A Qualitative Synthesis of Adolescents' Experiences of Living With Spina Bifida

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Abstract

In this article, I explore the experiences and perspectives of youth living with spina bifida, the second most common congenital condition in North America, to inform the development of health programs. I undertook a thematic metasynthesis to integrate qualitative evidence across studies examining the experiences of youth with spina bifida. I used 10 electronic databases to search for and review 4,051 abstracts, and identified 12 articles meeting the inclusion criteria. I examined those articles using a constant comparative approach, drawing on concepts of normalcy and biographical disruption to inform understanding of three emergent themes: (a) the medical management of spina bifida; (b) the importance of peer and family relationships (i.e., social support, belonging, and challenges in peer connections); and (c) identity and self-concept (i.e., normalization). This metasynthesis provides insight for youth, parents, and clinicians on areas of life in which youth could use further support.

Keywords

adolescents / youth; biographical analysis; disability / disabled persons; metasynthesis; self-care

Spina bifida, a birth defect that occurs in the first month of pregnancy (Sandler, 2004), is the second most common congenital condition in North America, and occurs in 20 out of 10,000 live births (Centers for Disease Control and Prevention, 2009). In spina bifida, the spinal column fails to develop properly, resulting in permanent damage to the spinal cord and nervous system (Bowman, McLone, Grant, Tomita, & Ito, 2001). It is a life-long complex condition that requires ongoing medical attention, including attention to functional mobility and cognition, neurosurgical issues, shunt malfunction, skin integrity, weight management, respiratory concerns, urologic and bowel concerns, orthotic and seating needs, and chronic pain (Bowman et al., 2001). Although research on the experiences of youth with spina bifida has increased, there has been little synthesis of its findings. Given that spina bifida is a complex congenital abnormality with long-term survival (Bowman et al.; Davis et al., 2005), understanding the experiences of youth with spina bifida is critical.

Among youth with spina bifida, there are several important medical and psychological issues that can arise during adolescence (Sandler, 2004). Youth with spina bifida face significant challenges to adaptation (Buran, Sawin, Brei, & Fastenau, 2004), which can affect their psychological and social well-being. They are at risk of maladjustment because of difficulties in self-management skills (Sawin, Bellin, & Roux, 2009); difficulties in problem solving and social skills (Simeonsson, Huntington, McMillen, Halperin, & Swann, 1997); and school challenges, discrimination, and delayed transition to independence (Bellin, Sawin, Roux, Buran, & Brei, 2007; Sawin et al., 2009). The unpredictable nature of the condition, along with the shifting of responsibility for care from parents to youth, can make it challenging for youth with spina bifida to maintain "personal and social normalcy" (Williams, Cortlett, Dowell, Coyle, & Mukhopadhyay, 2009, p. 1443).

Most research on young people with spina bifida focuses on the perspectives of health care providers or parents, and little is known about the perspectives of youth themselves. Researchers need to develop a better understanding of the experiences and perspectives of youth with spina bifida to better inform health and social programs, particularly those that target the transition of youth to adulthood. Adolescence is a critical period characterized by biological, psychological, and social changes in development (Kelly, Zebracki, Holmbeck, &

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Gershenson, 2008); as such, it is an important stage in the formation of health-related behaviors. Such changes in adolescence could be particularly challenging for youth with a disability when they are forming their identity and becoming more independent (Kelly et al., 2008). Poor adjustment during adolescence can lead to exaggerated vulnerability, such as unemployment and dependence, later on (Sandler, 2004).

Researchers are increasingly recognizing the importance of exploring the experiences of youth with illness and disability (Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012; Mayall, 2004); however, there remains a need for a more systematic approach to synthesizing qualitative studies to enhance the generalizability of results and identify implications for practice (Kramer et al., 2012). By integrating the findings of multiple qualitative studies, investigators can help to broaden our knowledge, uncover patterns within specific topics, identify common themes across studies, and provide deeper insight that might not be available from a single study (Erwin, Brotherson, & Summers, 2011); highlight a range of experiences and perspectives of youth living with illness and disability in different contexts (Tong, Jones, & Singh-Grewal 2012; Tong, Morton, Howard, & Craig, 2009); and enhance our understanding of evidence-based practices (Erwin et al., 2011). Such qualitative research can contribute to the appropriateness of health care (Grypdonck, 2006). Metasyntheses can also help investigators address the underuse of qualitative research (Sandelowski & Barroso, 2007) and identify gaps in research (Major & Savin-Baden, 2010).

Theoretical Approach

In this analysis, I drew on the concepts of "biographical disruption" (Bury, 1982, p. 167) and "normalization" (Williams et al., 2009, p. 1443) to guide my understanding of emergent themes. In this context, biography refers to self-concept that evolves over time; it is linked with social contexts or bodily functions which interact to give structure and continuity in a biographical time line (Bury; Wiener & Kayser-Jones, 1990). Having a chronic illness or disability can lead to biographical disruption (Bury), which leads one to readjusting one's biography. Each person's illness trajectory is different and influenced by many factors (e.g., medical, social, psychological, economical, biographical; Lindsay, 2009; Wiener & Kayser-Jones).

In relation to young people with chronic illness, the concept of normalization refers to the ways in which a person copes with his or her condition, both personally (i.e., "personal normality," which refers to one's hopes and expectations) and socially (i.e., "social normality," which refers to the expectations of others; Williams et al., 2009). An important aspect of normalization is "nondifference" and acceptance by peers and friends (Williams et al., 2009). In this article, I explore how normalcy is both threatened and maintained among youth with spina bifida, as well as how their biographies are disrupted and revised. To inform my discussion, I use four key attributes of normalization as outlined by Knafl and Deatrick (1986; see also Williams et al.): (a) defining family life as normal; (b) acknowledging the existence of the condition; (c) defining the social consequences of the condition as minimal; and (d) engaging in behaviors to demonstrate normalcy to others.

Methods

Qualitative research is important because it helps investigators develop a better understanding of social phenomena by exploring a range of in-depth meanings, experiences, and views of participants (Tong et al., 2009). The purpose of this article is to synthesize and critically interrogate the qualitative research on adolescents' perspectives of living with spina bifida.

Search Strategy

With the assistance of a hospital librarian, I searched the following databases for relevant articles: CINAHL, MEDLINE (OVID), Healthstar, PubMed, EMBASE, Web of Science, PsychInfo, Social Science Citation Index, Scopus, and Google Scholar. In my search strategy, I used the following subject headings and search terms: spina bifida or myelomeningocele or meningocele or hydrocephalus; and illness experience or psychological or sociological concepts (i.e., lived experience, coping, adaptation, stress, depression, mental health, satisfaction, social support, interpersonal relations, family, self-management, quality of life); and qualitative research or interview or focus group or phenomenology or grounded theory or hermeneutics. I also searched the reference lists of selected articles.

With the help of a research assistant, I reviewed the titles and abstracts of relevant articles and selected those for final analysis using the following inclusion criteria: (a) the majority of the sample included youth diagnosed with spina bifida; (b) the average age of the sample fell between 10 and 25 years; (c) the research was original and focused on the experiences of living with spina bifida (from the perspective of youth); (d) the research involved a qualitative design, data collection, and analysis; (e) the article was published in English in a peer-reviewed journal between 1980 and September 2012. If the authors did not delineate their findings by type of disability or link quotes to participants with spina bifida, we excluded articles with several different types of

disability represented in samples. Similar to previous reviews (Nyman, Dibb, Victor, & Gosney, 2012; Pound et al., 2005), we defined qualitative studies as those using qualitative methods for both data collection and analysis. We excluded articles that contained only quantitative data, opinions, or editorials.

Using this search strategy, I identified 4,051 potentially relevant articles. With the help of the research assistant, I reviewed the titles and abstracts of those articles and eliminated 4,015 because they were insufficiently relevant to our search. After removing duplicates and applying our inclusion criteria, 12 articles remained for final analysis.

Analytical Approach for Review and Synthesis

To conceptualize and interpret the data across articles, I used a metasynthesis approach—a rigorous method of integrating and interpreting findings from several qualitative studies (Saini & Shlonsky, 2012; Sandelowski, Docherty, & Emden, 1997). Based on the inductive and interpretive technique of Sandelowski and Barroso (2007; see also Quinn, Murray, & Malone, 2013), our metasynthesis method involved the following steps: (a) reading each of the articles selected for final analysis several times; (b) extracting from each article the findings related to living with spina bifida; (c) mapping key concepts; (d) clustering and translating findings into themes; (e) rereading each article using a constant comparative method to synthesize their findings into themes; and (f) describing the final themes and subthemes.

The research assistant and I read each of the 12 articles selected for final analysis in their entirety before summarizing its key attributes. I abstracted and compiled data from the articles, which the research assistant verified independently, using a structured abstraction form based on similar qualitative reviews (Tong et al., 2012; Tong et al., 2009). All direct quotes from the results section and statements from the interview data of each article were entered into NVivo 10 (QSR International, 2013) for coding. Then I began analysis with line-by-line coding and developed descriptive and analytical themes (Britten et al., 2002). Each of us independently grouped the findings by topic, identifying common themes (i.e., themes that occurred in at least two articles) through an iterative process. Then we reread the articles, using a constant comparison method to map the relationships between themes and translate key themes (Noblit & Hare, 1988; Saini & Shlonsky, 2012). We drew on the theoretical concepts of biographical disruption and normalization to guide our understanding of emergent themes, and we recorded quotes indicative of each theme and subtheme (Saini & Shlonsky).

Quality Appraisal

For each of the articles selected, we appraised the quality of research using the Qualitative Research Quality Checklist (Saini & Shlonsky, 2012; see Supplemental Table S1, available online at qhr.sagepub.com/supplemental). The research assistant and I independently appraised each of the articles. We made notes of each of the items from the quality checklist and then summarized them. We resolved by discussion any discrepancies between our appraisals until we reached a consensus. We found the quality of research was generally good, and we excluded only one article based on our quality appraisal (it lacked methodological details and appeared to be an opinion article). Although some of the studies were of better quality than others, the themes reported in each article reflected the findings (Quinn et al., 2013).

Results

Characteristics of Included Studies

Using our search strategy and inclusion criteria, we identified 12 articles for inclusion in our final analysis. In Supplemental Table S2 (available online at qhr.sagepub.com/supplemental) I provide an overview of the characteristics of selected articles and the studies reported therein. The majority of studies (9) were conducted in the United States, and the rest were conducted in Brazil, Canada, and Sweden (1 each). The studies included a total of 213 youth participants ranging in age from 9 to 26 years. Samples included various types of severity of spina bifida (i.e., hydrocephalous and myelomeningocele), but many studies did not specify the level of severity. Three of the studies had a female-only sample (Bellin et al., 2007; Roux, Sawin, Bellin, Buran, & Brei, 2007; Sawin et al., 2009), and seven studies had more women than men (Fägerskíöld & Mattsson, 2010; Kinavey, 2006, 2007; Ridosh, Braun, Bellin, & Sawin, 2011; Wollenhaupt, Rodgers, & Sawin, 2012). The few articles that specified ethnicity indicated that the majority of participants were White.

In 10 of the studies investigators conducted interviews; in two of them investigators used combined qualitative methods. In most of the data analyses (n = 9) investigators applied a content or thematic data analysis, but in two studies the researchers used a phenomenological approach. Investigators only applied a theoretical framework in five of the studies, which included Barrera's (1986) conceptualization of social support, ecological model of adaptation, and inner strength theory, and Goffman's (1963) stigma theory (see Supplemental Table S2 for details).

Youths' Experiences of Living With Spina Bifida

In the articles reviewed, we identified three key themes of adolescents' experiences of living with spina bifida: (a) the medical management of spina bifida; (b) the importance of peer and family relationships (i.e., social support, belonging, and challenges in peer connections); and (c) the effects of spina bifida on identity and self-concept. Although these key themes are interrelated and influence one another, I discuss them in sequential order. I also provide illustrative quotes that reflect each theme in Table 1. We found, in our review of qualitative research, that youth with spina bifida encountered many disruptions to their biography; however, they also had several strategies for revising their biography to maintain normalcy.

Medical Management of the Condition

According to the articles reviewed, managing the medical aspects of spina bifida was an ongoing concern for youth as they tried to maintain a normal lifestyle. Their outlook on their condition was a result of attempts to manage fatigue, pain, or daily self-care. In several of the articles, authors highlighted struggles to manage incontinence, catheterization, and bowel management (Bellin et al., 2007; Ho et al., 1997; Ridosh et al., 2011; Sawin et al., 2009). For instance, many youth were concerned about the unpredictability of incontinence, especially while at school, because of the stigma associated with its occurrence: "I am really incontinent, so I never know when it's going to happen" (Bellin et al., p. 61). Such unpredictability affected adolescents' personal and social normalcy as they dealt with the direct physical mess of incontinence and its social consequences. This example demonstrates the ways in which the biographies of youth were frequently disrupted.

Shared management. For youth with spina bifida, the ability to manage self-care activities while maintaining autonomy and social relationships was a key concern (Soares, Moreira, & Monteiro, 2008). Youth relied on their parents for help with self-care related to medication management and daily living activities (Blum, Resnick, Nelson, & Germaine, 1991); however, as they approached adulthood they had to strike an often-difficult balance between needing parental help and achieving greater independence. Some youth felt their parents were overprotective and needed to let them manage more of their care on their own (Bellin et al., 2007; Ho et al., 1997; Ridosh et al., 2011; Sawin et al., 2009; Soares et al., 2008; Wollenhaupt et al., 2012). Some felt a tension between being taken care of and becoming independent: "I didn't tell Mother, just so the doctors would talk to me" (Garibaldi, Gibson, Reiss, Villarreal, Haidet, 2004, p. 229).

Youth expressed concerns about their future (personal normalcy), especially as they prepared to transition to adulthood and independent roles (Wollenhaupt et al., 2012). Participants encountered several barriers to self-managing their condition, such as lack of information about their health and understanding of the complexities of spina bifida; self-care skills; and decision making and autonomy (Blum et al., 1991; Fägerskíöld & Mattsson, 2010; Sawin et al., 2009; Soares et al., 2008). Youth wanted more meaningful participation in health care decisions, including improved communication about their condition with family, clinicians, and teachers. In some instances, they viewed parents as a positive support and equal partner in helping to promote successful self-management. For instance, Wollenhaupt et al. found that identifying goals or priorities in care along with parents was important for youth, and it was a mechanism for maintaining normalcy.

Lifestyle management. Youth with spina bifida were aware of the impact their condition had on their ability to participate in everyday activities; for example, many youth with spina bifida had to adjust their leisure activities to keep up with the demands of bowel and bladder (i.e., catheterization and enemas; Fägerskíöld & Mattsson, 2010; Ho et al., 1997; Wollenhaupt et al., 2012). During school, this often meant less time to interact with peers because of the extra time needed to go to the washroom. Some youth minimized or avoided social interactions because of the fear of bowel and bladder incontinence and possible negative reactions on the part of peers (Ridosh et al., 2011); some youth used this strategy to help maintain normalcy and protect their biography. Other youth recognized that limitations in their mobility affected the activities they could participate in, and thus their ability to form friendships.

Managing the medical aspects of spina bifida often disrupted the behaviors and self-concepts of youth; however, they varied in the extent to which their condition affected their lifestyle. For example, Bellin et al. (2007) found that youth fell along a continuum of impact: some had a positive self-appraisal and others perceived a mixed or negative impact of spina bifida on their life experiences. In our review, we also found that youth actively sought ways to maintain normalcy and minimize disruptions to their biography.

Peer and Family Relationships

Although monitoring and managing spina bifida created stress for youth, participants reported a range of coping mechanisms—including seeking social support—to protect against distress (Bellin et al., 2007). In eight of the articles reviewed, authors emphasized the importance of

Table 1. Illustrative Quotes Reflecting Each Theme.

Theme	Subtheme	Quotes
Identity/self-concept	Normalcy/ strengths	"My parents try to keep me normal. They don't point out all the differences . . . they encourage me to do things that people with spina bifida normally don't do. . . . I mean they try to just get me out in the world so I'm not enclosed in my own little world." (Wollenhaupt et al., 2012, p. 74)
		"I lead a pretty normal life from any other teenager." (Sawin et al., 2009, p. 30)
		"I like that I am different." (Sawin et al., 2009, p. 30)
		"I think you build your strength as you go. You become tougher each day. You realize you can do certain things that no one else thinks you can." (Ridosh et al., 2011, p. 871)
	Vulnerability/ disablement	"The wheelchair represents, as whoever is in there is weak . . . is an outcast . . . an alternative for someone because they weren't capable of doing the regular things in life." (Kinavey, 2006, p. 1097)
		"I had a lot of body image problems . . . because I just figured that I would never be the ideal beauty, because the braces, and crutches weren't part of the outfit. . . . And so, I automatically wasn't pretty . . . and it had nothing to do with my personality or my face. It had everything to do with my disability." (Kinavey, 2007, p. 154)
		"I don't want to be treated like I'm in a wheelchair. I want to be treated like I'm a person." (Sawin et al., 2009, p. 32)
Peer and family relationships	Social support and belonging	"I am no different than other kids my age, making new friends." (Roux et al., 2007, p. 115)
		"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 became friends." (Antle, Montgomery, & Stapleford, 2009, p. 101)
	Impact of spina bifida on family	"Sometimes I feel like I stop them [family] from doing something that they want to do." (Bellin et al. 2007, p. 63)
		"My having spina bifida, it's changed a lot of stuff which I've found out recently. That was one of the reasons my mom quit her bakery business and took a job at the factory, 'cause she had to pay the bills and take care of my doctor bills. It kind of makes me feel kind of bad. Mom really enjoyed it. I know it's not my fault, but it makes me feel kind of bad 'cause she loved it." (Wollenhaupt et al., 2012, p. 80)
	Struggle for independence	"I feel sometimes that [my mom] thinks she knows more than I do about myself and I feel sometimes that she doesn't respect my . . . what I say . . . ." (Sawin et al., 2009, p. 31)
		"I don't know if I'll ever live on my own. I would need to learn to call my own doctors, call for my own diapers, try to have bowel movements on my own, do my own bath, put on my own clothes, I think that's it. I don't know what happens after graduation." (Wollenhaupt et al., 2012, p. 80)
		"I feel it should be my responsibility." (Sawin et al., 2009, p. 29)
		". . . my parents should have made me do it sooner. I was almost in 6th grade when I started catheterizing." (Ridosh et al., 2011, p. 869)
	Challenges in peer connections	"I go to the playground. I just sit there and watch everybody else play." (Roux et al., 2007, p. 116)
		"Sometimes people are afraid to come up to me and talk to me because I'm disabled." (Bellin et al., 2007, p. 61)
		"Because of the shame and the stigma that is associated with being disabled, I didn't want to get into a group of disabled friends." (Kinavey, 2007, p. 155)
		"I don't have too many friends in my school . . . I don't make friends easily." (Antle et al., 2009, p. 101)
		"It's really hard being a teenager with spina bifida, like getting around and in certain places with certain people looking at you and saying, well, she's not right because she's in that wheelchair." (Wollenhaupt et al., 2012, p. 76)
Managing health	Shifting the responsibility of care	"I need to learn to take care of myself." (Sawin et al., 2009, p. 29)
		"I was overprotective but he could do it (ADL) before. I just did it because it was easier for him. I would have had him become more independent earlier." (Ho, Stevenson, Nehring, Alpeter, & Grant, 1997, p. 53)
		"I have asked her nicely that I would like to go alone [to the doctors] . . . sometimes I'll let her come with me. It just depends. Basically, I do it on my own, I go in there on my own and then if they want to talk to my mother I'll tell them she's waiting outside or she'll come in the room but she'll let me do all the talking." (Ho et al., 1997, p. 53)
	Medical management	"I would like the [bowel program] to be different. I don't want to have to go through another 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, another hole." (Sawin et al., 2009. p. 29)
		"I am really incontinent, so I never know when it's going to happen." (Bellin et al., 2007, p. 61).
	Lifestyle management	"I can do everything but I can't run and I can't go to camp because of the enema." (Fägerskíöld & Mattsson, 2010, p. 473)
		"My mom wants me to have friends and be liked and everything so she pushes me like makes sure that I keep the lower part of me clean 'cause it's kind of hard because I leak . . . so she pushes me to do that." (Wollenhaupt et al., 2012, p. 78)
		"I have to use crutches and can't walk like everybody else and that I can't fully go to the bathroom like you can." (Bellin et al., 2007, p. 60)

family and peer relationships for enhancing social support, sense of belonging, and overall well-being. However, investigators also found that family and peer relationships could pose a threat to the biography of youth with spina bifida, many of whom encountered difficulties such as bullying and teasing from peers, as well as overprotection and lack of independence from parents and other family members (Bellin et al.; Fägerskíöld & Mattson, 2010).

Social support. In four of the articles reviewed, authors discussed the important role of social support for helping youth maintain normalcy (Antle, Montgomery, & Stapleford, 2009; Ridosh et al., 2011; Roux et al., 2007; Sawin et al., 2009). For example, Antle et al. found that mothers in particular were an important source of support (i.e., tangible support, information, advocacy, and emotional support), followed by fathers, siblings, and other family members. Parents often recognized that youth had particular needs arising from their disability. Some studies found that families tried to maintain a normal life as much as possible to reduce the impact of spina bifida on youth and others (Antle et al., 2009; Ridosh et al.; Roux et al.; Sawin et al.).

Peer support and relationships with friends were also important for enhancing adolescents' well-being and minimizing biographical disruption (Ridosh et al., 2011; Roux et al., 2007; Sawin et al., 2009). For example, Ridosh et al. found that a connection with family and peers provided youth with a source of strength to help them adjust to their condition. They also found that youth benefited from treatment as a "normal" teenager, whereas Roux et al. found that youth liked having peers with a disability because they could relate to what they were going through. Antle et al. (2009) found that most youth with spina bifida had at least one friend, and youth felt a sense of belonging (and normalcy) when they were able to share information about their health condition. Sawin et al. also found that youth with spina bifida were capable of making friends and fitting in.

Challenges in belonging and peer connections. Although peer relationships offered multiple benefits, many youth experienced challenges in connecting to peers and achieving a sense of belonging (Ridosh et al., 2011; Roux et al., 2007). Challenges in peer connections or concerns about belonging emerged as a theme in seven of the articles we reviewed (Antle et al., 2009; Bellin et al., 2007; Fägerskíöld & Mattsson, 2010; Garibaldi et al., 2004; Ridosh et al.; Roux et al.; Soares et al., 2008). Friendship and what constituted a friendship varied widely among youth with spina bifida, particularly in school contexts, where belonging and friendships often elicited mixed reactions. For instance, some youth reported experiencing isolation, teasing, bullying, and stigma related to their condition (Bellin et al.; Ridosh et al.; Roux et al.). This was often perceived to be a result of looking different from their peers and not being able to participate in the same activities: "I feel like a lot of people put me down because I have spina bifida and because I do look different than others" (Bellin et al., p. 61).

Youth also reported limited out-of-school contact with peers and limited participation in organized social activities. Mobility impairments resulting from spina bifida influenced their ability to make friends, particularly for those in a wheelchair, because this highlighted the fact that they were different from their peers (Wollenhaupt et al., 2012). For instance, many youth reported exclusion resulting from inaccessible public spaces and schools (Soares et al., 2008).

Some youth struggled to avoid isolation and to belong to a community, which were issues of particular concern as they prepared to transition to adulthood and independent living (Garibaldi et al., 2004). Fägerskíöld and Mattsson (2010) found that youth with spina bifida felt like an outsider in their community and did not have the same opportunities as typically developing youth. This was often related to mobility constraints, as well as the demands and challenges of attending to bowel and bladder needs, which they felt they needed to keep hidden from their peers: "Nobody knows [how I urinate] . . . everybody thinks I'm just ordinary. My best pal knows a little" (Fägerskíöld & Mattsson, p. 473). Youth continually worried about leakage in the presence of their peers. It was not so much the medical aspect of their condition that disrupted their biography, but rather the social response.

Many youth mentioned how their spina bifida affected their family. Some youth perceived that their family was not really affected by their condition; however, others perceived tensions and guilt arising from the sacrifices family members made to help manage their spina bifida, such as a mother quitting her job to help with ongoing care (Wollenhaupt et al., 2012). Others described how their condition prevented their family from taking part in certain leisure activities (Wollenhaupt et al.); there was little mention, however, of the role of siblings and the support they might have provided.

Identity/Self-Concept

Authors of six of the articles reported key themes related to identity and self-concept (Bellin et al., 2007; Kinavey, 2006, 2007; Ridosh et al., 2011; Roux et al., 2007; Wollenhaupt et al., 2012), including threats to and maintenance of normalcy. Intertwined with themes discussed above, the ability of youth to manage the medical aspects of their condition influenced their self-concept and their ability to maintain normalcy.

Threats to normalcy and biography. Identity formation and self-concept were associated with certain challenges. Youth experienced vulnerability and stigma resulting from their spina bifida (Bellin et al., 2007; Wollenhaupt et al., 2012), and they were aware that their disability could have a negative impact on their self-concept. For example, Kinavey (2007) found that youth with spina bifida encountered biological, psychological, and social challenges that might interfere with normative development of adolescence and identity formation. Specifically, while exploring the biopsychosocial impact of spina bifida, Kinavey (2007) identified the theme of "experiencing self as dissimilar other" (p. 153), which referred to ways in which youth viewed themselves disapprovingly in comparison to their peers.

Some of the article authors reported that youth with spina bifida experienced specific areas of self-dislike; for example, "I don't want to be in this chair. I wish I could walk and I wish I didn't have spina bifida" (Bellin et al., 2007, p. 60). Other articles described how stigma, teasing, or bullying interfered with social inclusion, self-esteem, and self-image (Ridosh et al., 2011; Soares et al., 2008). Soares et al. explored the sociopolitical factors that influence the self-perceptions of youth, and they offered an interesting perspective on youth identity formation. They found that young people with spina bifida were subjected to infantilization, a process in which the youth were viewed as fragile, vulnerable, and incapable. Such external perceptions of youth with spina bifida (threats to normalcy) influenced self-perception and led to either biographical disruption or biographical revision.

Maintenance of normalcy and biography. In several articles, authors discussed the concept of normalization (Ridosh et al., 2011; Roux, 2007; Wollenhaupt et al., 2012), including the desire of youth with spina bifida to be treated like "normal teenagers." For example, one youth participant wanted his or her peers to know that "people with spina bifida live normal lives too" (Ridosh et al., p. 870).

To maintain normalcy, youth used several strategies for revising their biography. Many youth described the importance of building on strengths, maintaining a positive outlook, and viewing themselves as normal teenagers (Bellin et al., 2007). For example, Kinavey (2006) described the explanatory models of self-understanding of youth and found they attached meanings to their spina bifida by viewing their identity as "overcoming disability." This involved denying a central component of self; for example, one youth said, "The wheelchair represents as whoever is in there is weak . . . is an outcast . . . an alternative for someone because they weren't capable of doing the regular things in life" (Kinavey, 2006, p. 1097). Thus, some youth chose to deny or minimize their disability as a means of achieving normality. Others shaped their identity by objectifying disability (i.e., keeping it separate from their core identity; Kinavey, 2006). Meanwhile, some youth integrated their disability into their self-concept and understood their diagnosis through personal experiences (Kinavey, 2006).

Bellin et al. (2007) found that most youth with spina bifida had an overall positive self-concept and realistic perceptions about their personal strengths and challenges. For instance, young women with spina bifida tried to integrate meanings and the implications of their condition into their lived experience (Bellin et al.). Antle et al. (2009) found that "celebrating successes" helped youth to build confidence; encouraging them to try new things helped them to develop an awareness of their own capabilities; and "treating the person like everyone else" helped to build their sense of self-worth (p. 102). In summary, although youth with spina bifida encountered threats to their self-concept resulting from their condition, they also employed several strategies for revising their biography in attempts to maintain normalcy.

Discussion

In this qualitative synthesis, I highlight the experiences of youth who live with spina bifida. Synthesizing qualitative research on the experiences and perspectives of youth, particularly as they transition to adulthood, is important for informing the development of health care programs. This adolescent stage of life is critical, given that the majority of youth with spina bifida live well into adulthood and must manage the complexities of their condition throughout their life (Sawin et al., 2009). Many of them experience biographical disruption and threats to personal and social normalcy because of their condition; however, they are able to revise their biography to maintain normalcy.

In assessing the extent to which youth with spina bifida meet the attributes of the definition of normalization (Knafl & Deatrick, 1986), I show that some families tried to define "life as normal" (Williams et al., 2009, p. 1444). It is important to note, however, that there was often tension between the views of youth and the views of their parents. Most youth acknowledged the existence of their spina bifida, although some described trying to hide their condition at times, especially at school. Youth with spina bifida clearly desired normalcy and belonging. The studies in this review provided examples of threats to social normalcy more than to personal normalcy. At this critical stage of adolescence, youth had an awareness of "social normality" that influenced their identity formation; however, it might have also caused tensions between "private lives and public selves" (Williams et al., p. 1446).

In contrast to the "family-management perspective" of normalcy (Williams et al., 2009, p. 1443), youth did not define the consequences of their condition as minimal; rather, they described ongoing threats to their self-concept and sense of normalcy. According to the articles reviewed, youth encountered several challenges in establishing peer connections and often encountered stigma because of their differences in appearance. These findings are consistent with quantitative research on youth with spina bifida who encounter more social difficulties and isolation than their typically developing peers (Kelly et al., 2008; Skar, 2003; Storch et al., 2006). Parallel evidence also demonstrates that youth with disabilities are more likely to be socially excluded from their peers (Lindsay & Edwards, 2013).

Youth with spina bifida also described their struggles to achieve independence, especially with regard to self-care for their condition as they approached adulthood; shared management of medical aspects of spina bifida emerged as a common theme in their experiences. Youth tried to manage their spina bifida as best as they could with help from their parents; however, they often felt they lacked information and independence in their efforts to do so. This is consistent with other research on youth with chronic conditions, which has found that parents are a source of both stress and support (Lindsay, Kingsnorth, & Hamdani, 2011). Youth often linger between wanting to be independent and still needing support from others for their self-care (Karlsson, 2008; Lindsay et al., 2011). Indeed, chronic illness often increases dependence on others and challenges a person's self-image (Atkin & Ahmad, 2001) and biography (Bury, 1982). Some parents might be reluctant to give adolescents autonomy over managing their condition because they worry it would burden or stigmatize them (Giarelli, Bernhardt, Mack, & Pyeritz, 2008). Thus, it is not surprising that parental overprotectiveness of youth with disabilities is common (Tong et al., 2012).

The findings in this synthesis are consistent with the experiences of youth with other chronic conditions, such as cystic fibrosis (Williams et al., 2009), asthma (Lemanek, 1990), arthritis (Tong et al., 2012), diabetes (Johnson, 1988), organ transplantation (Tong et al., 2009), and Duchene muscular dystrophy (Gibson et al., 2014), in that youth with other chronic conditions also focus on preserving normalcy and their social identity (Lindsay et al., 2011). Helping youth with spina bifida achieve autonomy is critical because they often have lower independent functioning compared to their peers with respect to independent living, employment, and community involvement (Greenley, Coakley, Holmbeck, Jandasek, & Wills, 2006). Without help, they might continue to struggle with ongoing threats to their biography.

The visibility of spina bifida and the unpredictability of its medical symptoms, especially bowel and bladder incontinence, provides another ongoing threat to self-concept and sense of normalcy. Not being able to conceal a condition easily can undermine opportunities for achieving normalcy because it is difficult to avoid stigma and "spoiled identity" (Williams et al., 2009, p. 1444). In this regard, the experiences of youth with spina bifida are similar to those of youth living with arthritis who experience disablement and differential treatment from others (Tong et al., 2012). However, although youth with spina bifida often see themselves as different from their peers, the articles reviewed in this synthesis did not ascribe to them experiences of pain or disfigurement, which are present in reports of juvenile arthritis (Tong et al., 2012). In fact, many other ongoing medical issues commonly associated with spina bifida—such as neurosurgical issues, orthotic needs, and weight-management concerns (Sandler, 2004)—were not mentioned in the articles reviewed for this synthesis. These areas deserve more attention in future research.

Consistent with the fourth aspect of normalcy, most youth with spina bifida engaged in behaviors to revise their biographies (Bury, 1982) and demonstrate normalcy to others (Knafl & Deatrick, 1986). The social support that youth received from family and peers helped them to construct their "life as normal" while managing their condition (Williams et al., 2009). Past evidence highlights that social support and belonging are linked with improved well-being, social competence, and self-management skills (Lindsay, Kingsnorth, Mcdougall, & Keating, 2014; Tong et al., 2012). Consistent with the work of Williams et al. on youth with cystic fibrosis, families of youth with spina bifida likely experience a pre-illness phase in which they must cope with the diagnosis before their child is born. This might have helped families revise their biography to achieve normalcy for their child. Some suggest that identity formation, especially during adolescence, can disrupt normalcy and biography, making it difficult to distinguish what is a part of development and what might be because of the condition (Williams et al., 2009).

It is important to note that investigators often use the concept of normalization in a family-management perspective to address how a family's response to a child's condition shapes coping strategies (Williams et al., 2009). Thus, perhaps some of the threats to identity and normalcy that youth with spina bifida encounter result from their striving for independence and reflect their personal normalcy rather than their family's response (Williams et al.). The findings in this synthesis demonstrate that youth with spina bifida mobilize social and emotional resources to find meaning in their diagnosis and revise their biography accordingly (Barnes & Mercer, 2008;

Bury, 1982; Roux, Dinley, & Bush, 2002); however, little is known about how other resources, such as financial or information support, might have helped them

Qualitative synthesis can help clinicians better understand the meaning or impact of a phenomenon (Gewurtz, Stergiou-Kita, Shaw, Kirsh, & Rappolt, 2008). This synthesis offers unique insight into the experiences of adolescents living with spina bifida. The strengths of this study include a comprehensive search strategy that was systematically conducted across several relevant databases, applying inclusion criteria that ensured the relevance of articles. An audit trail of notes and coding was also kept.

Several limitations of this review need to be considered. First, the 12 articles did not contribute equally to each theme; however, these themes were used to identify patterns across all articles. Second, the methodological rigor was not consistent across all studies; nonetheless, it was important to include all voices, given the limited availability of qualitative research on youth with spina bifida. I note the methodological limitations in Supplemental Table S1. Third, the wide age range of most of the samples makes it difficult to separate particular issues by age. This is an especially relevant point because youth are at a critical stage of their identity development when they begin transition to adulthood. Fourth, most articles did not describe whether youth attended integrated or mainstream classes or special education classes; this is an important aspect to consider in future research because school environments can affect the inclusion of youth with disabilities (Lindsay & Edwards, 2013).

It is also important to note that the concept of biography that I drew on was initially developed for adult-onset conditions and chronic illness among adults; therefore, it might be limited in its capacity to capture the complexities encountered by youth with congenital conditions (e.g., their sense of normality and how it shifts over time; the challenges they face while growing up with a disability, including peer stigma and bullying). Future work on biographical disruption among pediatric populations is needed, including application of concepts such as "illness centrality" to capture the developmental tasks that youth with disabilities encounter while struggling to develop a personal sense of self that is not dominated by their condition (Helgeson & Novak, 2007).

There are several other directions that future research might take. First, more work with diverse samples is needed to begin to tease apart some of the differences between genders, ethnocultural identities, socioeconomic statuses, and geographical contexts. Second, more longitudinal research is needed to explore how the experiences of youth might change over time, especially as they transition to adulthood. Third, future researchers need to recognize that illness experiences occur within a larger sociocontextual environment, in which adolescents must learn to cope with their condition and navigate changes in the health care system as well as their family, school, and social environments (Kelly et al., 2008). Fourth, research on illness experience should take into account the influence of the severity of spina bifida; thus, future studies could benefit from more comparative samples. Finally, most articles in this review were written from a nursing or psychological perspective; further work is needed from other fields, such as sociology, occupational therapy, social work, and rehabilitation sciences.

Conclusion

In this synthesis of qualitative research on the experiences of youth with spina bifida, I draw attention to important aspects of life that future health and social programs can target to help enhance youth well-being. Exploring adolescents' self-understanding of disability is critical because it can help clarify parental, societal, and clinical expectations and support the development of appropriate and meaningful treatment strategies (Kinavey, 2006). In this synthesis, I generated three themes on the experiences of youth living with spina bifida, including (a) the management of medical aspects of the condition; (b) the importance of peer and family relationships (i.e., social support, belonging, and challenges in peer connections); and (c) identity and self-concept (i.e., normalization and vulnerability).

Based on the articles reviewed, I suggest that youth with spina bifida experience disruptions in biography and threats to self-concept; however, they also have strategies for maintaining normalcy within the constraints of their condition. Although youth with spina bifida experience benefits of social support from their family, they also encounter stigma, social isolation, and challenges in developing friendships. Youth with spina bifida struggle with managing their health and independently caring for their condition. They also have concerns about the impact of their condition on their health and lifestyle. This synthesis provides insight and understanding for youth, parents, and clinicians regarding the elements of life for which youth could use further support in their journey of coping with their condition.

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