s like ‘It’s not my problem. You should have thought about [it].’ And he hung up on me.”

Being self-sufficient in activities was an important goal for selected participants. One older adolescent summarized her self-advocacy approach by indicating, “If there’s something I want, I go after it—try to get it and don’t let many things stand in my way.”

Subtheme b—peer and adult advocacy—is characterized by the phrase “He’ll stick up for me.” The importance of friends and family in combating discrimination was a consistent theme for some young women. Participants acknowledged support from boyfriends (“He’ll stick up for me and stuff.”) and advocacy from close friends (“I made it through OK because I had friends that took up for me.”). However, not all adolescent women had the advantage of peer advocacy. For some this may have been related to the challenges in establishing peer relationships (Bellin et al., 2007).

Adult advocacy was a more common thread to their stories. Assistance from school administrators, such as guidance counselors, was sought out and mobilized by some participants, “This woman…she was pretty nasty, and I was at school and she was treating me kind of mean…I went to the guidance counselor and told him about it. He talked to her and solved the problem.” Others relied more heavily on family members to address discrimination, “I’d probably tell my mom, and she’d go and complain to the manager, and say, you know, really like how they treated me. I don’t know if I’d have enough courage to do that.” Family advocacy was not always appreciated by the young women, however. Instead, it sometimes attracted unwelcome attention, as illustrated by the story of one participant in early adolescence: “It was a restaurant. My step-mom, she yelled at the manager and told him to fix the bathrooms. I couldn’t get in the bathroom; it was too small…. She does that all the time, and I go over to my dad’s and she’s always doing it. And I’m like, ‘Would you quit embarrassing me?’”

Discussion

One contribution of this study is a better understanding of self-management experiences...
for adolescent women with SB, specifically the SB-related self-management skills and knowledge needed to perform them, the challenges of activities and full participation in society with a condition that involves mobility limitations, and the integrated role of family. The prominence of the daily activities performed to manage SB was consistent with a recent review of the self-management literature (Grey, Knafl, & McCormick, 2006). Unlike some healthcare conditions without a mobility component, the inclusion of advocacy in self-management may be particularly important for these young women to fully participate in society.

However, these data suggest self-management skills are not prominent in every-day life. Self-management does not seem to be the driving force in some of these young women’s lives. For many, it is something that they assume they will grow into. For others, it seems more planned. When asked about a goal that is critical to them, these women described aspirations for school, relationships, or future careers. No response addressed “self-management of their condition.” Although the professional literature speaks frequently about planned increases in responsibility for self-management of chronic conditions (Farrell, Wicks, & Martin, 2004), this concept is not central to the stories of these young women. Perhaps that is because they perceive self-management as a fundamental task and not an external goal. Alternatively, perhaps for some a persistent reliance on their parents to take leadership in this area explains the absence of self-management as a life goal.

Self-management for adolescent women with SB is complex and pervasive in everyday life. Findings illustrated vulnerabilities and barriers to participating in self-management activities. For example, some participants in the study had not had opportunities to manage money, build job skills, or develop autonomy in self-care decisions, sometimes because of their parents’ protection. These findings are consistent with those reported by Davis, Shurtleff, Walker, Seidel, and Duguay (2006), who found adolescents with SB lag 2–5 years behind in acquiring many autonomy skills when compared to typical development schedule of peers. Although overprotection may be viewed as a “normal response to a difficult situation,” it can also potentially undermine the development of self-management skills and independence in youths with complex chronic conditions like SB (Lollar, 1994, p. 19). Fortunately, also observed in the participants’ stories were examples of strategies used by the adolescent women and their families to build self-management strengths through self-care activities, autonomy in decision making, money management opportunities, involvement with social and peer groups, and advocacy support when needed. This qualitative study did not directly address knowledge such as etiology of SB, the impact of SB on bowel and bladder function, or signs and symptoms of shunt infection. A recent study found many young adolescents had a limited understanding of SB and major functional issues common to SB (Greenley et al., 2006). Limited knowledge about SB may contribute to delayed autonomy. The effects of this knowledge deficit need further investigation.

Another essential ingredient for moving the adolescent with SB toward self-management is the developmental concept of shared decision making, in which the adolescent participates in making choices both in context of the home and in the service domain (Cavet & Sloper, 2004). Shier (2001) considered participation in decision making as occurring on a continuum, from listening to and supporting the expression of young people with disabilities to establishing a true partnership in which young people share power and responsibility for decision making. Yet, improving the self-management of youths with disabilities via shared decision making is often hampered by a lack of understanding by patients, families, and healthcare providers of their respective roles and responsibilities in the process of ensuring a step-wise progression toward self-management (Farrell, Wicks, & Martin, 2004).

A primary need, it therefore seems, is a patient- and family-centered intervention program that is geared toward equipping patients, families, and healthcare professionals with the knowledge and skills necessary for shared decision making (Cavet & Sloper, 2004) and, ultimately, self-management competency (Redman, 2005). The need for these family-centered programs is supported by our data from parents (Sawin, Bellin, et al., 2003) as well as adolescents (Roux et al., 2007) who both report connections and interactions with family as particularly central to these adolescent women’s lives. These programs can be developed as adjuncts to individual healthcare visits and can be in a variety of formats (e.g., workshops, camps, online). The emerging evidence (Benz, 2000; Blackorby & Wagner, 1996; Powers et al., 2001; Powers, Sowers, & Stevens, 1995) provides preliminary support for a multicomponent intervention. Length of program, attainment of personal transition goals, mentoring component, consistency of personnel, and focus on employment were all factors associated with positive outcomes in these programs and could be useful when designing self-management programs for youths with SB and their families.

Peer support and peer relationships were also important to some of these adolescent women’s self-management. Although for most participants family was clearly more central to their daily lives than peers, when peers were supportive they had a major effect on self-management. This and other data analyzed by our team (Roux et al., 2007) showcase the lack of

Rehabilitation Nursing • Vol. 34, No. 1 • January/February 2009 33
peer support and relationships for many participants in our study. Clearly, interventions that address self-management within the context of also improving social interaction skills may be particularly useful in this population.

It is interesting that few of the participants discussed increasing responsibility for their relationships with rehabilitation nurses or healthcare providers (HCPs) as a component of self-management. Participants were not directly asked about their relationships with HCPs, so they may have overlooked HCPs as players in self-management. It could be that HCPs are assumed to be such a fundamental part of these young women’s lives that they do not think to address them individually. Or, the HCPs may not be viewed as central to the individual living with SB. A study of transition-age youth with CHCs also reported that HCPs were rarely mentioned as central figures in this transition (Betz, Redcay, & Tan, 2003). However, when parents of “successful young adults with disabilities” were interviewed, common strategies for promoting self-management involved encouraging youths to be responsible for communicating with HCPs and minimizing adult involvement where possible (Luther, 2001). It is troubling that partnerships with HCPs were not visible in participants’ stories. Because of the complex and pervasive demands of self-management, HCPs need to be proactive in initiating negotiations regarding self-management.

The literature offers several suggestions for how rehabilitation nurses and other healthcare professionals may partner with adolescents with SB and their families. For example, a philosophy of care that respects individuals’ needs and responses to the experience of a physical disability, acknowledges cultural influences, provides a holistic approach to care that is based in the social context of the child and family, and enhances overall quality of life is regarded as fostering positive self-management outcomes (Glasgow, Davis, Fun nell, & Beck, 2003). The development and expansion of self-management activities has also been linked to healthcare practices that support self-determination (Koch, Jenkin, & Kralik, 2004), create an atmosphere conducive to learning and engaging youths in identifying self-management strategies that carry meaning for their lives (Kralik, Koch, Price, & Howard, 2004), and provide care in a patient- and family-centered manner (Kennedy & Rogers, 2001).

The data from this study support a definition of self-management for adolescents with SB and other CHCs adapted from Schilling, Grey, and Knaff’s (2002) work with adolescents who have diabetes (bold reflects adaptation).

An active daily and flexible process in which youth and their parents share responsibility and decision making for achieving control of their condition, health and well being through a wide range of activities and skills. The goal of this increasing responsibility is to develop skills needed for transition of adulthood and independent living. (p. 92)

In this study, adolescents with SB reported multiple activities for achieving self-management, including some aimed at reducing the effects of discrimination. The “shared decision making” and the incremental responsibility for self-management, however, is a process that is achieved somewhat later in this population. In addition, healthcare providers seem “invisible” in these adolescents’ reports of self-management experiences.

Implications for Practice
The results of this study indicate that an essential component of health care for these adolescent women should be a comprehensive assessment of self-management knowledge, skills, strengths, goals, and areas that need support as well as an individual or group approach to addressing self-management needs via tailored interventions. To have the optimal knowledge, skills, and competencies to be in charge, these young women need to assume planned incremental responsibility for self-management. The situation is complex and there is often no single solution. For example, some parents may need to perform self-management tasks for their teenagers on busy school mornings to meet the family’s complex scheduling needs. This may be appropriate and important for facilitating daily life in a busy family. However, other strategies then need to be developed to help these young women achieve the skills they need at another time. This may be an area where HCPs are able to proactively identify the problem and negotiate a mutually acceptable plan for family. It is also important that nurses address discrimination and advocacy with youths as they traverse adolescence. Developing advocacy skills is central to dealing with disability in the adult world. Although individual interventions are helpful, partnering with community-based agencies, such as independent-living centers, or transition programs that focus on consumer-driven advocacy, peer counseling, and empowerment of individuals, may be especially effective.

The incremental driver’s license model used in some states is a useful analogy for building self-management skills (Sawin, Bellin, et al., 2003). Initially, young people drive with intense monitoring using a “permit.” Even when teenagers earn a license, limitations are imposed such as driving only during specific times of the day and with few or no passengers to reduce distractions.
Parental monitoring is increased in unusual circumstances (e.g., driving long distances, new routes) or at the first signs of trouble (e.g., tickets, accidents). A similar graduated responsibility plan can be used for shared decision making in self-management. Young women would be expected to set up monitoring and take responsibility for self-management during predictable routine situations but would look to parents in unusual and unpredictable situations. Gradual shift of responsibility can be achieved as more and more complex tasks are successfully managed by the adolescent. It is important that each plan be flexible and allows for limited breaks or time off from responsibility when other demands are overwhelmingly high.

Often in a busy clinical rehabilitation practice or tertiary care setting the recommended comprehensive assessment is omitted, which makes the self-management plan weak and indistinct. At least five tools have been developed to help rehabilitation nurses and other healthcare professionals combat this challenge and take a more systematic approach to many of the components of self-management. These tools can provide the rehabilitation nurse or healthcare professional with critical assessment data in a time-efficient manner. Four of the five tools described in Table 3 are adolescent or parent self-report instruments and can be completed before a healthcare encounter, often in 15–20 minutes. Furthermore, using a systematic tool can increase communication with adolescents and their parents regarding strengths and needs in the area of self-management. These tools have different goals, methods of administration, and specificity, but each offers the team—comprising the adolescent women, family, and rehabilitation nurses—some structure to approach incremental responsibility.

Two of these tools are checklists created to assess skills for a broad range of CHCs. The Autonomy Checklist is a guide for family and providers to use throughout childhood. The Transition Assessment Tool is a more comprehensive scale that focuses on the extent to which the young woman has the knowledge and skills to manage her own self-care needs. There are also two tools that have been developed specifically with a population of individuals with SB. The Kennedy Independence Scales-Spina Bifida Version (KIS-S) is similar to the Transition Assessment Tool and addresses specific knowledge and skills fundamental to self-management. However, the KIS-S is unique because it is based on the assumption that executive functioning deficits (challenges with organization, initiation of activities, problem solving) underlie the child’s problems with self-management. This tool captures the parents’ assessment of the child or teenager’s ability to initiate and maintain activity independently without the parent present. The Adolescent Self-Management and Independence Scale (AMIS II) was developed from our team’s program of research as an outcome instrument to measure the amount of assistance the adolescent or young woman with SB needs in carrying out a self-management activity. The 17-item AMIS is an interview guide rated by HCPs. The procedure for interviewing and rating is similar to the WeeFIM®, a frequently used functional assessment tool for children and adolescents. None of the tools have the individual’s identification of self-management goals as a central component, although each could be adapted to do so.

Study Limitations
Several methodological limitations should be noted. The participants were primarily Caucasian adolescents. More research on the experiences of adolescents from varied ethnic and racial backgrounds is greatly needed. To ensure the development and testing of effective intervention programs, research on the experiences of self-management reflective of diverse adolescent populations with SB is needed. In addition, it is not clear whether the findings in this study of young women with SB are valid for young women with other disabilities or young men with SB. Additional research is needed to delineate the experience of self-management and determine the most effective interventions to foster self-management in the individual with SB and their family.

Conclusion
This study described the self-management experiences of young women with SB. Three themes emerged that encompassed these young women’s experiences in self-managing their condition. The first—opportunities to engage in self-management activities—involved SB-specific knowledge, skills, and aspirations, learning to be independent in daily life, and the need to develop employment or fiscal management skills. The second—dance of individuation—encompassed interactions with parents and shared responsibility for self-management with family. The third—advocacy with self-management—addressed confronting discrimination and stigma. These data indicate that assessment of self-management throughout adolescence and interventions to enhance gradual assumption of self-management by adolescent women with SB may be critical to optimal health care. As Luther (2001) suggests, failure to address this issue sends a subtle message that the child will not be able to care for him or herself, nor transfer to adult healthcare providers. Such low expectations are barriers to effective transition to adulthood. Several reliable and valid assessment tools can help rehabilitation nurses and clinicians assess self-management needs and develop tailored interventions to address the unique needs of the individual and family.
### Table 3. Assessment Tools for Measuring Self-Management

<table>
<thead>
<tr>
<th>Name of Instrument</th>
<th>Purpose</th>
<th>What It Measures</th>
<th>Reliability Validity Data</th>
<th>Comments</th>
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<tbody>
<tr>
<td><strong>General Checklist/Instruments</strong></td>
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<tr>
<td>Adolescent Autonomy Checklist (<a href="http://depts.washington.edu/healthtr/Checklists/intro.htm">http://depts.washington.edu/healthtr/Checklists/intro.htm</a>)</td>
<td>A general self-assessment checklist that allows adolescent/family/HCPs to check off the skills for which the adolescent has achieved independence. Individual indicates if they “can already do,” “need practice,” “plan to start,” or “have accomplished.” Skills at home are broken down into five subscales, such as kitchen, laundry, and housekeeping.</td>
<td>Skills at home (30*) Healthcare skills (17*) Community skills (12*) Leisure time skills (13*) Skills for the future (18*)</td>
<td>None, although widely used.</td>
<td>These checklists were developed by the Youth In Transition Project (1984–1987) at the University of Washington Division of Adolescent Medicine.</td>
</tr>
<tr>
<td>California Healthy and Ready to Work Transition Assessment Tool (Betz, Redcay, &amp; Tan, 2003)</td>
<td>A 72-item, self-reported instrument that measures skills of transition-age youth and managed healthcare needs.</td>
<td>13 domains  - Knowledge of healthcare condition management  - Preventive health care  - Monitor healthcare condition  - Track health records  - Manages special healthcare needs  - Communicate effectively  - Obtain information and reproductive counseling  - Responsible sexual activity  - Knowledge of emergency  - Understanding need for accommodations  - Knowledge of legal rights  - Use transportation safely</td>
<td>Data available from pilot study; 7 of the 14 scales had Kuder-Richardson greater than .78.</td>
<td>Uses a yes/no or with-assistance format. Data obtained routinely as a part of intake into a transition project.</td>
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<tr>
<td><strong>Spina Bifida–Specific Self-Management Assessment Tools</strong></td>
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<tr>
<td>Kennedy Independence Scales-Spina Bifida Version (KIS-S; Zabel, Ries, Mahone, Demetrides, Levey, &amp; Kinsman, 2003)</td>
<td>A parent-report rating scale of adaptive functioning in adolescents with SB. Breaks down tasks to identify whether there are problems with specific areas. The focus is on the impact of executive function on independence. The instructions tell parents to “imagine that your adolescent is home alone by himself or herself for the entire day. Please think about these questions and rate how well he or she would do without reminders or prompts from you.”</td>
<td>Three domains  - Medical (e.g., catheterization, bowel programs, self-inspection, medical communication)  - Educational/prevocational (e.g., getting up on time, scheduling appointments, arranging transportation)  - Community (e.g., maintaining social contact, personal hygiene)</td>
<td>Psychometric analysis currently underway.</td>
<td>The items address the adolescent’s ability to initiate and correctly complete specific tasks. Development of the KIS-S was undertaken to examine the potential relationship between executive and adaptive functioning in adolescents and young adults with SB.</td>
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</table>
### Table 3. Assessment Tools for Measuring Self-Management (continued)

<table>
<thead>
<tr>
<th>Name of Instrument</th>
<th>Purpose</th>
<th>What It Measures</th>
<th>Reliability Validity Data</th>
<th>Comments</th>
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<tr>
<td>AMIS II</td>
<td>Interview (of adolescent or parent) conducted by healthcare providers to identify how much assistance the adolescent needs in 17 core areas. Although the instrument was created to be used with teenagers who have a wide variety of chronic health conditions, to date it has only been used with teens that have SB.</td>
<td>This is an outcomes measure that documents the amount of assistance needed on 17 items such as medication management, ordering supplies, making appointments, preventing complications, advocacy, access, transportation, household, and community-living skills.</td>
<td>Used in pilot and current study of teenagers with SB. Cronbach alpha .91.</td>
<td>Scored on a 1–7 scale (7 = no assistance needed in area of specific item/skill and 1 = total assistance needed).</td>
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<tr>
<td>SB Needs Questionnaire</td>
<td>92-item, self-report questionnaire that measures individual's and family's needs for services in eight domains.</td>
<td>Domains include • transportation • finances and expenses • medical • communication • family • vocational rehabilitation.</td>
<td>Instrument has been used several times and reported in literature. Reliabilities differ by subscale. Very detailed assessment of needs the individual or family may have.</td>
<td>Needs measured on 1–7 scale. Includes items that address individual needs (e.g., clinics at convenient time) and system (e.g., vocational rehabilitation services).</td>
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### References


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