Transition to adulthood: Experience of Japanese youth with spina bifida

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A B S T R A C T

Background: Emerging adults with spina bifida have complex developmental and health care needs. Improvement in healthcare means there is greater interest in understanding and supporting the transition needs of children with spina bifida to adulthood. However, the experiences during transition for emerging adults with spina bifida in Japan remain unknown. The purpose of this study was to describe the experiences of transition to adulthood for emerging adults with spina bifida in Japan.
Methods: Qualitative descriptive design was used to explore experiences of emerging adults with spina bifida. Eight emerging adults between 20 and 29 years participated in semi-structured interviews.
Results: Six core themes were identified: (a) struggling with employment, (b) finding the meaning of "becoming an adult", (c) learning to implement self-management, (d) proceeding with and worrying over adult health care, (e) establishing and maintaining relationships with friends, and (f) broadening scope of experiences.
Conclusions: This study contributed to identification of both challenges and positive aspects in experiences of emerging adults with spina bifida in Japan. Participants shared the unique perspective of how to "become an adult" as a person with spina bifida in Japan. Ever-present were participants' experiences of struggling during transition to adulthood, especially when trying to find a job, establishing relationships with friends, and making the transition to adult health care. The challenges participants in this study faced striving to achieve adulthood-related milestones and transition to adult health care suggest that expansion of support and health care initiatives that reflects the Japanese social context are needed.

1. Introduction

Spina bifida (SB) is a congenital chronic condition that affects functions of multiple body systems, including orthopedic, urologic, gastrointestinal, neurological, and cognitive.[1] The prevalence of SB in Japan was 4.25 cases per 10,000 births in 2021.[2] While the prevalence of SB is generally declining or stable in European and North American countries, an increase has been observed in Japan.[3]

An increasing proportion of children with SB grow into adulthood due to advances in neurosurgical and other health care management.[4] As a result, issues related to their transition to adulthood received more attention. In the context of developmental and health care needs of individuals with SB, two components of transition to adulthood need to be considered: transition to adult life and transition from child-centered to adult-centered health care. According to Arnett, an adult is a person who is able to "stand alone as a self-sufficient person."[5] Transition to adult

life can be defined as the process of achieving developmental milestones typically achieved in adulthood, such as marriage, entry into parenthood, and to have a regular job.[5] When defining transition to adult life in this study, the socio-cultural environment surrounding Japanese emerging adults with spina bifida (EASB) should be taken into consideration. Additionally, for EASB, self-management is deeply connected with transition to adulthood. These emerging adults need to learn the behaviors that facilitate self-management of existing symptoms and prevention or alleviation of secondary conditions.

Transition from child-centered to adult-centered health care is a dynamic, life-long process that occurs for the purpose of fulfilling the needs of the individuals with special health care needs in a way appropriate for their developmental stages. The goal of the health care transition is to optimize functioning and potential of the individual through quality, developmentally appropriate, and seamless health care services.[6]

These components of transition to adulthood are consistent with the Guidelines for the Care of People with SB.[7] The guidelines[7] explicitly address both achievement of developmental milestones including self-management behaviors, independence and participation in adult roles, and transition from pediatric to adult care providers for this population.

Three theoretical approaches influenced the development of this study: the theory of Emerging Adulthood (TEA) as mentioned earlier, the Ecological Model of Secondary Conditions and Adaptation (EMSCA), and the Individual and Family Self-Management Theory (IFSMT). The TEA addresses a developmental stage that typically ranges from 18 to 29 years of age.[8,9] According to Arnett,[8,9] young people in developed countries nowadays enter adult life (i.e., a stable job, marriage, and parenthood) later due to societal changes. Emerging adults seek more independence from their family; however, they have not yet achieved firm commitment to adult life.[8,9] The later move to adulthood also likely exists in Japan. The EMSCA proposes that adaptation during transition in adolescents and young adults with SB is associated with both risk and protective factors.[10] Finally, the IFSMT proposes that self-management has three dimensions: context, process, and outcomes.[11–13] The development of the context dimension was influenced by the EMSCA. The process dimension refers to the process of behavior change. The outcomes dimension refers to both proximal and distal results of the self-management process.

Adolescents and emerging adults with SB are at risk of having challenges during transition to adulthood. Adolescents with SB have not demonstrated adequate engagement in decision-making, responsibility, or activities with peers.[14] Studies on psychosocial issues in adolescents and emerging adults with SB showed that they were faced with various challenges, including self-management demands, social isolation, stigma, and psychological distress.[15–17] On the other hand, experiences that could be protective of their healthy transition were also described, including development of inner strength[16] as well as social and professional support.[18] Studies on the experience of transition to adult-centered health care revealed barriers to the transition, such as parents' reluctance and lack of awareness of need to leave pediatric care, uncertainty of the transition process, lack of information, lack of access to health care, cultural gaps between pediatric and adult services, lack of support from primary care providers, and insurance coverage issues.[19–22]

Existing research literature that specifically focused on the experiences of EASB in Japan is very limited, typically conducted more than 15 years ago and only available in Japanese.[23–27] They demonstrated that adolescents and emerging adults with SB faced various psychological, social, and health challenges.[23–27] However, these studies often used samples with age ranges wider than that of emerging adulthood. Further, few studies described the experiences of EASB during transition to adulthood and what those experiences meant to them. Thus, the purpose of this qualitative study was to describe the experiences of transition to adulthood for EASB in Japan. The research question for the study was "What are the experiences of transition to adulthood for EASB in Japan?"

2. Material and methods

2.1. Design

This study used a qualitative descriptive design.[28,29] The qualitative descriptive method was chosen for this study to explore the experiences of EASB living in Japan during transition and meanings attached to their experiences in detail. Data were collected by conducting individual telephone or Skype interviews with the EASB that focused on their experiences during transition.

2.2. Participants and sampling procedures

Purposeful sampling[30,31] was employed. The inclusion criteria were: (a) a diagnosis of myelomeningocele, (b) ages between 20 and 29 years, (c) having no other major health problem(s) unrelated to SB, (d) able to give consent for participation, and (e) Japanese speaking. The age range was derived from Arnett's definition of an emerging adult as a young person in this age range, during which he or she experiences more independence than adolescence and at the same time more instability and uncertainty than adulthood.[9]

Individuals with myelomeningocele were recruited in this study because this type of SB is the most severe and poses more challenges to the individuals compared with other types (e.g., SB occulta, lipomyelomeningocele).[1] The age range of 20–29 was selected because, while Arnett[9] defines the typical age range of emerging adulthood as 18–29, at the time of data collection the age of consent for research in Japan was age 20. The exclusion criteria were: spina bifida diagnoses other than myelomeningocele, outside age range, and having moderate or severe intellectual disabilities.

The recruitment was conducted through the Spina Bifida Association of Japan (SBAJ). At the time of the study the SBAJ had 32 chapters across Japan, 1070 members and a number of resources including newsletters, telephone consultation services, negotiation with government, and collaboration with study groups.[32] After obtaining ethical approval, the approval for recruitment was granted by SBAJ. The president of the SBAJ sent advertisement materials with the president's cover letter to potential participants using their membership list. Potential participants contacted the researcher, who explained the research purpose and procedure and proceeded to recruitment. Interested potential participants were screened using the inclusion criteria. The study purpose and procedure were explained in detail to the potential participants before any data collection began. In this study, eleven individuals contacted the researcher. Two individuals could not be reached after they expressed an interest in the study, and one was not able to participate due to health problems. Consequently, eight individuals participated in the interviews. The data were collected from April to August 2019.

2.3. Ethical considerations

Approval was obtained from the Institutional Review Boards of the University of Wisconsin-Milwaukee (#18.311) and the Kobe University, Graduate School of Health Sciences (#766). During consent, participants were informed that if they were distressed or depressed, or experienced any physical health problems during the interview, the researcher would terminate the interview, if needed, and provide the participants with referral to appropriate resources. Before finalizing consent, the researcher administered a screening form to assess the individual's understanding of the purpose of the study and provide consent. In this study, the IRB approved the option to obtain verbal consent from all the participants because the interviews were conducted by telephone or Skype. The consent was documented in the transcript. To assure confidentiality, recorded data and transcripts were password protected and stored in a de-identified manner.

2.3.1. Data collection procedures

Data were collected using individual in-depth semi-structured interviews. Telephone ($n = 5$) or Skype ($n = 3$) interviews were conducted in participant's primary language (Japanese). The demographic and clinical variables for our Demographic and Clinical Information Form (DCIF) were based on previous studies of adolescents and young adults with SB[10,33,34] and were modified by adding variables specific to the purpose of current study (e.g., family members, extra support at home). The demographic data included age, gender, the participant's living situation, educational type and level, marital status, and employment status. The clinical data included diagnosis, history of hydrocephalus,

history of hospitalization and surgery, bladder and bowel programs, and ambulation status.

During the in-depth interviews, the participants were encouraged to share their experiences. The interviews were recorded, transcribed verbatim by the researcher first in Japanese, and then translated into English. The translations were double checked by a Japanese researcher experienced in English translation studies and qualitative research. Participants received a Thank You gift card with the Japanese equivalent of approximately $20 USD after the interviews. All the interviews were conducted before the COVID-19 pandemic.

2.3.2. Interview script

An interview guide with open-ended questions was developed based on the three related theoretical approaches to the transition period. Table 1 shows the interview questions and the theoretical framework that guided the development of each question.

2.4. Data analysis

Data analysis for this study consisted of several stages to move to higher levels of abstraction and identify themes.[35,36] The first author transcribed the first 4 interviews (which were conducted in Japanese) to English and created codes by summarizing the meaning of each segment that related to the research question and creating a short label and began identifying themes. The second author reviewed the English transcripts and confirmed the codes and potential themes identified by the first author. The first author then transcribed the last interviews in Japanese, created codes and organized the codes into themes. The second author reviewed and confirmed the codes and resulting themes. In the rare instances where the authors disagreed discussions were held until a common code/theme emerged. The third author provided overall guidance and participated in formulation and revision of the themes from the codes. Analytical notes were written during the data analysis to document analytical ideas and enhance the processes of "moving from empirical data to a conceptual level."[35] Techniques, such as clustering and making comparisons[35] facilitated the analytic process. Through this process, main themes that captured the experiences of Japanese emerging adults during transition as well as sub-themes were identified, and descriptions of the themes were developed.

3. Results

Eight participants who were 20–29 years old were interviewed (See Table 2). The sample consisted of both males and females and both individuals in early and late twenties. Six participants either graduated from or were enrolled in a two- or four-year college at the time of the interview. This college enrollment rate may be high for this population. All participants were single and living with one or both of their parents. One participant resided in a dormitory on weekdays. Two participants received special education during junior high school and high school. One participant was attending college and two were in vocational training programs. One participant who attended college also worked part-time and three worked full-time. Sixty-two percent of participants had a shunt, 75 % used a wheelchair for mobility, 87.5 % performed

Table 2
The Demographic and Clinical Characteristics of Participants.

Characteristics	n (%)
Demographic characteristics	
Gender	
Male	5 (62.5)
Female	3 (37.5)
Age (years)	
20–24	4 (50)
25–29	4 (50)
Education	
High school	2 (25)
2-year college	1 (12.5)
4-year college	5 (62.5)
Employment	
Full-time	3 (37.5)
Part-time	3 (37.5)
Unemployed	2 (25)
Clinical characteristics	
Hydrocephalus	5 (62.5)
Self-management behaviors	
Self-catheterization	7 (87.5)
Bowel program	
Large volume enema	4 (50)
Other	2 (25)
None	2 (25)
Means of mobility	
Wheelchair user	6 (75)
Ambulates with/without orthosis	2 (25)

Table 1
Interview Questions.

I will ask you questions about your experiences and thoughts during transition to adulthood. You can take breaks whenever you become tired during the interview.

Transition to adulthood is a process in which a person grows and becomes more able to take care of him/herself and make decisions by him/herself. But, it may be different from person to person, and we are also interested in what "growing into adulthood" means to you.

1. Could you tell me about your experiences during transition to adulthood? (TEA)
2. What are your feelings about growing into adulthood? (TEA)

What has it been like for you to grow into adulthood? (TEA)

If not addressed by the youth/young adult, ask:

– What do you think about achieving independence? (TEA)
– Have you felt that there are various possibilities or that you have choices while you grow into adulthood? If so tell me about the possibilities or choices you see. (TEA)
– Could you tell me about your thoughts on and experiences of finding a job and working? (TEA)
– Could you tell me about your thoughts on and experiences related to building friendship and romantic relationship? (TEA)

3. Have you felt challenged in the process of growing into adulthood? If so, tell me about them. (TEA, EMSCA)
4. What are the positive aspects you have found in the process of growing into adulthood? (EMSCA)
5. What have been the main physical challenges of spina bifida for you? Have you had any health problems last year? (EMSCA, IFSMT)
6. Have you faced any learning challenges? (EMSCA, IFSMT)
7. Do/Did you need extra help when you are/were in school or at work? If so, who offers/offered help to you? What is/was helpful to you? (EMSCA, IFSMT)
8. What tasks have you needed to learn to care for your spina bifida? (e.g., Clean intermittent catheterization, bowel program, doing skin checks?) (IFSMT)
9. Is it important to you and your family for you to learn to do those tasks/behaviors on your own? If so, where are you in that process or how has it worked for you to learn to do these tasks yourself? (IFSMT)
10. Was there a change of health care settings between childhood and adulthood? If so, how did the change of care settings go? (IFSMT)
11. What does successful transition into adulthood look like for you? (TEA)
12. Is there anything else you want to tell me about growing up into adulthood with spina bifida?

Theoretical frameworks that guided the development of each question:

TEA=Theory of Emerging Adulthood, EMSCA=Ecological Model of Secondary Conditions and Adaptation, IFSMT= Individual and Family Self-Management Theory

intermittent catheterization to manage the neurogenic bladder and 50 % used a cleansing enema for their bowel program. The interviews lasted for 70–160 minutes. In participant quotes, some nouns and hospital or city names were removed for confidentiality.

Six core themes were identified from the interview data: (a) struggling with employment, (b) finding the meaning of "becoming an adult", (c) learning to implement self-management, (d) proceeding with and worrying over adult health care, (e) establishing and maintaining relationships with friends, and (f) broadening scope of experiences. Several concepts were present in more than one theme, and all these are presented in ranked order of participant's experience with the first theme listed being the most important. The concept of self-management was present in the themes of "struggling with employment," "finding the meaning of becoming an adult" and "proceeding with and worrying over adult health care." Also, the concept of struggling was present in the theme of "establishing and maintaining relationships with friends." The six core themes had 16 sub-themes distributed across the themes which will be discussed below (See Table 3 for themes and sub-themes).

3.1. Theme 1: struggling with employment

This theme captured the participant's experiences of struggling with securing and thriving in a job. The two sub-themes included: (a) *struggling with finding a job* and (b) *challenges faced while working*. Participants were faced with significant barriers at various stages and in various situations of employment.

3.1.1. Struggling with finding a job

Participants felt that their struggles with finding a job were caused by lack of understanding or accommodation of their special health needs at workplace and lack of legitimate appraisal of their ability. Only two participants reported that they received professional support when transitioning to employment. Some participants also implied that they felt the employers' reluctance to hire individuals with disabilities during the process of searching for a job.

> I guess I failed [employment interviews] because I wrote in the documents that I had bowel and bladder dysfunction and that I couldn't stand because of the level of my spina bifida lesion — and so

Table 3
Themes and Sub-Themes Describing Participants' Experiences during Transition to Adulthood.

Themes	Sub-Themes
1. Struggling with employment	Struggling with finding a job
	Challenges faced while working
2. Finding the meaning of "becoming an adult"	Trying to achieve what the common definition of "becoming and adult" means
	Struggling with relationships with family
	Exploring the meaning of "becoming an adult" for a person with spina bifida
3. Learning to implement self-management	Learning to implement self-management behaviors
	Learning to seek help when necessary
	Preparing environment for self-management
4. Proceeding with and worrying over adult health care	Feeling unprepared to transfer to adult health care
	Worrying over health status and receiving health care
5. Establishing and maintaining relationships with friends	Establishing friendships with peers who have a disability
	Maintaining relationships with peers in school and community
	Struggling to be involved in a romantic relationship
	Lack of peer support
6. Broadening scope of experiences	Creating opportunities by learning to get around on one's own
	Barriers to broadening scope of experiences

> I wrote that I wanted the company to equip the workplace with a chair and that I also needed a bed, so I guess I failed because I told the people at regular companies about those things. (321−328, 03)

3.1.2. Challenges faced while working

Several participants worked jobs while managing significant challenges including an inaccessible work environment and internal culture of unwritten rules at the workplace that did not fit the participants. Some participants also reported a lack of understanding and accommodation of their special health needs at the workplace and described their challenges in protecting their own health while working. They had difficulties with preventing pressure sores or securing time to catheterize regularly during work. One participant explained that it was difficult for him to communicate with his co-workers about his health care needs.

> Even if I'm told, "Prepare this document within two hours." or "Within four hours", I definitely have to go to the bathroom in two hours, otherwise there will be a problem in my lab results. Nevertheless, they say, "You have to. We'll need this document in four hours. You have to prepare it because you're an office worker." And, you know, the document is prioritized over going to the bathroom in this case. (278−285, 01)

Further, another participant reported that his ability was not appraised appropriately by the employer and that he could not build his career due to such inappropriate appraisal of his ability and lack of the employer's understanding.

> Nonetheless, like I said earlier, my co-workers in their 50's always rely on me when it comes to computer skills. However, I get paid less than anyone else because of my employment contract, I'm a bit dissatisfied with that, though. (684−688, 08)

3.2. Theme 2: finding the meaning of "becoming an adult"

Participants actively engaged in finding the meaning of "becoming an adult." The three sub-themes included: (a) *trying to achieve what the common definition of "becoming an adult" means,* (b) *struggling with relationships with family,* and (c) *exploring the meaning of "becoming an adult" for a person with SB*. Participants explored these different mental images of an adult simultaneously.

3.2.1. Trying to achieve what the common definition of "becoming an adult" means

The participants shared that the goals they set reflected what emerging adults might typically aim for during transition to adulthood. Such goals included becoming mature, learning to take care of oneself, becoming able to take responsibility, and living on one's own.

> I'm aiming to live on my own in the future. Although I would say I am satisfied with my current environment, my goal is to live on my own. (598−599, 04)

3.2.2. Struggling with relationships with family

Participants had ambivalent emotions toward the relationship with their family. They were thankful to their parents for the care and support they had received, both material and psychological, since childhood.

> Anyway, my mother gave me the opportunity to join the [band], and by joining the [band]…, I think that the [band] was the biggest trigger leading to my personal growth. (138−141, 03)

However, some participants described their struggles with the relationship with their family. They experienced disagreement with their family and/or felt that it required effort to live with their family.

I have to pay attention to the time because I live with my family, and I have to cooperate [with other family members] because I am not living alone. (645−651, 02)

I [wanted to go to a different school] because of my own physical disability although it was the times when people had never thought about changing schools for a personal reason. … I think my parents didn't understand me at all. Well, as parents, their way of thinking was that I would definitely struggle in the future if I went that way, so we had conflicting thoughts. (377−382, 01)

3.2.3. Exploring the meaning of "becoming an adult" for a person with SB

The participants perceived the differences between what was commonly expected as an adult and their actual life situations, thus exploring what "becoming an adult" meant uniquely for them. One participant shared his perspective on what it meant to become an adult for a person with SB.

When it comes to people with this condition, if you consider those who can do everything by themselves as fully grown adults, I feel that that will mean I haven't become able to do anything yet. Well, I think that one could be considered a fully grown adult as a person with SB if he can go out for a certain distance or for a certain amount of time. (20−25, 08)

Another participant considered learning about the condition and becoming able to implement self-management behaviors as the core elements of "becoming an adult" for a person with SB.

I think that [becoming an adult means] becoming able to take care of myself, for example transportation, and learn about myself, and think by myself, in the future. (332−334, 05)

3.3. Theme 3: Learning to implement self-management

This theme captured the process in which the participants learned to implement self-management of their SB. The three sub-themes included: (a) *learning to implement self-management behaviors*, (b) *learning to seek help when necessary*, and (c) *preparing environment for self-management*.

3.3.1. Learning to implement self-management behaviors

This sub-theme captured the process in which the participants learned to implement self-management behaviors, including bowel and bladder management, getting cleaned up when soiled, pressure sore prevention, making hospital visits, obtaining medications and medical devices (e.g., urinary catheters), and communicating with the health professional during an appointment. Participants learned to implement the self-management behaviors to maintain their health and prevent complications.

Participants described the factors that led to their learning self-management behaviors. These factors included changes in their living environment, developmental changes in family relationships (e.g., the participant entering rebellious phase), and changes in family role structure.

Well, I wonder until when…, I'm not sure whether it's embarrassing or not, but my parents did it for me until I graduated from junior high school, but I had to do the enemas in the dorm when I was in high school, you know. Because I do it twice a week. I had to learn to do that. (391−397, 04)

My grandpa used to live with my family, but, I guess it's been two years already… he went into a nursing home since his [illness] was a bit severe. So, my mother got busy taking care of grandpa, and therefore, I thought that I just had to do [the self-management tasks] by myself. (533−537, 02)

Some participants also stated that their parents' advice had an

impact on their self-management behaviors. Several participants described health providers' assistance with their self-management. The participants reported their experiences of receiving health providers' advice on their self-management; however, it had differing impacts on their own behaviors.

Some participants still required family's help with performing some self-management behaviors, such as bowel management and communicating with health professionals; however, they tended to have the motivation to learn to do those tasks by themselves or already explored ways to do so.

The participants began to learn how to perform select self-management tasks in childhood. By the time they reached their 20's they had learned not only to simply follow the procedure of the tasks but also to monitor and assess the outcomes of their self-management and explore methods for better management. In addition, the self-management behaviors were incorporated into the participants' daily life.

When I have lab classes [in college], I go to the bathroom before the class begins, and stuff like that, because I can't be late or miss the lab classes. I'm always thinking about it, like I should go to the bathroom between the 1st and 2nd period, I'm thinking about those things. (266−273, 05)

3.3.2. Learning to seek help when necessary

In addition to learning to manage their condition by themselves, the participants learned to seek help to accomplish their self-management when needed. They learned to rely on their friends and people other than family as they grew up and spent more time outside of the family unit.

And, well, ummm, I get my diaper changed by my friends [during a trip], and I don't know if I should say "they are happy to do it," (laughs) but they just say, "We'll do it if you need help." I'm really thankful to them. (700−704, 03).

3.3.3. Preparing environment for self-management

Participants requested understanding and accommodations at the workplace when they were necessary for balancing both work and self-management. For example, some participants reported that they requested time to catheterize during work or use of a bed for pressure sore prevention. The participants also learned to use services to implement their self-management without assistance from their family. Some participants actively managed services, such as home care workers.

At present, the [disability support] program doesn't allow me to have a care worker 24 hours a day. So, I'm talking to the social worker about transferring to the program that allows me to have the service 24 hours a day. Well, I can't actually do everything on my own even if I live alone, so I think I have to do it by using the care worker's help on it. So, now, I'm thinking about it, I think I should make a transition to it little by little. (609−615, 04)

However, others were dependent on their parents for the service management. Thus, there were variations in their roles in the utilization of services.

3.4. Theme 4: proceeding with and worrying over adult health care

The participants described their experiences of transferring to adult health care or to health care services different from the ones they used in their childhood. Two sub-themes included: (a) *transferring to adult health care* and (b) *worrying over health status and receiving health care*.

3.4.1. Feeling unprepared to transfer to adult health care

Most of the participants described their experiences of transferring from pediatric-focused health care services to adult care services.

Participants reported several different pathways of transferring to adult health care. Three participants reported that in their childhood they received health care at a children's hospital, which had multiple specialists including neurosurgery, urology, orthopedics, and ophthalmology. Except for one participant who continued to receive care at the children's hospital after she turned 18 years old, those participants transferred to adult health care since they were no longer eligible for care at the children's hospitals. These participants shared their experiences of transferring from pediatric to adult-centered health care without transitional support.

> Children's hospitals are for children who are 18 or younger, right? Because the government says that you are called "a child" until you are 18 years old… You know, you are a child until you are 18. So, I used to go to the children's hospital until I was 18. … Then, one day the doctor said to me, "Now that you're already 18, you should graduate from the children's hospital." So, I graduated from the children's hospital shortly after I turned 18 years old. (497−504, 04)

Half of the participants reported that they went to multiple specialists at different health care facilities since childhood. Some participants transferred to health care services different from the ones they used in their childhood for reasons other than transition to adult health care, such as its closeness to their houses and retirement of the physician. In addition, one participant reported that she moved from the university hospital to the nearby clinic for ophthalmology follow-up because her condition was sufficiently stable.

Three participants described their feelings about communication with the health care providers. They reported that the health care providers whom they saw in their childhood or they continued to see over the years were approachable and knew them well. They also described their smooth and frank communication with those providers on their condition and self-management.

> I feel like [the health care providers] at the hospital I used to go to before treated me more empathically. … I feel like [the providers] at the hospital I go to now treat me more poorly (laughs). (295−298, 307, 05)

3.4.2. Worrying over health status and receiving health care

Several participants had worries over their future health status. Their worries were mainly over worsening of complications or conditions related to SB. Other participants described their concerns over receiving health care. These participants were concerned about the lack of adult health providers who had expertise in SB, possible risks in emergency situations, and financial burden of the health care.

One participant described his effort to explain both his condition and health needs to health care providers who did not specialize in SB. He found the process of receiving health care from such providers arduous.

> I have a family doctor, so it's easy in my case because I can count on the doctor when I need to receive primary care, but, when I see other doctors I have to explain my condition and what medicine I can't take due to the condition. In addition, I have to explain my whole medical history to the doctor when I'm hospitalized, and the process is so tough, even tougher than explaining my symptoms. (481−486, 08)

3.5. Theme 5: Establishing and maintaining relationships with friends

This theme captured participants' experiences of nurturing relationships with their friends and challenges with their friendship, including four sub-themes: (a) *establishing friendships with peers who have a disability*, (b) *maintaining friendships with peers in school and community*, (c) *struggling to be involved in a romantic relationship*, and (d) *lack of peer support*.

3.5.1. Establishing friendships with peers who have a disability

Some participants reported that they established relationships with their peers with SB or with other physical disabilities. Two participants who went to special needs junior high schools and/or high schools reported that they had opportunities to nurture friendship with other students with SB or other physical disabilities at school. One participant shared his experience of growing his friendship with peers through the activities at the special needs school and the student dormitory. Another participant reported that she nurtured friendship with her peers with SB of the same age through wheelchair sports.

> It's fun to play the sport, and I could make friends there. I made friends with people in the same age with the same condition. I chat with them and take a trip with them, and stuff like that. (62−65, 05)

One participant shared her challenge with relationships with her classmates at a special needs high school. She perceived the disagreement over perspectives on career choices as a barrier to friendship.

> I went to the employment transition support program and then got a job at a regular company. Other students went to programs with different goals, and because of the difference, I felt that I could never get along with them… (343−346, 02)

3.5.2. Maintaining friendships with peers in school and community

Participants described the relationships with their friends at school and in their communities. Some participants shared their positive feelings about their relationships with those friends. Continued friendships from childhood were especially valued. One participant described her strong bond with friends from high school and expressed her gratitude for the friendship that enabled her to participate in various activities, such as taking a trip.

> I really appreciate it when I enjoy myself with [my close friends from high school], and there was once a time when I said to them, "I've had a lot of great experiences," and then they just seemed comfortable saying, "Why don't you do what you think is fun?" So, I really like it. (737−740, 03)

Some participants experienced difficulties with maintaining relationships with their friends in community. One participant shared his experience of separation from his friends in his community due to his enrolment into special needs school.

> The relationship with my friends from elementary school…, they went to the neighborhood junior high school, and I went to the special needs school, so, well, my friends at elementary school, uh, I am still friends with one of them, but you know, the relationship with them got broken from that time. (72−76, 04)

Another participant described her encounter with the biased attitude in people around her toward her condition and disability.

3.5.3. Struggling to be involved in a romantic relationship

Participants had differing feelings about being involved in a romantic relationship. Some of them had a sense of expectation and stated that they hoped to have a romantic partner. On the other hand, others expressed concerns or hesitation over getting involved in such a relationship or getting married although few participants explicitly associated the concerns with their condition/disability.

> If the person says, "Do you want to go out on a date?" but there is no accessible bathroom near the place, then I won't be able to be there. I would feel sorry for not being able to fulfill the wish, but there is nothing I can do about it. (273−275, 08)

3.5.4. Lack of peer support

Two participants sought more peer interactions and activities. The participants who attended regular schools tended to hope for more

communication with peers with SB or other disabilities. These participants hoped to connect with individuals with SB, share their experiences, and support each other.

> So, when it came to the question like "what people with disabilities in the same age are like?" I had little chance to talk with people [with disability] in the same age. (105−108, 01)

3.6. Theme 6: broadening scope of experiences

Participants described the process in which they broadened the scope of their experiences during transition to adulthood. The theme included two sub-themes: (a) *creating opportunities by learning to get around on one's own* and (b) *barriers to broadening scope of experiences.*

3.6.1. Creating opportunities by learning to get around on one's own

Many participants became able to get around by public transportation, by car, or using wheelchair, thereby broadening the scope of their experiences. By learning to get around without their family's assistance, they had more opportunities to enjoy spending time with friends. Also, one participant reported that he became able to enjoy spending time alone. This impact of being able to get around on one's own was not limited to the broadened sphere of activities; it also influenced various aspects of life, including encounters with people and a way of thinking.

> By going to school by train, I met many people, and I encountered various emotions, and in myself I think I probably wouldn't have thought like this if I hadn't gone to school by train. (129−131, 03)

3.6.2. Barriers to broadening scope of experiences

Some participants shared their challenges in broadening the scope of their experiences. Lack of accessible transportation, insufficient built environment accessibility, and insufficient care worker services for individuals with disability led to the challenges. One participant reported that there were times when she gave up opportunities to go out with her friends due to lack of accessible transportation. In addition, another participant stated that he hesitated to go out with his friends because he was afraid of bothering his friends due to the limitations on his activities.

> I got my driver's license when I was a first-year college student, and so [when I was in high school] my parents gave me a ride when I went out [with my friends] and I had to tell them what time I was going home, and stuff like that. Isn't that a bit annoying in the circle of friends or students? I had to say to them, "I've got to go now."… I thought that I might end up causing them trouble… So, I just went to Karaoke with some of my close friends when I graduated from high school, but other than that, I never went out or stayed somewhere overnight with someone when I was a student. Never. (239−248, 08)

4. Discussion

The major contribution of this study was the delineation of the major challenges EASB face when transitioning to adulthood in Japan. Specifically, our participants struggled with employment, determining what it means to be EASB, experiencing social isolation, and navigating the uncoordinated transition to adult health care.

Our findings suggested that the primary concern of EASB in Japan was struggling with finding a job and confronting challenges in the workplace. Employment for individuals with disabilities is limited in Japan although it has been promoted by adopting employment promotion systems, including legal employment quotas at regular companies through the special subsidiary program.[37] The challenges and concerns related to under-employment among EASB were also reported in research conducted in North America.[18] Barriers to employment for individuals with SB need more attention internationally.

Participants in our study explored the meaning of "becoming an adult". The Japanese social and cultural context is vital in understanding their developmental challenges. Similar to other developed countries, becoming financially and psychologically independent as well as taking care of oneself are valued during emerging adulthood in Japan.[38] However, since the mid-1990s, due to the limitations of Japanese economy, typical emerging adults have experienced difficulty achieving milestones, such as living on one's own, getting married, and having children.[39] In addition, co-residence between young adults and their parents tends to be accepted in Japanese culture.[40] Considering limited opportunities for social participation due to the health care needs of EASB, it may be even more difficult for them to achieve the typical milestones of adulthood. Emerging adults in other countries with strong family-centered cultures, such as Italy, may have similar experiences.

Participants of this study shared the process in which they learned to implement behaviors needed to manage their SB. Previous research conducted in the U.S. found that peer conferences and camps provided young people with SB with opportunities to learn self-management behaviors.[16] In this study, participants described factors that led to their learning self-management behaviors, including changes in living environments and in family relationships and role structure. These changes in their lives made them motivated or feel the need to perform self-management behaviors more independently.

Some participants coordinated their bowel and bladder care routines to make it fit in with their daily lives. Further, some participants stated that they monitored and assessed their self-management skills and outcomes. This finding was consistent with previous research that revealed young people's engagement in self-management activities.[17] Preparation of environment for self-management by requesting understanding and accommodations, which had been described in previous research in a school context,[18] was reported in the context of employment by the participants of this study. In addition, some participants learned to rely on the help from people outside family. This finding may suggest that the participants of this study, most of whom had moderate to severe physical disability, explored a feasible way to implement self-management outside the home when they broadened their range of activities.

The typical participants in our study reported lack of planning and preparation for the transition to adult health care. The findings in both our study and previous research[25,41–43] may reflect insufficient transitional support for EASB and other chronic conditions (e.g., cerebral palsy, epilepsy, organ transplant recipients). Lack of professional knowledge regarding chronic conditions and disability including SB in adult health care settings was also noted in Canada.[22] EASB may not have encountered this type of challenges until they move from pediatric to adult health care because pediatric care facilities tend to provide comprehensive, coordinated health care services that meet their complex health care needs.

Participants of this study described how they established and maintained relationships with their friends at school and in community as well as their peers with the same condition or other physical disabilities. Consistent with previous research that revealed challenges with relationship with friends both in North America and in Japan,[15,16,27] social isolation and difficulty with developing romantic relationships were major issues for participants in our study. Previous research showed that community participation in leisure and recreation activities and social integration is low in this population.[14] "Normative expectation about able-bodiedness"[44] may become a barrier to friendship and social participation for individuals with chronic conditions. In addition, previous research showed that inferiority feelings were significantly higher and subjective well-being was lower in Japanese EASB than in typically developing controls.[26] To reduce isolation and promote mental health, initiatives that connect individuals with disabilities to a broader community are needed.

Disagreement over values with peers with SB or other disabilities was also reported in this study. Friendship quality tends to change during the

emerging adulthood period, and it is typical that emerging adults experience some conflicts.[45] Nonetheless, it is important to promote the quality of relationships with peers, since further evidence on psychological health in EASB in Japan supports positive association between the number of peers with SB and sense of happiness.[46]

The participants' experiences of barriers to broadening the scope of their experiences implied limited opportunity for social participation due to insufficient accessibility of the environment and inadequate support for EASB in Japan. This finding is consistent with the previous research that demonstrated inadequate participation in social activities in adolescents with SB in the U.S.[14] It also suggests a higher risk for reduced adaptation outcomes in the light of the EMCEA.[10]

5. Trustworthiness of findings

Several techniques were used to enhance trustworthiness in qualitative research including credibility, transferability, dependability, and confirmability.[47] Credibility was addressed by documenting and assessing the influence of timing and environment of the interview. In addition, data were analyzed with constant supervision of two researchers in nursing who had extensive experience in qualitative research and in research on self-management and transition of individuals with SB. Documentation on the context where the research was conducted, methodological decisions, analytic decisions, and personal responses to research elements was done to enhance dependability and confirmability.[48]

6. Limitations

A potential limitation of this study is small sample size (n=8). In particular, romantic relationships in EASB may not be fully understood in the current study as no participants reported their experience in such relationships. Data saturation was not achieved in this study due to constraints on time and resources and difficulty with recruiting participants. The themes need future confirmation with larger sample. However, this is the first study to describe the experience of transition to adulthood and adult health care in Japan. Another potential limitation is that the use of telephone or Skype interviews prevented the researcher from seeing nuances of communication with interview or from confirming whether each participant had sufficient privacy in the place they chose when participating in the interview. If there was a lack of privacy, this could have prevented participants from fully answering questions of personal and private nature. The use of technology to conduct interviews, might also have been a strength, because this interview method allowed data to be collected from individuals who represented a wider geographical area including both urban and rural areas of Japan and was more convenient for participants who did not need to travel to an interview site.

The participants in this sample were all members of the Spina Bifida Association of Japan. As a result, the sample may consist of individuals who are more active or have more opportunities to receive support when they belong to a patient advocacy group compared to those who do not. In this study, the sample did not include individuals with cognitive challenges. Consequently, the experiences of individuals who have cognitive or other communication difficulties may not be reflected in the findings. Also, the participants of this study had myelomeningocele and primarily consisted of individuals with physical limitations necessitating the use of a wheelchair for ambulation as well as bowel and bladder care and may not reflect the experience of those who have a milder form of SB.

7. Implications for practice

The participants shared experiences of struggling with securing and thriving in a job. Few participants reported experiences of receiving professional support in a timely manner when searching for employment. Nurses and other health care providers should provide appropriate information on possible employment pathways as well as available employment support programs to the emerging adults and assist them in making decisions by offering advice on self-management and workplace accommodations. Health care providers also need to frame self-management interventions, especially those that optimize bowel and bladder continence, as important employment-related outcomes. In addition, children and adolescents need to be given typical household and family chores and responsibilities to build pre-employment skills.[10,49]

Struggles with transition to adult health care may be alleviated if the health care system had mechanisms to assist EASB to plan and prepare for the transition. Currently, transition support programs for Japanese individuals with chronic conditions are limited and typically provided only at large health care facilities.[50] To reach all individuals with chronic conditions and their families, programs need to be easily accessible for individuals in both urban and rural areas. Nurses and other health care providers in transition support programs can assist emerging adults with chronic conditions by helping them identify adult health providers and learn to assume adult role in health care setting. In addition to maximize transition to adult health care, pediatric health care providers need to foster function and independence by setting expectations for adult independence and the transition to adult care throughout the family's healthcare trajectory.[49]

Educational programs for healthcare professionals who work with adults are needed to improve the quality of transition. Emerging adults and their families' concerns about care coordination, future health status, and adult health care should be discussed during an organized and planned approach to transition readiness in adolescence. However, adult health care providers are often unaware of these issues and needs. The educational programs need to address knowledge of the medical and social issues related to transition to adult life and health care.[49] The Basic Act for Child and Maternal Health and Child Development, which aims to provide coordinated care for emerging adults with chronic conditions in transition, was enforced in Japan in 2019.[51] Seeking national and local funding to develop health policy initiatives to support EASB in transition should be a priority for the healthcare communities throughout the world.

The fact that participants perceived lack of support from peers with the same condition is also an important point to consider. Lindsay et al.[18] pointed out importance of social support from peers in transition to post-secondary education and employment. Further evidence supports that adapted sports programs, camp opportunities and social support programs enhance social functioning and decrease isolation.[52,53] Community-based initiatives that are culturally sensitive and create these opportunities should be supported for children, adolescents and young adults.

8. Recommendations for future research

At present, no transition support programs for individuals with SB in Japan appear to be informed by theories or developed based on research findings. One of the priorities for future research is to develop and test interventions to facilitate healthy transition to adulthood and adult health care. The findings of this study will contribute to research that develops and tests interventions that are culturally sensitive. Findings will also contribute to instrument development to quantify transition readiness and its associated outcomes for EASB. The findings from this study also support similar initiatives to develop transition support programs internationally. In addition, the findings of this study support the need for further research on risk and protective factors of employment and social participation, and defining barriers and facilitators of health care services for adults with SB. This is consistent with the research gap pointed out in the guidelines of transitional care.[49]

9. Conclusions

This qualitative descriptive study explored experiences of emerging adults with spina bifida in Japan during their transition to adulthood. Participants shared the unique perspective of how to "become an adult" as a person with spina bifida in Japan. Emerging adults with spina bifida in Japan struggled with finding a job and working, establishing relationships with friends, implementing self-management, or making transition to adult health care. While the themes identified in this study were generally consistent with previous research, emerging adults with spina bifida in Japan had unique experiences in the Japanese social context. Programs facilitating transition to adult life and adult health care based on research and guided by theories will be needed.

Ethics statement

This study was approved by the Institutional Review Boards of the universities in USA and Japan. This is the authors' original work, which has not been previously published elsewhere. All authors have approved the manuscript and agreed with its submission to Health Care Transitions.

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Shiho Murayama: Writing – original draft, Methodology, Investigation, Conceptualization. **Jennifer J. Doering:** Writing – review & editing, Supervision, Methodology. **Kathleen J. Sawin:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data Availability

The data that has been used is confidential.

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