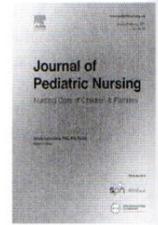




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## Nurse-led eHealth transition care program for adolescents with spina bifida: A feasibility and acceptability study

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### ABSTRACT

**Purpose:** This study aimed to evaluate the feasibility and acceptability of a nurse-led eHealth transition care program for adolescents with spina bifida.

**Design and methods:** This study used a single-arm, pretest-posttest intervention study. Adolescents with spina bifida, aged 12–15 years, and their parents participated in the program. A 6-week program was delivered through an online platform in real-time by nurses. We evaluated feasibility and acceptability using criteria such as the completion rate, program satisfaction, changes in transition readiness, social support, career preparation behavior, sexual knowledge, and sexual worries at three time points from July to September 2021.

**Results:** Thirteen adolescents completed all sessions and surveys (13/14, 92.9%). All adolescents expressed high satisfaction with both the content and delivery methods of the program. Significant benefits in transition readiness, career preparation behavior, and sexual knowledge were identified over the study period. However, the evaluation of social support and sexual worries did not demonstrate any significant improvements. Additionally, through family counseling, adolescents benefited from experiences such as reflecting on their current transition readiness, setting and achieving individualized goals and plans using a self-checklist with their parents and nursing professionals.

**Conclusion:** This nurse-led eHealth intervention was feasible and acceptable for adolescents with spina bifida. Furthermore, our results highlight the practicability and the potential for strategic dissemination of using this eHealth program in transitional care during the COVID-19 pandemic.

**Practice implications:** The eHealth transition care program contributes to broadening existing nursing interventions not only in medical areas but also in daily life areas.

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### Introduction

Spina bifida (SB) is the most common congenital malformation, occurring because of incomplete closure of the neural tube (Phillips et al., 2017). Owing to a range of spinal cord impairments, various levels of impairment related to mobility, sensation, cognition, bladder, and bowel function developed in children with SB (Liu et al., 2018; Sawin et al., 2015).

With advances in treatment, most children with SB can survive into adulthood (Beierwaltes, 2019; Phillips et al., 2017; Sawin et al., 2015; Wiener et al., 2017). However, recent studies on health outcomes in adults with SB have reported increased incontinence, obesity, and chronic pain (Bendt et al., 2020; Lidal et al., 2021), resulting in secondary complications, such as cardiovascular disease, pressure ulcers,

restricted mobility, and decreased quality of life (Lidal et al., 2021; Wiener et al., 2017). As most of these complications are preventable, providing adequate health care support to children and adolescents with SB could aid in their transition to healthy adulthood (Fremion & Dosa, 2019; Logan et al., 2020).

Many previous studies have suggested the necessity of well-established interventions for transition, particularly during adolescence, and have emphasized the role of nurses as transitional care coordinators for enhancing transition readiness among adolescents with SB (Betz et al., 2015, 2016; Hopson et al., 2018; Patel et al., 2019; Seeley & Lindeke, 2017). In the United States and Europe, many nurses act as coordinators of transition care programs, and the effectiveness of nurse-led programs has already been reported (Betz et al., 2015, 2016; Choi, Bae, & Jang, 2021; Hopson et al., 2018; Patel et al., 2019; Seeley & Lindeke, 2017). Among healthcare professionals (HCPs), nurses are in the best position to understand the daily challenges experienced by adolescents with SB (Holmbeck et al., 2021). A systematic review of transition programs provided preliminary evidence that nurses initiated

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the development and implementation of most programs that were reviewed (Betz et al., 2016; Choi, Bae, & Jang, 2021; Seeley & Lindeke, 2017).

However, the systematic review suggested that existing transition programs were limited due to the lack of a systematically developed program (Choi, Bae, & Jang, 2021). Therefore, in a previous study, we methodically developed a nurse-led transition care program for adolescents with SB using a multidisciplinary panel that included both clinical experts and young adults with SB (Choi, Yun, & Bae, 2022). When the program was developed, we considered the possibility of the COVID-19 pandemic continuing for a long time, presenting challenges for participants gathering in one place. Hence, we developed the real-time eHealth program (Choi, Yun, & Bae, 2022). Consequently, this study aimed to evaluate the feasibility and acceptability of a nurse-led eHealth transition care program for adolescents with SB.

### Conceptual framework

Of the theoretical frameworks explaining the transition of adolescents with SB (Holmbeck et al., 2021; Hopson et al., 2018; Swanson, 2010), the Life Course Model (Swanson, 2010) provides a comprehensive viewpoint, considering multidimensional factors affecting the transition according to developmental stages. The Life Course Model focuses on long-term outcomes related to what may happen to children when they become adults (Swanson, 2010). Children and their families move forward with a long-term outlook and perform appropriate tasks step-by-step according to their developmental stages from preschool through young adulthood to prepare for the future (Swanson, 2010). In addition, based on the biosocial model, the Life Course Model contends that environmental factors could affect children's development as a result of the interactions between impairments and environmental factors (Swanson, 2010). Hence, it considers the responsive and supportive environment that could lead to a higher degree of function and participation (Swanson, 2010). Therefore, this model includes three domains: self-management and health (e.g., self-care, bladder or bowel management, physical activity, safe sex practices), personal and social relationships (e.g., family, friends, peer groups), and major areas of life (e.g., education, employment, work; Swanson, 2010). By enhancing said three domains including the acquisition of self-management knowledge, transition readiness would be improved. Based on the Life Course Model, this study aimed to examine the applicability for future research, by evaluating the feasibility and acceptability of the eHealth transition care program for adolescents with SB.

### Methods

#### Study design

This study used a single-arm, pretest-posttest design to evaluate the feasibility and acceptability of a 6-session eHealth transition care program, consisting of two individual sessions and four group sessions that included an online evaluation at baseline (T0), post-intervention (T1), and a 4-week follow-up (T2; Fig. 1).

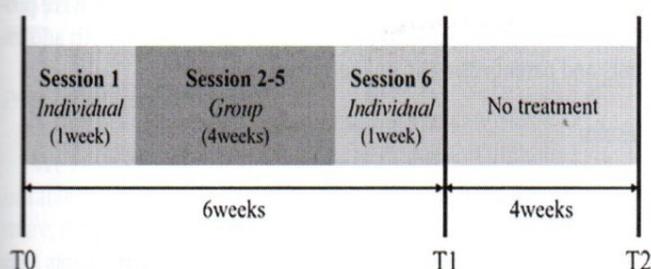


Fig. 1. The design of the nurse-led eHealth transition care program.

#### Participants and recruitment

Participants were adolescents with SB and their parents who underwent regular check-ups for SB at the largest SB clinic at Severance Children's Hospital in Seoul, South Korea. For adolescents with SB, the eligibility criteria included the following: (1) adolescents with SB who were aged 12–15 years, (2) an ability to access online platforms using any smart devices with or without the help of their parents, (3) an ability to communicate verbally with others, and (4) provided voluntary consent to participate in this study. The exclusion criteria included: (1) having an illness or disabilities other than SB and (2) being unable to communicate with others and respond to the questionnaires.

According to the rule of thumb, the sample size of 12 per group is appropriate for a pilot study focusing on estimating the average and variability in planning a large-scale follow-up study (Julious, 2005). Additionally, in a previous study, 14 adolescents and their parents were included in a pilot study (single group pre-and post-test design) of a transitional care program for those 11–17 years old with SB in the United States (Seeley & Lindeke, 2017). Thus, based on these references, we planned to recruit 12–14 study participants.

Participants were recruited using two methods: identification through a patient dataset or cooperation with an outpatient SB clinic. First, participants who were included in the patient dataset in our previous study and consented to be contacted for a follow-up study received an invitation via text message. Second, pediatric nurse practitioners in the SB clinic at Severance Children's Hospital introduced this study to patients who regularly visited the clinic. Finally, those who wished to participate in this study were contacted telephonically to explain the study's aims and methods.

#### Intervention and procedures

The research team systematically developed this nurse-led eHealth transition care program (Choi, Yun, & Bae, 2022) for adolescents with SB based on the Life Course Model (Swanson, 2010). In a previous publication (Choi, Yun, & Bae, 2022), we described its well-organized development process and program details. This eHealth program (Appendix 1) comprised six sessions, including two individual sessions and four group sessions, and was delivered through the online video platform in real-time. A principal investigator (i.e., a professor of nursing) took the initiative of leading the entire program, and the research team, including six nursing professionals and two social workers, delivered the program together.

During the first and last sessions, the principal investigator, along with the adolescent participants and their parents, discussed and identified individual goals, established plans, and checked the achievement of transition goals, with consideration to their family, environmental, and personal factors. Before each session, adolescents checked their current transition readiness using the transition readiness checklist. Subsequently, an individual transition plan (Hopson et al., 2019) translated into Korean by the research team was provided to each adolescent to encourage them to practice toward their goals. From the second to the fifth session, each session was divided into lectures in the first half and group activities in the second half, based on the Life Course Model (Swanson, 2010).

#### Domain 1: self-management/health (self-care)

Six lectures were provided regarding health care related to SB: (1) an overview of SB, (2) orthopedic and integument management, (3) health care system, (4) bladder management, (5) bowel management, and (6) sexual health. The educational content on the said six topics were developed and delivered by the pediatric nurse practitioners currently working in the relevant clinical fields and validated by the multidisciplinary clinical specialists. At the end of each lecture, the principal investigator led a question-and-answer session related to the topic.

*Domain 2: personal and social relationships*

After the lectures, two social workers conducted group activities for cognitive-behavioral-motivation (CBM), divided into a boys' and girls' group due to the sexually sensitive nature of the adolescence. During the CBM program, adolescents shared their experiences and coping strategies related to their relationships with family and friends and school life.

*Domain 3: employment/income support (major life areas)*

In the fifth session, an adult mentor with SB shared experiences about their school days, friendships, college entrance, career preparation, employment, and romantic relationships and shared her sincere advice or tips to the adolescents.

*Measures*

We measured outcomes consistent with three domains of the Life Course Model (Swanson, 2010) thrice using self-report questionnaires delivered and completed online between July and September 2021.

*Domain 1: self-management/health (self-care)*

*Transition readiness (self-management skills).* We used the revised Transition Readiness Assessment Questionnaire-Spina Bifida (TRAQ-SB; Johnson et al., 2019) after we obtained permission from the original author to translate it into Korean. TRAQ-SB is combined with both a 20-item disease-independent measure of general self-management skills from the original Transition Readiness Assessment Questionnaire (TRAQ; Wood et al., 2014) and an 11-item SB-specific measure on the self-management skills that were essential for transition (Johnson et al., 2019). The research team translated the TRAQ-SB into Korean, and then a bilingual pediatric urologist reviewed the translation, which was back-translated by a professional translation company. Next, six professionals, including two pediatric urologists, two pediatric nursing professors, and two pediatric nursing practitioners, assessed its content validity. The scale-content validity index (CVI) score was 0.87, with item-CVIs ranging from 0.33 to 1.00. We deleted one item ("Do you get financial help with school or work?") since it was inappropriate for the Korean context where the middle school did not offer such financial support and it was rated with an item-CVI of 0.33 by three experts. Thus, the Korean translation of the TRAQ-SB used in this study included 30 items. The disease-independent measure includes five domains: Appointment Keeping, Tracking Health Issues, Managing Medications, Talking with Providers, and Managing Daily Activities (Wood et al., 2014), and the SB-specific measure include Self-Management Knowledge and Skills Related to Shunt Care, Bladder or Bowel Management, and Integument Management (Johnson et al., 2019). The response patterns on the TRAQ-SB were based on the Stages of Change Model (Prochaska & Diclemente, 1986): Stage 1 (Pre-contemplation: "No, I do not know how to do this"); Stage 2 (Contemplation: "No, but I want to learn"); Stage 3 (Initiation: "No, but I am learning how to do this"); Stage 4 (Action: "Yes, I have started doing this"); Stage 5 (Mastery: "Yes, I always do this when I need to"). Higher scores indicated better transition readiness, including general and SB-specific self-management skills (Johnson et al., 2019). The Cronbach's alpha was 0.92 (Johnson et al., 2019).

*Sexual health.* To assess sexual health, we used the Spina Bifida Sexuality Knowledge Questionnaire (Sawin et al., 2002) and the Spina Bifida Worries Scale (Sawin et al., 2002). The Spina Bifida Sexuality Knowledge Questionnaire is a 13-item tool assessing sexuality knowledge related to SB, with items rated on a 5-point Likert scale, from 1 (*strongly disagree*) to 5 (*strongly agree*). The Spina Bifida Worries Scale is a 7-item questionnaire assessing the worries related to SB rated by a 6-point scale from 0 (*no worry at all*) to 5 (*worry a lot*). Higher scores indicated a higher degree of SB-specific sexuality knowledge and worries. The Cronbach's alphas were 0.80 and 0.83, respectively, at its development (Sawin et al., 2002).

*Domain 2: personal and social relationships*

*Social support.* We used a 24-item tool, namely social support, to assess the perceived social support from parents, friends, and teachers (Han & Yu, 1996). Adolescents rated items on a 5-point Likert scale, from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher scores indicated a higher degree of perceived social support. The Cronbach's alpha for the scale was 0.88 at its development (Han & Yu, 1996).

*Domain 3: employment/income support (major life areas)*

*Career preparation behavior.* We used a 10-item instrument, namely career preparation behavior, to measure adolescents' degree of execution related to practical and specific actions for career selection (Kim & Kim, 1997). Adolescents rated items on a 5-point Likert scale, from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher scores indicated a higher degree of behavioral execution for career preparation. Cronbach's alpha for this tool was 0.85 at the time of the tool development (Kim & Kim, 1997).

*Program satisfaction.* We assessed the acceptability through program satisfaction after completing the sixth session program using 10-item questionnaires. Adolescents rated the satisfaction of each content and the appropriateness of intervention delivery methods rated on a 6-point scale, from 1 (*not helpful at all*) to 6 (*very helpful*). Furthermore, overall program satisfaction was measured using a 10-point numerical rating scale. In addition, adolescents commented on what was particularly impressive or helpful in the program and what required improvement in the future.

*Transition readiness checklist.* Prior to the first and the last session, each participant reviewed their transition readiness using a 50-item transition readiness checklist (Appendix 2) developed by our research team (Choi, Yun, & Bae, 2022). This checklist comprises five domains: health care (e.g., an overview of SB, bladder or bowel management, medication management, neurological management, orthopedic management, and sexual health), the health care system, daily and school life, preparing for the future, and relationships with family. Responses were measured using a three-category scale (*yes, no, and not applicable*). Using this checklist, we established individual transition plans and goals for each adolescent.

*Data analysis*

Data were analyzed using IBM SPSS Statistics software (version 26.0; IBM Corp., Armonk, NY, USA). Descriptive statistics were used to summarize the participants' characteristics and satisfaction, and repeated measures analysis of variance were used to determine the program's effects. Statistical significance was set at  $p < .05$  for the two-tailed test.

*Ethical considerations*

Before conducting this study, ethical approval was obtained from the institutional review board of the Yonsei University Health System (No. 4-2021-0584). Voluntary participation, anonymity, and confidentiality were also addressed. All participants were informed that they had the right to decline participation at any time. Details of the study were provided, and written informed consent was obtained from both adolescents and parents using an online survey.

**Results***Participant characteristics*

The demographic and clinical characteristics of the participants ( $n = 13$ ) are described in Table 1. The mean age of the adolescents was 13.8 years ( $SD = 0.8$ ). The participants' residences were evenly distributed

**Table 1**  
Participants' characteristics (N = 13).

Variables	n (%)
Gender	
Male	7 (53.8)
Female	6 (46.2)
Age (Range: 12–15), M (SD)	13.8 (0.8)
Area of residence	
Capital region	7 (53.8)
Provinces	6 (46.2)
Current romantic relationship	
Yes	3 (23.1)
No	10 (76.9)
Diagnosis	
MMC	3 (23.1)
LMMC	8 (61.5)
Unknown	2 (15.4)
VP shunt in situ	
Yes	2 (15.4)
No	11 (84.6)
Method of voiding <sup>a</sup>	
Self-voiding	6 (46.2)
CIC	9 (69.2)
Urinary incontinence	
Yes	6 (46.2)
Wearing pads <sup>b</sup>	2 (15.4)
No	7 (53.8)
Method of defecation <sup>a</sup>	
Self-defecation	7 (53.8)
Enema	6 (46.2)
Laxatives	2 (15.4)
Fecal incontinence	
Yes	3 (23.1)
No	10 (76.9)
Method of mobility <sup>a</sup>	
Independent	8 (61.5)
Orthosis	3 (23.1)
Crutches	2 (15.4)
Wheelchair	3 (23.1)

Notes. <sup>a</sup>Multiple response allowed; <sup>b</sup>Sub-question asking the number of participants with urinary incontinence whether wearing pads; M, mean; SD, standard deviation; CIC: clean intermittent catheterization, LMMC: lipomyelomeningocele, MMC: myelomeningocele, VP shunt: ventriculo-peritoneal shunt.

throughout the metropolitan area and provinces. Overall, 23.1% ( $n = 3$ ) of adolescents reported currently having a romantic relationship. Numerous participants were diagnosed with lipomyelomeningocele (LMMC; 61.5%), required clean intermittent catheterization (CIC; 69.2%), needed additional methods of regular bowel emptying, such as transanal irrigation (46.2%), and had urinary and fecal incontinence (46.2% and 23.1%, respectively). Moreover, 61.5% ( $n = 8$ ) could walk independently without any device. Only 15.4% ( $n = 2$ ) had a V-P shunt in situ.

#### Program completion rate

Initially, 14 adolescents with SB, including seven boys and seven girls, participated. After the second session, one girl (15 years old) could not complete the program due to personal schedules that overlapped with our study. Therefore, 13 adolescents completed the transition program and all questionnaires, with a program completion rate of 92.9% ( $n = 13/14$ ).

#### Program satisfaction

We evaluated participants' satisfaction with the program, as shown in Table 2. Overall satisfaction was high, with a score of 9.1/10. Furthermore, the program's contents and delivery methods were valued as >5 of 6. The mentorship program received the highest score. In addition, Table 3 presents the list of comments provided by the adolescents and their parents.

**Table 2**  
Satisfaction with the transition care program (N = 13).

Domain	Subdomain	Item	M (SD)
Content <sup>a</sup>	Lecture	Overview of spina bifida	5.3 (0.8)
		Management of mobility and integument	4.9 (1.0)
		Healthcare system	5.3 (0.8)
		Bladder management	5.2 (0.9)
		Bowel management	5.2 (0.9)
	Group activity	Sexual health management	5.3 (0.9)
		Relationships with my family	5.1 (0.6)
		My school life	5.4 (0.7)
		Relationships with my friends	5.2 (0.8)
		Mentoring	Mentoring with seniors
Methods <sup>a</sup>	Delivery	Delivered by real-time and online platform	5.2 (0.7)
	Duration	Duration per session	5.1 (1.0)
	Period	Period of the entire program	5.2 (0.8)
Establishment of the individual transition goals and plans <sup>b</sup>			8.8 (1.4)
Overall satisfaction <sup>b</sup>			9.1 (1.3)

Notes. M, mean; SD, standard deviation; <sup>a</sup>Likert scale of 1–6 from 1 (strongly dissatisfied) to 6 (strongly satisfied); <sup>b</sup>Likert scale of 1–10 from 1 (strongly dissatisfied) to 10 (strongly satisfied).

**Table 3**  
Adolescents' and their parents' comments regarding the transition program.

Adolescents' responses
<b>What was particularly good or impressive about this program?</b>
• Useful content ( $n = 5$ )
• Mentoring ( $n = 4$ )
• Talking with peer group (same disease and gender; $n = 2$ )
• The method used to run the program ( $n = 2$ )
<b>What do you think needs improvement in this program?</b>
• Some terms and content were a bit difficult. ( $n = 2$ )
• The time length per a session was a bit long. ( $n = 2$ )
• It seems that a lot of time was wasted because the discussions with my peers had limited participation. There were some shy friends, so I think it would have been nice to communicate using a chat feature instead of talking on the microphone. ( $n = 1$ )
Parents' responses
<b>What was particularly good or impressive about this program?</b>
• It seems to be motivated by self-management (e.g., bowel management such as enema and laxatives, hospital visiting schedule, outpatient system, medication management; $n = 8$ )
• They were positively influenced by the mentor, so they became interested in going to college and thinking about their career path in detail. ( $n = 3$ )
<b>What do you think needs improvement in this program?</b>
• It was burdensome to tell their story and to be asked questions. ( $n = 2$ )

#### Mean changes in outcome variables

Table 4 presents the mean change for each outcome variable at each evaluation point, with a significance level of  $p < .05$  for the effects of the transition care program on the outcome variables. The mean changes in transition readiness, career preparation behavior, and SB sexuality knowledge showed significant increases over the intervention period ( $p < .05$ ). However, social support and SB worries did not significantly change over the study period.

#### Transition readiness checklist

Individual transition readiness was evaluated using a self-checklist before each family counseling session (Fig. 2). After completing the program, all participants' transition readiness improved across all domains, except for a slight decrease in the domains for daily and school life and relationships with family.

#### Discussion

This study examined the feasibility and acceptability of a nurse-led eHealth transition care program for adolescents with SB in South Korea. Through transition program, adolescents could improve

**Table 4**  
Mean changes in a transition care program (N = 13).

Variable	M (SD)			p-value		
	T0	T1	T2	Overall	T0-T1	T0-T2
Transition Readiness	3.33 (0.20)	3.79 (0.16)	3.99 (0.13)	<0.001	0.027	0.001
Social Support	104.0 (4.06)	104.69 (3.85)	107.62 (3.64)	0.395	0.990	0.661
Career Preparation Behavior	3.09 (0.20)	3.50 (0.20)	3.63 (0.21)	0.006	0.112	0.013
Spina Bifida Sexuality Knowledge	3.63 (0.12)	4.32 (0.14)	4.34 (0.14)	<0.001	0.008	0.003
Spina Bifida Worries	1.36 (0.46)	1.17 (0.42)	1.48 (0.40)	0.780	0.990	0.990

Notes. M, mean; SD, standard deviation; T0, baseline; T1, post intervention, T2, 4-week follow up.

transition readiness, sexual knowledge, and career preparation behaviors. Furthermore, both the completion rate and program satisfaction showed the acceptability of the eHealth intervention. We discussed our findings across the three domains of the theoretical framework (Swanson, 2010)—self-management/health, personal and social relationships, and major life areas.

*Domain 1: self-management/health*

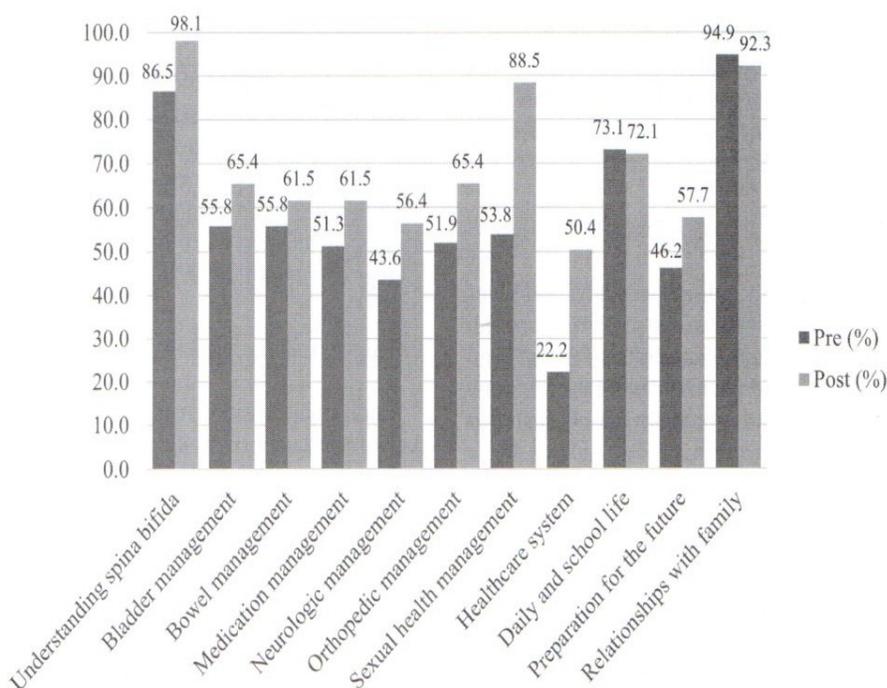
This domain included transition readiness and sexual health. First, adolescents' transition readiness (i.e., self-management skills) showed a significant improvement at the end of the program, maintaining an upward trend at the 4-week follow-up. Transition education is readily identified as a modifiable factor to enhance transition readiness (Varty & Popejoy, 2020), and transition readiness is sensitive to interventions by providers (Johnson et al., 2019). Numerous studies have reported that transition programs effectively improved transition readiness (Betz et al., 2016; Choi, Bae, & Jang, 2021; Kaufmann Rauen et al., 2013; Levy et al., 2020; Seeley & Lindeke, 2017). In addition, self-management skills are critical for the transition when HCPs lack knowledge regarding their adult patients' childhood-onset chronic diseases or disabilities (Swanson, 2010). Further, adolescence is a developmental stage that involves increased independence and autonomy, including gains in self-care responsibilities (Choi, Bae, & Jang, 2021; Hopson et al., 2018; Kaufmann Rauen et al., 2013). In particular, intensive self-management knowledge and skills related to complex chronic conditions are essential for older adolescents and young adults (Logan et al., 2020; Sawin et al., 2021). The need for these skills also increases the need for advanced and repeated interventions (Choi et al., 2019;

Sawin et al., 2021), such that enhanced self-management education to maintain continuity into adulthood should be further provided (Swanson, 2010).

Subsequently, sexuality knowledge related to SB significantly increased after the intervention. A previous qualitative study reported that young adults with SB want to talk about their sexual concerns with their HCPs and want to receive adequate care (Streur et al., 2019). People with SB are sometimes considered asexual, although they have sexual desires and are sexually active (Streur et al., 2019). In addition, many individuals with SB experience problems related to their sexual functioning (Choi et al., 2018; Choi, Ji, & Han, 2017). Therefore, our sexual education focused on their chronic conditions was beneficial for participants. However, participants' pre-test scores for sexual worries related to SB was 1.36 of 5 (0 = no worry at all), which was quite low, and there was no significant change observed at post-test. Adolescents were questioned regarding their future situations, such as pregnancy, becoming parents, and living independently. Because the participants were still middle school students, they might not have thought about this topic or been willing to discuss it during the online forums. A previous study found that adolescents with SB tended to not prepare for life as adults (Strömfors et al., 2017), and we speculated that they might not have reflected on these future issues related to their sexuality. However, since we did not conduct in-depth interviews with the adolescents, further studies on the sexual issues are necessary.

*Domain 2: personal and social relationships*

In this domain, we measured perceived social support (Han & Yu, 1996). Although the mean scores at each time point improved, there



**Fig. 2.** Transition readiness checklist for individual transition plan.

were no significant differences between pre- and post-tests, due to the large amount of variance in the data. This result is supported by a previous study on friendships among youth with SB that reported significant variations in the quality and reciprocity of friendships (Devine et al., 2012). Besides, among adolescents with milder physical disabilities, both emotional and social problems were more prominent than among those with severe impairments (Strömfors et al., 2017). Previous transition preparation programs for addressing the adolescents' emotional and social difficulties found that mean overall satisfaction with social support showed a slight, but non-significant increase (Betz et al., 2015), whereas a camp-based psychosocial intervention was effective in improving social functioning (Holbein et al., 2013). Therefore, additional targeted and enhanced interventions are needed to help adolescents develop quality social relations in future studies, particularly for those who have difficulties with relationships.

### Domain 3: employment/income support (major life areas)

Career preparation behavior significantly improved after the intervention at a 4-week follow-up. After the mentoring sessions, the adolescents shared that they became interested in entrance exams or employment supporting systems and started looking for further information. In a previous study, adolescents and young adults with SB needed additional support for major life areas (Swanson, 2010), such as education, employment, relationships, and finances (Choi, Bae, Ji, Jung, & Yang, 2021; Lindsay, Fellin, Cruickshank, McPherson, & Maxwell, 2016), and health insurance system (Choi, Bae, Ji, Jung, & Yang, 2021). Moreover, young adults with SB are at risk for community isolation due to low employment rates and independent living (Seeley & Lindeke, 2017). However, a few transition programs included a comprehensive intervention to address these aspects of their future life (Betz et al., 2016). This study's positive results are consistent with previous research showing that mentorship programs are an effective intervention to encourage adolescents with chronic conditions to prepare for the future, particularly regarding education and employment (Lindsay, Hartman, & Fellin, 2016; Shamambo et al., 2020). Therefore, interventions involving mentorship should be considered as a part of transition programs for youth.

### Personal and family factors

Considering personal and family factors (Swanson, 2010), we tried to establish individualized, family-centered transition plans using a self-checklist during each family counseling session. Most domains on the checklist showed improvement at the post-test compared to the pre-test, particularly the sexual health management and healthcare system, while daily and school life and relationships with family did not. The program effectively improved transition readiness because we developed the program content based on the educational needs of adolescents and young adults with SB (Choi, Bae, Ji, Jung, & Yang, 2021). Since transition readiness is a key mediator leading to a successful transition (Fremion & Dosa, 2019; Holmbeck et al., 2021), repeatedly assessing the transition readiness checklist at regular intervals and consistently collecting longitudinal data into adulthood is necessary (Seeley & Lindeke, 2017). On the other hand, self-reported relationships with family were already at a high level in the pre-test, and the lack of changes in daily and school life could have been due to the program being conducted during the participants' summer vacation. In conclusion, establishing individually tailored transition plans was effective and satisfactory for both adolescents and their parents. The findings provide evidence supporting the importance of the family-HCP partnership (Betz et al., 2016; Kaufmann Rauen et al., 2013; Seeley & Lindeke, 2017; Thibadeau et al., 2010), using a family-centered, individualized approach (Hopson et al., 2019), and having parental involvement (Swanson, 2010) in transition preparation. Furthermore, we plan to continue to study the adolescent cohort with SB including these 13

individuals at a later time point and determine the long-term effects of this program.

### Practical implications

Compared to existing transition programs (Betz et al., 2016; Kaufmann Rauen et al., 2013; Seeley & Lindeke, 2017; Thibadeau et al., 2010), this program has several practical implications. First, it was a theory- and evidence-based transition intervention (Choi et al., 2022). Based on theoretical framework (Swanson, 2010), the program comprehensively addresses not only self-management but also relationships, education, and employment. The program's content was organized in accordance with the priorities of adolescents with SB regarding their educational needs (Choi, Bae, Ji, Jung, & Yang, 2021). In addition, we used a recommended strategy (Choi, Bae, & Jang, 2021) to motivate adolescents by setting tailored transition goals and plans based on participants' characteristics and transition readiness using an individual approach.

Second, it was a nurse-led intervention. Previous studies highlight the nurse's role as a coordinator of the transition program and identify nurse coordinators as an essential component of interventions (Choi, Bae, & Jang, 2021; Holmbeck et al., 2021; Patel et al., 2019; Seeley & Lindeke, 2017). Since this intervention demonstrated improvements in transition readiness, nurses have the initiative to provide an effective transition program.

Third, since the intervention was delivered online, there were no space limitations, adolescents from various regions could participate in the program. It lacked infection risks during the COVID-19 pandemic. Furthermore, with this delivery method, both completion rate and program satisfaction were high. Consequently, the potential for strategic dissemination among a large number of adolescents with SB exists.

### Limitations

Limitations of this study included its small size and single-arm design, which were appropriate for our feasibility study but limited the level of detailed exploration of data and generalization to the broader population. Further studies are needed to test larger samples with a control group and conduct more in-depth statistical data analysis, including potential mediators and moderators.

Individuals in this study had a higher percentage of LMMC and were highly functioning. Unlike the distribution of SB types in the West, about 70% of Koreans with SB generally have LMMC types (Choi, Im, & Han, 2017). In Korea, prenatal screenings are more intensively performed; therefore, fetal malformations are more easily detected. Hence, unfortunately, fetuses with myelomeningocele are often terminated, which is not legal but often occurs (Choi et al., 2018; Choi, Ji, & Han, 2017). Therefore, our findings are difficult to generalize to adolescents with SB with lower cognitive function and restricted mobility. Further studies are needed to develop a tailored transition program for lower functioning adolescents with SB.

Despite the many advantages of this online intervention, it was difficult to encourage some adolescents to actively participate in group activities depending on their characteristics. In the program's comments, some adolescents expressed that it was burdensome and difficult to talk about themselves with peers, despite providing a good opportunity to discuss SB-related issues with peers with similar conditions. Therefore, future research should apply communication methods with adolescents using alternative or supplementary methods such as chat features and avatars in virtual spaces.

### Conclusions

This nurse-led eHealth transition care program is a feasible and acceptable intervention for adolescents with SB. Above all, adolescents with SB could significantly improve their transition readiness by

participating this eHealth transition program. Finally, HCPs can use this eHealth program as a promising intervention, regardless of limitations related to space or pandemics. Overall, this program could have the capacity to disseminate to large numbers of adolescents with SB.

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## CRedit authorship contribution statement

**Eun Kyoung Choi:** Conceptualization, Methodology, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Eunjeong Bae:** Methodology, Data curation, Investigation. **Hyeseon Yun:** Methodology, Data curation, Investigation, Formal analysis, Writing – original draft, Visualization.

## Declaration of Competing Interest

None.

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