

Transition in young adults with spina bifida: a qualitative study

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Abstract

Background Adolescents and young adults with spina bifida are an at-risk population because of the complexity of their condition, developmental stage and social challenges. The purpose of this qualitative study was to examine the transition to adulthood in young adults with spina bifida and to explore condition-related needs and life skills required during the transition process.

Methods This qualitative study using narrative inquiry was part of a larger multi-site study of adaptation in young adults with spina bifida. Interviews were completed with 10 participants ranging in age from 18 to 25 years. The guided interview questions focused on specific dimensions of the transition experience related to the ecological model: self-management, independence and inner strength.

Results Three themes capturing different dimensions of the young adults' transition experiences emerged in the analysis. The themes included: (1) Struggling for independence, (2) Limiting social interactions and experiences with stigma, and (3) Building inner strength.

Conclusion The qualitative study contributes to a better understanding of the challenges of transition to achieve self-management and social development for young adults with spina bifida. Findings in the life stories highlighted issues that necessitate increased advocacy and interventions from professionals within the health and social system.

Keywords

independence, inner strength, qualitative, self-management, spina bifida, transition

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Introduction

Spina bifida is a congenital chronic health condition caused by a failure of neural tube closure in a critical period of foetal development. Spina bifida occurs in approximately two of every 10 000 live births (CDC 2009). Advances in care have led to improved management of the condition, increasing life expectancy through adulthood regardless of shunt status for those treated after 1975 (Davis *et al.* 2005). However, health outcomes and psychosocial functioning in individuals transitioning to adulthood are understudied. For the purpose of this

study, transition is defined as the developmental period when the adolescent becomes a young adult while increasing self-management of their chronic condition and independence in their social environment. The specific aim of this qualitative component of a larger multi-centre longitudinal interdisciplinary study exploring adaptation in transition-aged individuals with spina bifida (Bellin *et al.* 2010, 2011) was to describe the experience of transition in participants who lived in a large metropolitan city receiving health services at a university health system. Participants' perspective of self-management and independence and the role of inner strength in the pursuit

of independence associated with transition to adulthood were gathered through semi-structured interviews.

Background

Transition and spina bifida

The Ecological Model of Secondary Conditions and Adaptation was used as a theoretical touchstone for this study (Sawin *et al.* 2003a; Sawin & Thompson 2009). This model frames the trajectory of adaptation during transition for adolescents and young adults with spina bifida, delineating three risk factors: condition-specific risk factors (e.g. level of lesion, hydrocephalus status, neurological complications and perceived severity), demographic risk factors (e.g. age, gender, socio-economic status) and neuropsychological risk factors (e.g. executive functioning, working memory and processing speed). The three protective factors for adaptation included in the model are adolescent/young adult resilience (e.g. hope, coping, attitude or inner strength), family resourcefulness (e.g. cohesion, satisfaction, mastery and family activities) and healthcare adequacy (e.g. family-centred care and care satisfaction). This model delineated self-management as a critical component of physical health (Sawin *et al.* 2003a). In addition, the choice of inner strength as a variable of interest in this study was supported by the Theory of Inner Strength, which has added to the understanding of resilience factors that may enhance self-management, independence and quality of life (Roux *et al.* 2002).

Transition programmes across a variety of chronic health conditions have emphasized the development of self-management skills as an essential precursor of positive health outcomes and independence in living with a chronic condition (Betz *et al.* 2010). However, emerging adults with spina bifida have a number of challenges that may make this journey even more difficult. The complexity of the condition with potential life-threatening shunt complications, incontinence, respiratory problems, problems with mobility and skin breakdown, neuropsychological challenges, overprotectiveness, lower levels of behavioural autonomy, more dependence on adults as well as the stigma and social interaction problems can contribute to immense challenges in this transition period (Holmbeck *et al.* 2010; Sawyer & Macnee 2010). Struggles with bladder and bowel management remain highly prevalent in young adults with spina bifida (Verhoef *et al.* 2006) and families report issues with parental role negotiation and overwhelming stress related to incontinence (Sawin & Thompson 2009). Past studies of self-management in adolescents and their parents reveal that

building adolescent self-management skills is generally not a high priority for either the adolescent or their parents. Adolescents and parents fail to appreciate the extensive repetitive practice of self-management skills many adolescents, even those with normal intelligence, will need due to their neuropsychological challenges (Sawin *et al.* 2003a,b, 2009). In addition, cognitive abilities can influence parental overprotection in adolescents with spina bifida more so than typically developing adolescents (Holmbeck *et al.* 2002).

The literature on transition for young adults with spina bifida to date is limited, but it can be characterized by one young adult who indicated 'I was ill prepared' (Betz *et al.* 2010). Both research (Sawin *et al.* 2010) and clinical reviews (Sawyer & Macnee 2010) have identified transition as a high priority for action. The CDC Transition Project has identified self-management as one of key focuses of preparation for transition and independence (Thibadeau *et al.* 2010). This work group (Thibadeau *et al.* 2010) along with others has acknowledged the prevalence of anxiety and depression (Bellin *et al.* 2010), limited experiences in self-management and restricted quality of life (Bellin *et al.* 2011), and suggested age-appropriate family actions across the lifespan to build adolescents' resilience. However, understanding how young adults develop effective self-management behaviours that facilitate independence and how inner strength contributes to developing these behaviours in young adults at this difficult time of transition is unknown. Therefore, this qualitative study was developed to explore three specific dimensions of the transition experience: (1) self-management; (2) independence; and (3) the role of inner strength in the pursuit of independence.

Method

Narrative inquiry was the qualitative design used for this study (Polkinghorne 1988, 1995; Chase 2007). This method was selected as it is intended to focus on the relationship between individuals' life stories and it guides synthesis of data to represent the participants' stories as a whole (Polkinghorne 1995). The need of storytelling arises from the desire for the participant to have their stories heard (Chase 2007).

Ten participants aged 18–25 years were recruited from one site for this qualitative component of the study. This site was one of the five sites in the longitudinal multi-site study on transition in young adults with spina bifida (Bellin *et al.* 2010). The participants had either myelomeningocele ($n = 7$) or lipomyelomeningocele ($n = 3$), both of which can affect functional and motor capacities. However, the stories they shared regarding their self-management and independence described similar

thematic issues and they were reported as a single sample. Participants were living in a Midwest metropolitan city in the USA and receiving care at a large teaching hospital. One of the researchers spoke with the potential participants about the study during their clinic appointments. With their agreement, the researcher scheduled a time to call the potential participants to discuss the interview component of the study. If they agreed to participate, an interview was scheduled at the teaching hospital. The convenience of the interview schedule and accessibility of the teaching hospital was important as most of the potential participants relied on public transportation or transportation with a parent. Informed consent was obtained and a hospital classroom or conference room which were private and wheelchair-accessible were utilized for the interviews. Parents who accompanied the participants were asked to bring reading or other materials and were instructed to wait in the cafeteria until the researcher called them at the conclusion of the interview. The interview questions were derived from concepts pertaining to the protective factors of The Ecological Model of Secondary Conditions and Adaptation, specifically, exploring resilience, family resourcefulness and healthcare adequacy (Sawin *et al.* 2003a; Sawin & Thompson 2009). Semi-structured interview questions were used to elicit sharing of participants' personal stories (Table 1). Questions prompted reflection regarding what was most helpful to manage their own care through the period of adolescence and young adulthood. Transition issues explored included specific ways to promote independence and elicit support in the community. Social context was examined with questions on relationships with family, friends, siblings and primary caregivers. Self-management strategies and satisfaction with bladder and bowel management programmes were discussed. Reflective questions on building inner strength were included to more fully explore their experiences. See Table 1 for selected interview questions.

Generally, interviews lasted from 45 to 90 min and were completed over a 3-month period. Interviews were conducted separately from the completion of demographic and quantitative instruments for the larger multi-site study, as the time and

response burden were too extensive to complete at once. The interviews were conducted until saturation was established and no new data emerged. The interviews were audio-taped and transcribed verbatim.

Narrative inquiry requires that the researcher become interpreter of the participants' voice, focusing on the relationship between individuals' life stories and the quality of their lives (Chase 2007). This method of analysis introduces 'retrospective meaning making' while informing society of the reality of the experience. The participants were asked to share their stories as they retrospectively reviewed their experiences over adolescence into young adulthood. The interviews were examined by listening to the voices within each narrative to discover the particular subjective experiences unique to these participants. As participants told their stories, an understanding of past experience as related to actions and associated events was constructed. The interpretive process was enhanced by identifying emotions, thoughts and interpretations as expressed within each narrative (Chase 2007).

Initial analysis was conducted collaboratively by the first two authors. The researchers read and reread transcripts to identify unique experiences of the participants versus commonalities within each interview individually. The narrative strategy was to listen to the particular responses related to self-management, independence and inner strength. Specifically, what was said and how it was expressed were examined. Particular attention to the participant use of 'I' and their exact quotes were utilized in sharing their stories in the results. The researchers then met to discuss findings and themes that described the experience. Three additional investigators with extensive research and clinical expertise with young adults with spina bifida contributed to the final analysis and validation of findings. The researchers collectively selected the following narratives to tell the story. The epistemological underpinnings of this narrative were told through a post-modern lens in the context of each individual's experience of living with spina bifida.

Standards of rigour in qualitative research meet Lincoln and Guba's (1985) criteria of credibility, dependability, confirmability, transferability and authenticity. Strategies to achieve rigour in this study included collection of field notes relevant to the context of each participant and verbatim transcription. Confirmability and dependability were addressed by review of results with three additional clinical experts and researchers. Narrative inquiry gives voice to the participants' realities, and actual quotes of the participants were used to describe the themes. Transferability may be limited to adolescents and young adults living with spina bifida who are accessing care for their condition and live with their families.

Table 1. Selected semi-structured interview questions

- | | |
|----|--|
| 1. | As you think back when you began managing your own care, what was most helpful to you to develop independence? |
| 2. | What would you have liked to be done differently?
What would you have liked your parent/s and or caregiver to do differently? |
| 3. | What is your experience in building inner strength while living with spina bifida? |
| 4. | What are your suggestions for ways to promote your independence and community support? |

Results

The 10 participants were mostly 22- to 24-year-old young adults. Half had a mid-high lumbar level of lesion based on functional assessment. The participants were comprised of six Caucasians, three Hispanics and one African American. All were single and living with either one or more parents or friends except for one participant who lived alone. All completed a high school education, two were in vocational school, and two were attending college. Half of the participants were employed part-time and one full-time. Two participants had a driver's license. The majority of participants reported having access to and using public transportation, but their primary mode of transportation was their parents. Half of the participants used a wheelchair and the other half needed orthotics for mobility. See Table 2 for details of characteristics of the participants. Most of the participants remain engaged with the same neurology clinic providers that they have had since childhood.

Narrative analysis tells the story of these participants as they reflected back to their adolescent and young adult period. At the time of the study, the participants continued to work to achieve more independence with challenges in their employment status, completion of educational degrees, mobility and living arrangements. Full-time employment needed to gain independence including health benefits was achieved by only one of the par-

ticipants. Seven of the participants lived with their parents. The participants spoke of what could have been done differently and sooner to change where they are now in their trajectories to achieve independence. They wished to educate others about who they are and of their desire to contribute as full participants in society. Narrative analysis uses their language as a vehicle for social change to improve transition of adolescents and young adults with spina bifida.

Three themes capturing dimensions of the participants' experiences emerged in their responses. The themes included: (1) Struggling for independence, (2) Limiting social interactions and experience with stigma, and (3) Building inner strength.

Struggling for independence – 'My parents should have made me do it sooner'

The struggle for independence was heard as participants spoke of their wish to rely less on others for care at an earlier age. This was illustrated by one participant who recently started college as he reflected back on his experiences with the procedure of self-catheterization during his middle school years.

I didn't want to do it. I was really scared I'd hurt myself even if it hadn't hurt when he or my mom did it before. I didn't want to do it at school either. I didn't want anyone to see. But I had an accident one time when I didn't do it and wet my sleeping bag at a sleepover. I rolled it up but always catheterized after that. My dad made sure too . . . my parents should have made me do it sooner. I was almost in 6th grade when I started catheterizing.

The participants primarily learned to manage their condition from the experts and peers at conferences and camps. Recurring references to camp experiences were retold as being the most helpful in managing their own care.

I've gone to the adult camp for 3 years now but I never went when I was younger. I was the only one in my school with spina bifida. Now I know more. I didn't really care about it (self-management) till I met other kids.

I think camp is really helpful. You are kind of on your own but not if you know what I mean. The first time I went to camp (when I was 13 years old) was really the first time I was away from my mom/family for any time. It was hard but the counselors were there but didn't baby you. You were given goals to help yourself, to move forward. I

Table 2. Characteristics of the participants

Characteristic	n
Gender	
Male	6
Female	4
Age of participants (years)	
18–20	2
22–24	7
25	1
Race/ethnicity	
Caucasian	6
Hispanic	3
African American/Black	1
Primary diagnosis	
Myelomeningocele	7
Lipomyelomeningocele	3
Functional motor level	
High lumbar	3
Mid lumbar	2
Low lumbar	2
Sacral	3
Other chronic conditions/diagnoses	
Arnold Chiari	5
Hydrocephalus	7
Shunt	7

guess just meeting others (with spina bifida) also helped. There were older kids there that I saw could do things themselves.

One participant beamed as he shared an opportunity to be independent while participating in wheelchair sports.

When we'd win a level, we'd sometimes have 'one nighters' and we pretty much had to do everything (self-management to include catheterization). We'd stay in groups of 2–3. Everybody did their own thing.

Several other participants described wheelchair sports as a way to engage in activities and gain independence.

I know from talking to others that I can do different things. I've played sports and won! That's been pretty much fun and has helped me . . . made me feel more confident about myself, that I can do things for myself.

The struggle for independence continued to be heard as several of the participants spoke of their current desire to be hired and to sustain employment.

I would really like to find a job and work, I really would.

I would like to have more opportunities for jobs, they are really hard to find and if so only want you a few hours or days a week. I'd like to work full time.

Limiting social interaction and experiences with stigma – 'the looks'

Limiting social interaction

Limited functional independence in bladder and bowel incontinence and mobility impacted participants' social interaction. These limitations inhibited most participants from active or frequent interaction with people of their same age. One participant expressed the desire for others to know that people with spina bifida lead 'normal' lives too. Participants frequently made reference to the time in junior high and high school as a period of isolation with few friendships. Embarrassment due to incontinence in the school setting was evident in many participants. A teary-eyed account of embarrassment follows:

I didn't want to get up if I messed. They really thought I could control or should . . . and I did try new things but in gym it was hard because I wore a diaper . . . people not feeling I could do normal things because I was in a chair, just the kids making fun, the looks. I didn't really know anybody else with spina bifida unless I came to clinic.

One participant shared frustration by stating: '*Nobody listened to me*'. Ineffective communication patterns with families, healthcare providers, school teachers and school nurses were evident in many stories. The participants explained they often did not have opportunities to participate in shared decision making regarding care until young adulthood. An example of difficulties with self-management was the delay of independent skill building of self-catheterization. This procedure was not reinforced as a self-management skill until late adolescence. A plea for meaningful participation in care was heard from several participants seeking more involvement in the decision-making process for their treatment and advancement in self-management.

My mom tried to tell them, the school, about spina bifida but I don't think, the school teacher and school nurse always 'got it'. The kids were okay but the school nurse would always call my mom anytime I had an accident or headache or anything. I didn't like going to the nurse or office because I always got sent home.

Experiences with stigma

Stigmatization was evident in their stories with language portraying their feelings such as '*freak*', '*kids making fun*' and '*the looks*'. One of the young adults shared their feeling of limited work opportunity.

I like to work, can do a lot but I think sometimes when people see me in my wheelchair they get turned off.

One participant shared that catheterization made her '*feel like a freak*'.

He (participant's brother) really convinced me I could do this (catheterization) and not be considered a freak.

The researcher then clarified through member checking by stating, 'Let's talk about that a bit more, do you consider yourself a freak because you catheterize yourself?'

Well I kind of did at first but after getting so many urinary tract infections and landing in the hospital and feeling so bad, I just wanted to feel better.

Building inner strength – '*I believe I can accomplish most things*'

Participants referred to their connectedness with family and a spiritual power as sources of strength to adjust and accept their condition. Participants also frequently described engagement in

activities as strategies to build their inner strength. They described various life events to develop strength and exhibit resilience as:

I just believe in myself and give the rest to God.

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.

I don't like having spina bifida, I just accept it. I am positive and get through each day. What else can I do? I like quotes and look for positive quotes/sayings and think about them a lot. I try to keep positive.

One participant described relationship with family and friends that demonstrated how she reflected on the reality of her condition to construct meaning.

It's no one's fault I have spina bifida. It just happens. I have friends who have diabetes, have been in car accidents. Life isn't easy for them all the time either. My family has always been there for me. I believe I can accomplish most things. I might have to make an adjustment here and there but most things I can do. I go to church and I know this helps my family too.

Discussion

This study contributes to a better understanding of self-management and independence experiences and the role of inner strength in addressing challenges encountered by individuals with spina bifida who are transitioning into adulthood. Findings in the life stories highlighted risks and barriers that necessitate increased advocacy and interventions to address delay of independence, limited social interaction, and experiences with stigma. Previous research with this population has shown that the families usually remain engaged and active in these participants' lives to help manage care (Bellin *et al.* 2007; Sawin *et al.* 2009; Holmbeck *et al.* 2010) and that self-management experiences, in both condition-specific tasks and activities of everyday living, may be restricted (Bellin *et al.* 2011). In this study, we found the transition to independence to be similarly delayed. In particular, financial dependence on parents was a common experience, although our participants were seeking opportunities to gain employment and 'move forward' in their lives.

The plea for meaningful participation in care management decisions was frequently shared as participants spoke of a need for improved communication patterns with family, school

nurses and school teachers. Their desire to be heard regarding care decisions was evident in stories shared by older adolescents and young adults alike and was consistent with findings from previous qualitative study of the experience of self-management in adolescent women with spina bifida (Sawin *et al.* 2009). Participants described a fluctuation of trying to transition between individuation and still being dependent on care from their parents. However, participants in this study were slightly older 18–25 years of age, and findings demonstrated some progress in self-management towards gaining their independence.

The experiences of social interaction with peers, family and providers describe challenges faced. As the participants experienced limited social interaction and stigma, they learned to respond to uncomfortable 'stares' and educate others, 'the ones that care'. The 'teasing' and 'turn offs' were understood as limitations of others. The limited social interaction had hindered these participants from building diverse relationships with peers of their own age. Participants shared that the support systems of family and friends who understood them were the ones that became most important.

As study participants were transitioning to adulthood, most were lacking peer support and relationships, which was consistent with recent findings of the qualitative study on peer relationships in adolescent women living with spina bifida (Roux *et al.* 2007). When participants had strong peer relationships and support, these factors functioned as protective processes.

While the participants described their time in high school as one of challenges to manage their own care and deal with stigma, some of the participants shared stories of building inner strength through activities such as playing wheelchair team sports. Their reference to family support, participation in church and faith in God were also shared as sources of inner strength. Stories told on the acceptance of their circumstances demonstrated some participants achieved a sense of accomplishment that they could do what others can do. These moderating factors are congruent with the ecological model (Sawin *et al.* 2003a) and the Theory of Inner Strength in women with chronic health conditions (Roux *et al.* 2002), and highlight strategies that can assist individuals and families to develop resilience and build strengths during transition to adulthood.

The study findings suggest an expansion of The Ecological Model of Secondary Conditions and Adaptation (Sawin *et al.* 2003a; Sawin & Thompson 2009). While three categories of protective processes are delineated in the model (adolescent/young adult resilience, family resourcefulness and healthcare adequacy), data from this study would suggest including peer relationships and community engagement (e.g. school, camp, wheelchair basketball) as important protective factors.

Consistent with narrative analysis, through retrospective meaning making, these participants shared what could have made their trajectory different regarding self-management and independence. While they shared stories of their progress, they also shared stories of remaining challenges. The participants were articulate about their need to gain employment but lacked plans of how to develop to achieve goals. Targeted interventions are needed at various stages of the transition period to promote early role negotiation, improve family and community communication patterns, create opportunities to practise independence, and support employment opportunities. Interventions that foster connectedness with others and educational peer interventions to prevent labelling could facilitate peer relationships and help build inner strength. See Fig. 1 for implications based on the themes identified from participants' transition experience.

Future research should focus on effectiveness of interventions to reach goals during this transition period and to build inner strength to help them find meaningful daily life living with a disability. Studies on older 'young adults' may help researchers test interventions to promote effective transitions in young adults with spina bifida.

Limitations

The themes that emerged from this analysis may be influenced by the interview guide developed. While the semi-structured interview questions were developed from previous qualitative and quantitative findings of the researchers, the questions did centre on evaluation of independence, inner strength and self-management in transition. It is possible that additional themes might have emerged if items specific to other concepts such as the perception of the severity of spina bifida or neurocognitive functioning had been included. In addition, participants were asked about their experience building inner strength living with spina bifida, allowing each participant to respond with their own interpretation of inner strength. This approach does allow for individual interpretation of the meaning of this concept. Finally, the data from this study are captured from just one of the five sites in the larger transition study. It is possible that the factors facilitating independence, self-management and inner strength might be expanded if other sites included participants who lived in rural settings, other geographical locations or those who did not have access to camps or athletic experiences. In addition, although there was some diversity in the sample, it was limited.

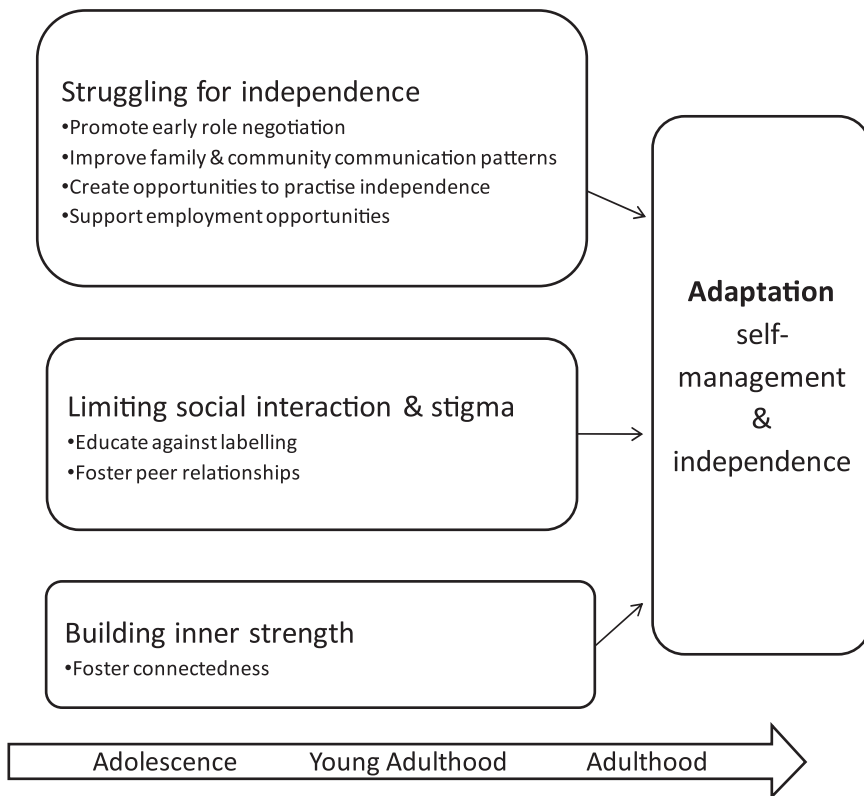


Figure 1. Themes and implications for interventions.

Therefore, further study is needed with participants from diverse geographical regions and those with broader ethnic heritage.

Conclusion

Implications for practice include targeted interventions for education of families to promote social and peer relationships, early building of job skills, and interdisciplinary tailored care models to promote self-management in adolescence. Common issues evident in multiple studies of reflection included social stigma, limited peer interaction, desire for involvement in care decisions and improved continence programmes, and a need for further employment opportunities (Sawin *et al.* 2003b, 2009; Bellin *et al.* 2007; Roux *et al.* 2007; Sawin & Thompson 2009; Holmbeck *et al.* 2010). This aggregate of qualitative findings contributes to growing evidence on the transition needs across the span of early adolescence to young adulthood in individuals with spina bifida. The consistent findings of multiple studies from research groups across the nation specializing in individuals living with spina bifida and their families warrant implementation of improved treatment models in community-based programmes at schools and health systems. Further intervention studies need to be conducted to enhance health outcomes and build strengths during transition and improve self-management of care for individuals living with spina bifida.

Key messages

- Narrative inquiry revealed the life stories of transition for young adults living with spina bifida.
- Themes included (1) Struggling for independence, (2) Limiting social interactions and experiences with stigma, and (3) Building inner strength.
- Independence was generally delayed but actively pursued as many of these participants were seeking opportunities to gain employment and 'move forward'.

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