The Many Layers of Social Support: Capturing the Voices of Young People with Spina Bifida and Their Parents

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Young people with physical disabilities experience greater difficulty than their able-bodied peers in many psychosocial domains as they transition toward adulthood. However, firsthand knowledge of the dimensions of social support that young people with physical disabilities find useful during this stage is lacking. This qualitative study involved 50 participants (21 youths with spina bifida and 29 parents) and focused on gaining an insider's perspective on the nature of social support. Building on the work of LaGreca, themes were mapped into four broad support domains: tangible, information, companionship/belonging/mutuality, and emotional. This research indicates that parents provide substantial all-purpose support in each of the four domains. A second major finding shows that support from peers and friends follows a unique and varied path with distinctive characteristics related to the realities of living with a disability. Implications for social work practice with targeted populations and systems are considered.

KEY WORDS: *physical disability; psychosocial; social support; spina bifida; youths*

Social support is an umbrella term, encompassing various types of support and processes, which need to be more precisely defined (King, Willoughby, Specht, & Brown 2006). Indeed, Ryff and Singer (2000) stated that social support is a broad category of protective factors that deal with social relationships and ties to others. Furthermore, King et al. (2006) asserted that social support is a crucial element affecting how individuals adapt to adversity. Given that social support serves as a buffer against many sources of stress and marginalization in adults (Alloway & Bebbington, 1987), it is important to look closely at social support from the perspectives of both youths living with a disability and their parents to determine what more can be learned to bolster social functioning, independence, and community participation. The social model of disability asserts that the hardships experienced by people with disabilities emerge from stigma, marginalization, and the absence of subtle and overt personal and societal support rather than from physical differences (Barnes, 2000; Oliver, 1996; Tregaskis, 2002). As such, this model provides further impetus to explore the nature of social support from the unique perspectives of youths and their parents. Understanding more about the nature of social support provides a foundation for clinical interventions that effectively serve youths living with physical disabilities and their families.

BACKGROUND

The nature and impact of social support networks on children and youths with chronic health conditions and disabilities has recently received considerable attention in the empirical literature (Edwards, Patrick, & Topolski, 2003; Emond & Eaton, 2004; Farmer, Marien, Clark, Sherman, & Selva, 2004; Kieckhefer & Trahms, 2000; von Weiss et al., 2002). King et al. (2006) noted that at different life transition points, individuals need different types of support, which could include emotional support—being accepted, valued, and believed in—and instrumental support—guidance, strategies, and cognitive or information support.

Barrera (1986) offered a useful conceptualization of social support organized into three broad categories: *social embeddedness*: having connections to significant others, frequently measured by social networks; *perceived social support*: perceptions of the availability and adequacy of supportive ties; and *enacted support*: actions of others in actually offering assistance. LaGreca (1990, 1992; LaGreca, Bearman, & Moore, 2002), in research on the relationship between social support and the health of adolescents with diabetes

mellitus, offered refinements that are relevant to young people with chronic health conditions such as spina bifida. She described four major categories of social support: (1) *tangible or instrumental support*, which involves practical assistance (equivalent to Barrera's, 1986, enacted support); (2) *information support*, which includes providing condition-specific information in a neutral or positive manner; (3) *companionship,/belonging/mutuality*, which while closely allied with Barrera's social embeddedness, also highlights the reciprocal nature of the inter-action, with appropriate accommodations for the person's medical condition; and (4) *emotional support/self-esteem enhancing support*, which, while related to Barrera's perceived support, focuses on actions that give encouragement in relation to a health condition and not treating the person differently because of the condition. Furthermore, LaGreca's (1990, 1992) research determined that the types of support offered by family and friends differed. Family members offered more tangible support, and friends offered more companionship support. Although both family and friends provided emotional support, the nature of this emotional support varied.

Groundbreaking work by Wallander and Varni (1989) highlighted the importance of social support from both parents and peers as protective factors in overall adjustment. Antle (2004) further found that parents are a vital source of support for young people with physical disabilities, and they will likely have a longer-than-average commitment to supporting their child with a disability.

Young people with physical disabilities tend to have smaller social networks than their able-bodied peers (Varni & Wallander, 1988). Among children generally, research indicates that having opportunities to play and to be in contact with other children is an important dimension of friendship formation for children and preteens (LaGreca, 1990). Young people with physical disabilities often face pragmatic barriers to friendship formation, such as difficulties accessing the homes of potential friends, losing contact through either lengthy or repeated hospitalizations, and having more limited time after school due to special transportation arrangements or the need to take part in various therapies.

METHOD

Sample and Recruitment

This is a follow-up study to previously conducted research investigating the correlates of self-esteem in children, youths and young adults with spina bifida or spinal cord injury (Antle, 2004). The sample of young people with spina bifida for the original study was drawn randomly from a large children's rehabilitation facility in a Canadian urban center. The sample for the follow-up study was composed of participants from the original research who agreed to take part in an interview or focus group at a later date. A total of 50 people took part in this current study, 21 young people with spina bifida from nine to 15 years of age and 29 parents, mostly mothers. Two ethics review boards approved this study, and there were no adverse events reported.

Data Collection

In-depth qualitative interviews were conducted with a purposive subsample of young people ($n = 10$) living with spina bifida between the ages of nine and 15 years and their parents ($n = 14$), who consisted primarily of mothers ($n = 10$). There was an even split of boys and girls. Interviews were conducted by a social worker trained in qualitative interviewing in a location chosen by the participants. Parents and young people were interviewed separately on the same day. A semistructured guide was developed for both the individual interviews and the focus groups. The questions were designed to explore the dimensions of support as defined in the literature, synthesizing the work of LaGreca (1990) and Barrera (1986).

Following analysis of the individual interviews, two focus groups were conducted involving different young people living with spina bifida and their parents from the same subsample. These groups were used to further confirm the findings from the individual interviews, to increase reliability and validity of the study through member checking, and to enhance data richness. The parents' group ($n = 15$) again involved mothers primarily, as it consisted of 11 mothers, three fathers, and one grandmother. The young people's group ($n = 11$) was comparable in age and gender split to the young people who participated in the qualitative interviews. The authors facilitated these groups.

Data Analysis

All individual interviews were transcribed verbatim and coded in keeping with the long interview method (McCracken, 1988), which is consistent with prevailing qualitative data analysis standards (Creswell, 1998; Strauss & Corbin, 1990). To enhance

data analysis, the transcribed data were introduced into NUD★ISTVIVO, a computer software program designed to facilitate the analysis of textual data. Throughout this study, careful attention was given to excellence and authenticity of the research process by using recognized techniques for validation and trustworthiness in qualitative research (Creswell, 1998; Erlandson, Harris, Skipper, & Allen, 1993). These techniques are detailed in Table 1.

RESULTS

The four support domains outlined by LaGreca (1992) provided a framework for the data that emerged from the individual interviews and focus groups. The emerging themes centered on the types and importance of social support received and pro-vided. Also included were participants' perceptions and experiences of living with spina bifida.

Tangible Support

Mothers were identified as a central source of tangible support, followed by fathers, siblings, and other members of the extended family. It was noted that when young people spoke about their parents, their mother was frequently mentioned first. For example, in answer to the question, "How do you usually get from place to place?", most indicated "my mom or my dad." Sometimes "my mom" alone was identified, but very rarely "my dad"

alone. When a father's help was described, it was most often in relation to a recreational activity—for example, going to a hockey game, going to the beach, or teaching guitar. Tangible support included all tasks that many parents perform on a daily basis for their children, such as making sure they get up on time, ensuring that they have the kind of clothes they need, and facilitating their involvement in recreational activities. It is interesting to note that the youths perceived that they received a minimal level of tangible support. For example, when one youth was asked if he needed help, his response was "a little bit." Further questioning revealed that it was necessary for his parents to help him with dressing and his braces. When asked who might help if the parents were unable to provide support, the youth indicated that there was no one else and that such a situation had never happened. Most parents stated that they would not be comfortable having others meet their child's special needs.

Another type of specialized tangible support related to tracking and cuing. Parents, particularly mothers, often expanded tracking to include the need to cue the young person and encourage him or her to follow through on an activity:

> Well if I don't prompt him to do stuff, he'll just basically be on the computer or just you know, some nights he'll just watch TV. And you want

Table 1: Criteria for Trustworthiness

Criterion	Qualitative Term	Techniques for This Project
Truth value	Credibility	*Triangulation:* Analyzing data from different sources—in this instance, from young people and parents and in individual interviews and group sessions
Applicability	Transferability	*Purposive sampling:* A method of recruiting participants on the basis of a common characteristic—in this instance, young people living with spina bifida, ages nine to 15 years (gender being equally represented), and their parents.
		Reflexive journal: Extensive field notes by the research assistant following interviews and focus groups
Consistency	Dependability	*Audit trail:* Minutes from co-investigators' meetings, field notes, and final report
		Reflexive journal: Extensive field notes by the research assistant and co-investigators following interviews and focus groups
Neutrality	Confirmability	*Peer review:* Findings from the interviews were brought back to focus groups. Participants were offered a copy of their interview transcript if they wished.
		Audit Trail: Minutes from co-investigators' meetings, field notes, and final report

him to get up and do something, you know, move about more.

Parents were particularly careful to make sure their child did not experience any disadvantage. The following quote highlights the depth of attention to detail embodied in the nature of tangible support offered to children:

Like he wears clothes that all his friends are wearing. Um, it makes it extra work for myself, makes it extra work for [him], but he feels happy and accepted and comfortable.

The youths also recognized that tracking and cuing was provided in several different areas of life. Many indicated that they would mostly call a friend only when reminded and prompted by their parent; others indicated that they were given assistance in meeting deadlines and staying on schedule:

Well, on school days if I do get up late like around eight or seven-thirty, she [the mother] would usually drag me out of bed and she would get me dressed and say, "Get into your wheelchair."

Personal hygiene support is another unique need of youths living with spina bifida. Parents demonstrated awareness that underlying their concern was the need not only to ensure social acceptance, but also to monitor the present and future health of their child:

I would usually make sure that he has gone to the bathroom before he leaves. . . . Uh, I usually have to remind him he always has to take his bag, his bag with him that has his [incontinence] supplies in it. Which he will forget it if you don't remind him and even if you do remind him he forgets or leaves it behind and then he'll run into problems.

In the following quote, a mother talks about her son's bowel routine and how they juggle this routine with his social life. Notably, he is offered the choice to skip this routine and "live with the consequences":

So he knows if he's gonna choose to miss it, there's a party or something he wants to go to

and I tell him, you know, you might be sick and he knows that's a consequence so, that hasn't really happened though, we've been lucky. If he has a friend over, the friend has to leave at least like four o'clock, so that he's not up till three in the morning on the toilet. So we sort of plan around it.

Parents highlighted concerns about the need to maintain privacy around bathroom routines and the challenges and stressors these routines present. In addition, many parents noted that their children demonstrated a general lack of awareness about personal hygiene—such as noticing odors—and that as their children became older, there was increasing resistance to taking medications. As parents prepared their teenage children to be more independent, they indicated concern for obvious increased health risks related to monitoring bowel and bladder function, tissue trauma, and nutrition, as they could not be sure that their teenagers would follow proper health routines.

Adhering to bowel and bladder routines was highlighted by parents as a major concern as their teenager became older. Very little was said in this area by the youths who were interviewed. Only two teenagers mentioned that they needed help "changing"—one while at school (assisted by a nurse), the other while at home (assisted by a parent). However, changing was not clearly defined, and follow-up questioning yielded no more information.

Parents provided tangible support to a significant degree. Most parents stated that they did not do anything extra or special for their children with spina bifida; however, it was notable how much parents altered their lifestyle to meet their child's special needs:

And he sleeps over at friends a lot. And what we do is, 'cause he has to be catheterized we usually just go over and catheterize him 'cause he can't do it himself and uh, overnight like we'll send him over and uh, we'll go over, catheterize him there, or bring him home, and in the morning it has to be the same thing. If he's going to be there in the day, obviously we have to go again. Sometimes, sometimes he'll be gone almost the whole weekend, at different times I have to see him to change him, and then the next weekend his friend's here the whole time. You know.

       *   *   *

[Our child] goes on the handicap bus and we drive the other kids to school. Um, then I go to school some days of the week to help out. Other days I drop off the other guys and then don't go back until lunch … we bring [child] his warm lunch 'cause he'd rather bring his lunch to school 'cause he'd like to stay and play with his friends, so I bring [him] warm lunch 'cause he doesn't eat very well.

Another mother and father mentioned that their son needed help not only with activities of daily living, including catheterization and dressing, but also with mobility around the house:

Mother: Well in our house, yeah, we lift him and lug him to go up and down the stairs . . .
    Father: [Our house is] seventy-five, eighty percent adapted for him. . . . You know, so, we still do a lot of things for him, by way of carrying him and getting things [for him].
    Mother: He uh, I don't think we do very much for him really um, like yeah besides like dressing him. . . . You know if there's something he can't get he'll just ask . . .
    Interviewer: Uh what happens if uh you're sick or away?
    Mother: If you're sick you have do it anyway!

Although the majority of tangible support is offered by parents, some parents noted that their child's friends would help in areas such as transferring out of a chair or organizing books at school:

He has [a friend who] sits beside him at school. He'll help him pack his knapsack, which has all his homework. Because the knapsack's on the back of his wheelchair it's, obviously he needs somebody's help. So [the friend] does that.

Information Support

When the youths were asked to whom they spoke about a health concern, most indicated that they would talk to their mother. Some said they would talk to their mother first, and then their mother would make an appointment with a doctor if warranted. As one mother commented:

If he's in here at home, he'll ask me. Sometimes he'll ask me a question, I'll say, well you need to talk to the doctor, ask the doctor about that so you know, I will try to remind 'cause he won't remember that he has asked that question.

Almost half of the parents talked about the need to advocate on behalf of their child, particularly with doctors, and to question recommendations for treatment:

Mother: Nobody has a cut and dry route for anyone to take and if I was talking to other parents, the first thing I'd say is go with your instincts; if you're taking your child to a doctor that you don't think [the doctor] is giving you the correct answers, leave.
    Father: Or at least get a second opinion.

Companionship Support/ Belonging/Mutuality

Generally, youth participants had friendships and experienced companionship support from both family and friends. All could name at least one close friend, and for the most part those friends were from their own age group. In some instances, parents noted that their child preferred to play with younger children, sometimes for convenience (for example, owing to the configuration and demographics of the neighborhood) and other times because it was easier for the youth to fit in. Some youths also indicated paid helpers as friends. Almost all youth participants identified an adult family member or sibling as a part of their friendship network. All parents described special activities that they did as a family that were a source of companionship for their child.

Many of the youth participants reported meeting their friends primarily at school; however, the school setting also presented challenging relationships:

Some people I knew from elementary school and others I just met waiting at the bus stop and some of them are in my classes this year, so we started talking and we became friends.

       *   *   *
You know it's funny because at school he is so well liked you know I mean, one kid would say, "Oh well, [name] can't play Manhunt, he's in a wheelchair."

       *   *   *
I don't have too many friends in my school. I like my friends here [in her neighborhood]. I don't make friends easily.

In addition, parents highlighted the need for school professionals to be more sensitive to the needs of young people with disabilities so that the responses and actions of teachers can better facilitate companionship for all students.

Emotional Support

Parents are clearly a prominent source of emotional support. Parents demonstrated great effort to help their children feel positive about themselves and to develop a good quality of life. Youths themselves also recognized the unique impact of having a visible physical disability and the subsequent emotional needs related to this issue. Four subthemes emerged as important dimensions of emotional support:

1. Celebrating Successes. Parents appreciate that providing recognition and attention for success builds self-confidence and enhances the parent–child relationship:

> I just think you can just show them a lot of love and attention; I think it helps any child even if there isn't any disability. I think just positive input from the parents as much as you can be . . . but communication's really important, just open communication.
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> * * *
>
> Well, lots of praise and encouragement. "Wow! You got an 80 on that test!" And just be proud of him. Putting it up on the fridge for everyone to see. And, and as the teenagers come in: "Wow! Look at what [participant] got on his project!" So as they'll say, "Wow! Way to go!"

2. Challenging Limits. Parents understand that encouraging their children to try new and different activities helps them to gain valuable awareness of their own capabilities:

> I would pay attention to them. Um, I spend time with them. Let them have a good time. Don't really restrict them to things that won't, like, try to get them to their limits.
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> * * *
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> Well just the constant part of reinforcement that they can do anything if they try. And I mean sometimes things don't turn out the way you want them to be, but if you try to get them at least trying, it makes them feel good about themselves to try it.

A significant component within this theme is parents' recognition of the importance of allowing their child to struggle and persist:

> Don't do so much for them all the time . . . even though it would break our hearts sometimes to watch her struggle. I mean, today we are like you know glad that we [did]. . . . I watch her struggle and struggle and I just want to go put that sock on. But you can't go put the sock on because, you know, I am not going to be there every morning to put her socks on.
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> * * *
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> You know, he'll um, he's not a very strong swimmer . . . he'll swim underwater more so than up. Gosh, you got a couple of more strokes in there, you're going to reach it.

The youths themselves identified the need to feel challenged, as shown in the following exchange:

> *Youth:* Yes, I like to get challenged.
> *Interviewer:* What does challenging mean to you?
> *Youth:* Like not too hard, but like hard enough.

3. Treating the Young Person Like Everyone Else. Parents inspire a sense of equality and self–worth in their children by showing them that they have the same rights as their peers:

> And, you know, just being to her what I am like to my other daughter . . . treat them equally. You have to treat them equally. You can't do for one what you don't do for the other.
>
> * * *
>
> I think he needs to know that he's the same.

The youths spoke of the importance of being treated like everyone else, as shown in the following exchange on friendship:

> *Interviewer:* What is it that [your friend] does that works so well to make you feel good?
> *Youth:* Uh, she treats me like a normal kid.
> *Interviewer:* She treats you like a normal kid. What does that mean?
> *Youth:* Uh, I don't know, she does things with me like she does with other people.

Further, a parent reported her perceptions of how her son's friends treat him:

I think because they understand things that he's been through and they don't sort of treat him special, they don't look at him and say, "Oh poor [child]," you know, they aren't feeling sorry for him. They accept him for who he is.

4. Parental Vigilance Regarding Child's Emotional Needs. Parents, particularly mothers, tracked their child's mood, degree of socialization, and health needs. The following quote captures the subtleties of this tracking and, in doing so, how well positioned the parent is to provide the emotional support:

I don't know how to explain how a mother can read, tell his eyes, but there's just something in his face, its expression and I just know when there's something wrong, it's just a feeling I get, it's a mum, just a mother's instinct, so the two of us will just go out and that's just when he'll just start talking to me.

Perceptions and Experiences of Youths and Parents Living with Spina Bifida

The journey toward acceptance of their disability, as reported by the youth participants, had moments of sadness, yearning, and reconciliation:

Sometimes, oh, I feel, I don't feel sad, it's just feels different when I see people running and like, I don't know like skipping or whatever and like I'm, when I was younger I used to miss that, yes, but now as I'm older it's just like okay, they can do that, I can't so it doesn't bother me anymore. I guess when I was younger I just couldn't understand why I couldn't do that, but I'm okay now.

Furthermore, the emotional need for youths to appear visibly the same as their peers was foremost on the minds of the youths and their parents:

Youth: Well, when I'm in the water, then it doesn't even look like I'm supposed to be in a wheelchair. It looks like I'm supposed to be up and walking by myself, running around, playing with my friends.
Father: It's like her swimming . . . one spot [where] she's er, the same as the rest of us.

Mother: [She] can get into the swimming pool and walk.
Father: [Our child] in a pool you wouldn't know . . .
Mother: . . .was disabled
Father: . . . that she was disabled. And [our child] on the snowmobile, when she's got the handlebars in her hands and I'm sitting behind her, she's driving the snowmobile. . . . When the snowmobile comes to a stop and we have to go get the truck then it turns into a problem.
Interviewer: What problem?
Father: Well she can't walk over to the truck and get in. I have to pick her up and either put her on a toboggan and drag her, she's getting bigger.

Although most of the youths indicated that they would speak to their mother if they had concerns, a few of the participants reported that they would also speak with a friend. Feeling a sense of belonging and mutuality occurred when the youths were able to share information about their health condition:

And I told her what I had and she understood. She had some questions but I, she understood what I was saying, so I can trust her that she won't tell anybody if I told her something. When I was born I had a sac on my back and em I didn't, I had to get it removed and now I just have a scar on my back.

DISCUSSION

Unlike the findings by LaGreca (1992), which highlighted differential support roles for parents (tangible, information) and peers (companionship, emotional), parents, particularly mothers, were found to be the most important source of support across all four domains for young people with spina bifida. Parents were found to be especially instrumental in providing the following: tangible support, such as tracking and cuing important daily health-related activities; information support, such as imparting health-related knowledge; advocacy for both in-formation and services; and support of their child's emotional well-being and sense of self.

Moreover, parents went to extraordinary lengths to support their children with special needs and to ensure they had as many opportunities as possible. Indeed, it was important to parents that their child be included and challenged and feel that he or she

was being treated "just like anyone else." However, parents perceived their efforts as being nothing special or different. This apparent contradiction was observed by Robinson (1993), who noted that family members came to normalize the health routine of a family member with a disability, such that even extraordinary efforts were seen as just something that all parents do. Given that physical impairments may require extra physical effort and time, extensive accommodations or modifications, and (at times) an essential need to be treated differently, normalization is not an easy task for parents.

Parents commented on being uncomfortable allowing informal support systems (extended family and friends) meet their child's disability-specific needs and that, therefore, the onus was completely on them to provide for their child's needs. Parents minimized the support they provided, and the youths minimized the support they received. This finding is in keeping with the youths' expressed desire to feel "just like anyone else" and with the parents' ability to offer support in a way that does not leave their child feeling diminished (Antle et al., 1999).

Companionship support, including belonging and mutuality with peers and friends, was found to follow a unique and varied path for adolescents with spina bifida. Friendship varied widely by definition of who constituted a friend, the ages of such friends, and the inclusion of paid helpers. In addition, friendships involved negotiating, accommodating, and managing accessibility and other challenges of the disability. These challenges may limit, in comparison to the experiences of peers, the range and depth of experiences of having close friends. Furthermore, school as a place of belonging and friendships was met with mixed reactions from the participants. Unlike the findings of LaGreca (1992), tangible support from peers, such as transferring youths from their wheelchair and organizing their books, was present and seen as helpful. As found by LaGreca (1992), peers also provided companionship support, belonging, and mutuality. Youths reported that simply feeling able to share health information with a friend or having assistance with a knapsack served a positive and protective function that contributed to their emotional well-being. Both the youths and their parents clearly stated that a mutual goal was to be accepted by peers and to appear to be no different from them. The participating youths spoke warmly about activities (for example, swimming) that closed the gap between disability and ability. At the same time, participants and their parents indicated that the process of emotionally accommodating to and accepting their disability was aided immeasurably by recognition and acceptance by peers, friends, and society at large. This phenomenon fits with the social model of disability (Barnes, 2000; Beaulaurier & Taylor, 2001), which emphasizes the compelling influence of sociocultural norms on the physical, emotional, and cognitive lived experience of people with disabilities and their families.

IMPLICATIONS FOR SOCIAL WORK PRACTICE

The findings of parents celebrating successes, challenging limits, and treating their child like everyone else supports a strengths-based approach (Saleebey, 1996) and, particularly, underscores the importance of a family-centered model of practice in pediatric rehabilitation (King, King, Rosenbaum, & Goffin, 1999; King et al., 2002). Furthermore, the intensity and enduring nature of the role that parents play in supporting young people with physical disabilities has been clearly demonstrated. Social workers can play a crucial role in gradually shifting the onus from parents as being solely responsible for and responsive to their children to a more interdependent model. This perspective is informed by the shared management model offered by Keickhefer (Kieckhefer & Trahms, 2000). In this model, there is a gradual progression from shared management, with parents as decision makers, to a more interdependent management model with youths sharing in decision making. Optimally, as youths transition into adulthood, they take on an increasing decision-making role. Recognizing the need for shared management of disability-related issues is vital to managing transitions for youths with disabilities, and it may foster a better fit between professional standards and goals in relation to client and family realities, values, and preferences.

The finding that parents are intensely involved in supporting their children may raise professional concerns about overprotectiveness (Holmbeck et al., 2002) and independence. However, the label of "overprotectiveness" needs to be revisited in light of medical requirements, sociocultural realities, and emerging evidence of the helpful role that parents play in contributing to their child's sense of self and well-being (Antle, 2004; Antle et al., 1999). As key members of an interdisciplinary health care team, social workers can facilitate team dialogue

to meaningfully address the potentially conflicting professional goals related to best practice, which are often based in normative Western standards, with client and family preferences, which are often based in practical realities and potentially life-threatening health consequences. What appears as overprotectiveness may be viewed, in light of these present findings, as essential support in dealing with extraordinary medical needs and societal barriers.

Furthermore, in applying the social model of disability (Barnes, 2000; Beaulaurier & Taylor, 2001), social workers, as cultural agents of change, need to initiate strategies within the broader community to counteract social stigma and the prevailing negative stereotypes of living with a disability. These findings underscore the fact that more work is needed to eliminate attitudinal, physical, and practical obstacles to the facilitation of social interactions outside the home.

CONCLUSION

This article contributes firsthand knowledge from the perspective of youth with spina bifida and their parents regarding significant dimensions of social support. Parents provided extensive and intensive support in all four support domains. The voices of the youth participants and their parents were also clear in illustrating that companionship/belonging/mutuality follows a unique and varied path for adolescents with spina bifida. Youth and parents shared valuable insights into the challenges of daily life and emphasized the importance of recognition and acceptance by peers and society at large. Awareness of the complexity and importance of social support enhances the ability of the health care team to more effectively support the healthy development and social adaptation of young people with physical disabilities. Social workers have reason to use an interdependent shared model of health care and to promote the social model of disability to increase participation, independence, and societal acceptance of youth with physical disabilities. **HSW**

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