Specific Aims

Spina bifida (SB) is a common congenital neural tube defect affecting the spine that impacts approximately three of every 10,000 live births in the United States (Centers for Disease Control and Prevention [CDC], 2011). This defect can occur throughout the spine as a result of the neural tube's incomplete closure. When this defect occurs, the backbone shield does not form and develop as it should, potentially leading to damage to the spinal cord and nerves (CDC, 2011). The degree of severity of an individual's SB and the extent to which physical challenges manifest are determined by the size and location of the spinal opening and the damage to the underlying nerves (CDC, 2015). Any such physical impairments invariably affect other dimensions of the lives of individuals with SB, such as their psychological, social, and intellectual competencies. Among adolescents with SB, for example, those experiencing continence issues (48% to 76%) are at risk of limited participation in social activities, fewer peer relationships, and diminished self-esteem (Fischer, Church, Lyons & McPherson, 2015).

Social functioning is defined as individuals' interactions with their environment and their ability to fulfill their role within that environment. For instance, social functioning encompasses participation in activities at home and in school; engaging in leisure and recreational pursuits; and fostering close relationships with friends, partners, and families (Kelly et al., 2011). Researchers have found that adolescents with SB tend to have a reduced capacity and inclination to become naturally socially proficient compared to healthy children or those with other chronic ailments such as spinal cord injury and cystic fibrosis (Flanagan, Kelly & Vogel, 2013). Perhaps more importantly, social functioning promotes increased self-esteem and social support, both of which facilitate good health and functional independence (Levasseur et al., 2010). Researchers have established that adolescents with SB tend to have limited social functioning (Barf et al., 2009; Fischer et al., 2015). It is likely that children and adolescents are influenced--both positively and negatively--by their parents' expectations for their behavior, and it is possible that parents' limited expectations can create boundaries for children's social functioning (Grusec & Dany, 2007). If this is the case, parents' expectations could pose a critical social obstacle for children and adolescents with disabilities such as SB.

Facilitators and barriers to social functioning: Researchers have identified various contributing factors in reducing SB children's social participation including continence issues, impaired motor functions, limited accessibility and transportation, and emotional distress (Peny-Dahlstrand et al., 2013; Fischer et al., 2015, Barf et al., 2009). Children with spina bifida have physical disabilities, learning disabilities, and intellectual disabilities, which may increase the risk that they would not participate in social activities (Barf et al., 2009; Liptak et al., 2010).

Parents' perceptions and expectations: Yamamoto and Holloway (2010) define parents expectation as realistic beliefs or judgments regarding their children's future achievements (Yamamoto & Holloway, 2010). Researchers have shown a strong link between parents' opinions in this regard and their children's own beliefs and achievements (Bandura et al., 2001; Neuenschwander et al., 2007). Studies of parents' expectations have generally focused on parents' aspirations for their children to become strong academic achievers and successful professionals in the future.

Little is known about adolescents' and parent's perceptions of facilitators and barriers to social functioning, adolescents' perceptions and expectations of their social functioning and their parents' perceptions and expectations of social functioning for their adolescent with SB. Therefore, the purpose of the proposed descriptive, qualitative study is to describe adolescents' and parents' perceptions and expectations of social functioning for the adolescent with SB. The specific aims for this study are: For adolescents with SB and their parents,

Aim 1: Describe adolescent's and parent's perceptions of facilitators and barriers to social functioning.

Aim 2: Describe parents' perceptions and expectations of social functioning for their adolescent.

Aim 3: Describe adolescents' perceptions and expectations of their social functioning and perceptions of their parents' expectations.

Impact

Study findings will increase awareness and understanding of the nature of parents' and adolescents' perceptions and expectations of social functioning. The study is expected to provide foundational knowledge for future research and development of interventions to assist adolescents with SB to maximize their social functioning which has been associated with positive health outcomes and better quality of life.

Research Strategy

Significance and Background

Spina bifida (SB) profoundly affects not only the individuals having the condition but also entire families and communities. In 2016, the estimated lifetime cost of care for a person with SB in the US, including caregiver costs, was $791,900 (Grosse et al., 2016). Another study of a national inpatient sample conducted in the US in 2013 showed that hospitalizations related to birth defects of the brain and spine (including SB) cost more than $1.6 billion for people of all ages (Arth et al., 2017). Among adolescents with SB, those who experience continence issues (48% to 76%) are at risk of decreased participation in social activities, fewer peer relationships, and diminished self-esteem (Fischer et al., 2015). Due to the complexities of their condition, adolescents with SB tend to exhibit poor social engagement (Barf et al., 2009; Kelly et al., 2011). The challenges faced by adolescents with SB have long-term implications that contribute to ongoing and increasing impairment of their social functioning (Fischer et al., 2015).

Social functioning poses a significant challenge for adolescents with SB. Researchers have reported that unlike adolescents with cystic fibrosis, who do engage in recreational activities outside the family, adolescents with SB tend to curb their participation in leisure activities even with family members (Field & Oates, 2001). This limited participation was attributable to their physical disabilities such as bowel/bladder incontinence, hydrocephalus, shunt, and lesions (Barf et al., 2009; Fischer et al., 2015). Furthermore, in one study that investigated the experiences of adolescents with SB and their parents related to social participation and peer relationships, most parents who participated in interviews did not view their children as "typical." Rather, those parents pointed out many differences between their own children and others in the domains of peer relationships and social participation (Bakaniene et al., 2018). Although previous studies have shown that adolescent and children with SB have lower ability or desire to be involved in social functions is curtailed in children and adolescents with SB, the reasoning and attitudes behind parents' expectations of social functioning in their adolescents with SB remain elusive.

Children and adolescents with chronic diseases tend to have limited social function compared to healthy children and adolescents (Pinquart & Teubert, 2012). This limitation can be due to a variety of factors, as some chronic diseases limit the type and extent of physical activities, contact with peers, and school attendance. In addition, this limitation may be attributable to physical restrictions (e.g., for cerebral palsy and SB), reduced motivation and persistence (e.g., for chronic fatigue syndrome), prolonged or repeated hospitalizations or frequent doctor's appointments (e.g., during cancer treatment), and special transportation requirements (e.g., for paraplegia) (Pinquart & Teubert, 2012). Furthermore, cognitive impairment related to diseases of the central nervous system (CNS) such as SB can impair academic functioning as well as social understanding, which is an aspect of social functioning (Pinquart & Teubert, 2012). Moreover, associations between physical disability and child functioning may be related to limitations of the members of the social network, such as parents, teachers, and peers. Finally, behavior problems associated with chronic illness, such as aggression or depressive mood, may affect social and academic functioning (Pinquart & Shen, 2011).

Some previous research in this area has focused on the limitations and challenges that children with SB faced when engaged in social activities. For example, continence issues were considered to be a major limitations for most participants in studies by Fischer et al. (2015) and Kelly et al. (2011). Among the studies that have reported on incontinence problems in children with SB,

difficulties ranged from minimal to significant depending on the type of SB present. Children with SB considered their incontinence to be a significant issue, not only because of the physical discomfort they experienced, but also because they tended to feel embarrassment and a need to hide it from their peers. In fact, incontinence issues have been identified as a major barrier to social participation in most studies (Fischer et al., 2015; Kelly et al., 2011). Moreover, researchers have found that bowel incontinence was associated with lower health-related quality of life (HRQOL) and that satisfaction with bowel training was associated with higher HRQOL (Sawin et al., 2007). In another study, the researchers emphasized the importance of overcoming incontinence issues by encouraging caretakers to offer increased support; they also stressed the importance of encouraging children and adolescents with SB to feel more empowered by helping them better understand and accept their bodies rather than view themselves as broken or shameful (Goodey & Runswick-Cole, 2013).

One study of social functioning and physical activity in children with SB was sponsored by the Portuguese Association of Spina Bifida and Hydrocephalus in 2013. That study involved 31 students with SB aged 10 to 17 years (Marques et al., 2015), and explored the relationships among adolescents with SB; physical activity involvement; and psychosocial factors such as attitudes, sports interests, and perceptions. The researchers found no significant relationships among having SB, physical activity involvement, and psychosocial characteristics except for perceptions, as most of the participants did not engage in regular physical activity. Among the study variables, only participants' positive perceptions were significantly associated with greater participation in non-organized physical activity. These researchers' direct probing of students' propensity to engage in physical activities provided evidence of these individuals' low interest in social and physical interactions with others, especially organized activities that were typically school-directed. Another reason cited for students' reluctance to engage in school-directed organized activities was that they involved required fees. Predictors of physical activity involvement among individuals with SB included barriers such as lower levels of musculoskeletal development and aerobic fitness. With respect to students' perceptions, a perceived ability to engage in leisure and social activities was deemed an important motivator for participating in physical activities (Marques et al., 2015).

Social participation is an important determinant of health and has been associated with quality of life (Levasseur et al. 2010). Furthermore, social functioning promotes increased self-esteem and social support, both of which facilitate good health and functional independence (Levasseur et al., 2010). Children and adolescents with SB have poor social adjustment throughout developmental stages (Landry et al., 2013). Participation in community-based activities can promote development, and health for children's (Mahoney, Schweder & Stattin, 2002). Moreover, attending school and playing with others facilitate children's ability to learn social skills, social relationships with others, and self-determination (Larson, 2000; King, 2004).

Facilitators and barriers to social functioning adolescents with myelomeningocele have significant difficulties due to the involvement of multiple systems dysfunction (Buran et al., 2004). Myelomeningocele is associated with negative consequences throughout life. Researcher found that bowel and bladder problems limit physical activities and social life (specifically children who can-not catheterize themselves) (Boudos & Mukherjee, 2008; Flanagan, Kelly, Vogel, 2013). The main limitations in the participation of spina bifida children were found to be due to bowel/bladder incontinence, hydrocephalus, shunt, and a high level of lesions (Barf et al., 2009; Fischer et al., 2015). Wheelchair dependent participants tended to have more limitations in social activities due to difficulties related with building accessibility and long-distance transportation (Barf et al., 2009). Furthermore, children's intellectual disabilities play a major role in their level of participation in social and physical activities.

Parents' perceptions and expectations have been found to play a critical role in adolescents' academic success (Yamamoto & Holloway, 2010). Students whose parents held high expectations tended to earn higher grades, achieve higher scores on standardized tests, and persist longer in school than those whose parents had relatively low expectations (Davis-Kean, 2005; Pearce, 2006; Vartanian et al., 2007). Furthermore, in a study that focused on the relationship between parents' expectations and post-school outcomes of adolescents with disabilities, parents' expectations that

their adolescent would achieve each of the study outcomes (graduating from high school with a standard diploma, post-school employment, and enrollment in and completion of postsecondary education) were significantly and positively associated with adolescents' level of autonomy (Doren, Gau & Lindstrom, 2012).

Parents' expectations and children's outcomes were investigated in a study called the National Longitudinal Transition Study (NLTS)-2, which examined the main effects of parents' school and post-school outcome expectations on the actual outcomes achieved by typical children (Doren, Gau & Lindstrom, 2012). That study considered parents' intentional alignment of their children's future endeavors with their own expectations. In the NLTS-2, parents' expectations were found to significantly predict the study outcomes. In other studies of families, a direct pathway has been established between parents' expectations and their children's academic prowess, college education or degree, and professional achievements (Blustein et al., 2002; Chen & Gregory, 2009). In fact, many studies have shown that parents' expectations for adolescents' abilities, skills, and education have a strong influence on the outcomes experienced by adolescents and young adults (e.g., Agliata & Renk, 2008 and Yazedjian, Toews & Navarro, 2009). For instance, positive parents' expectations have been associated with better academic skills and college outcomes among students (Yazedjian, Toews & Navarro, 2009).

Overall, little research data are available on parents' perceptions and expectations about social functioning of children with disabilities. The literature frequently notes the importance of children's--especially disabled children's--engagement in social and physical activities to strengthen their mental, emotional, and physical attributes (Doren, Gau & Lindstrom, 2012). With respect to children with SB, however, parents' expectations of such engagement remain unclear. Especially given the importance of perceived ability in children with SB, the parents' perceptions and expectations of social functioning for their adolescent having spina bifida, adolescents' expectations of their own social functioning, and adolescents' perception of their parents' expectations need to be explored. In addition, it is important to better understand both parents' and adolescent's perception of facilitators and barriers to social functioning.

Theoretical Framework

According to Holmbeck & Devine (2010), the bio-neuropsychosocial model focuses on adjustment in youth and young adults with SB and proposes that adolescent adjustment of individuals with SB is likely determined by the interacting influences of multiple biological, neuropsychological, and social factors. These factors likely have a causal relationship with each other with each evolving and changing over time. For the purpose of this study, the principal investigator (PI) will focus on two theoretical constructs: social factors (family/parenting, peers) and adolescent adjustment (social adjustment, quality of life, functional status) (see Figure 1) to develop a semi-structured online interview guide for adolescents with SB and their parents. Furthermore, after conducting semi-structured online interviews with study participants, the PI will use the same components of model as a framework for interpretation, analysis, and coding of the interview data. As Chih-Pei and Chan (2017) have pointed out, a theoretical lens is typically used in qualitative research to provide a "transformative perspective" that guides how data are collected, shapes the questions asked, provides a foundation for data analysis, and supports any recommendations made.

Innovation

The proposed study is innovative because it will be the first known qualitative exploration of parents' perceptions and expectations regarding the ability of their adolescent children with SB to engage in social activities and of the adolescents' perceptions of those expectations. The findings arising from the study will increase awareness and understanding of parents' perceptions and expectations in these circumstances, how children perceive them, and their effects on adolescent social functioning, regardless of the degree of physical limitation present. Moreover, this study will provide a better understand both parents' and adolescent's perception of facilitators and barriers to social functioning. The foundational knowledge provided by the study will support future development

of interventions to help adolescents with SB achieve greater social functioning with the goal of building rewarding human relationships.

Summary

SB greatly affects not only adolescents having the condition but also their families and communities. Past research has shown that such adolescents have limited social functioning for a variety of reasons, including impaired mobility, deficits in cognitive and communication competence, and medical issues such as incontinence. For adolescents with SB and their parents, no known studies have explored adolescents' expectations of their social functioning or their perceptions of their parents' expectations of their social functioning. Investigators have provided some evidence about adolescent's and parents barriers to social functioning, but limited evidence about facilitators.

Approach

Design

To address the study aims, the PI will use a descriptive qualitative design supported by a semi-structured interview guide. The study will follow the bio-neuropsychosocial model (Holmbeck & Devine, 2010), which will be used to direct exploration of adolescents' perceptions and expectations of their social functioning and their parents' perceptions and expectations of social functioning for their adolescent with SB and adolescents' and parents' perceptions of facilitators and barriers to social functioning. The interpretive framework for the study will be social constructivism, to guide understanding of the experience of parents living with adolescent children with SB and how they view the world through their experience.

Sample and Setting

A total of 20 participants, including 10 adolescents with SB and 10 parents (one mother or father of each adolescent) will be recruited online. The inclusion criteria for adolescent participants are: (1) diagnosed with myelomeningocele, (2) aged 12 to 18 years, (3) able to speak English, and (4) have the cognitive ability to participate in an interview. Inclusion criteria for the parent participants are: (1) mothers or fathers of one of the adolescent participants and (2) able to speak English. Under the exclusion criteria for the study, adolescents with severe cognitive impairment (e.g., cerebral palsy or neuromuscular disorders) will be excluded because it would be difficult to explore the parents' expectations of social functioning. I intend to recruit adolescents and parents through the Spina Bifida Association (SBA). Although the SBA has expressed interest in facilitating the study, I have been informed by the SBA that to participate in research and recruit study participants, I am required to submit the following documents: IRB approval, all informed consent/assent materials, abstract/detailed description of the study, copy of interview guide, all advertisement materials to be used for recruitment, and agreement to share study outcomes at completion of study. I may also seek to recruit participants from Spina Bifida Wisconsin (SBWIS) and Illinois Spina Bifida Association (ISBA) if needed. They will require similar materials to SBA. Thus, once approved by the UIC IRB, I will submit these documents to the SBA and request permission to recruit parents and adolescents to participants and to conduct my research. If needed I will also submit materials to SBWIS and ISBA. For this descriptive qualitative study, data from an estimated 10 parent-adolescent dyads will be sufficient to meet the study's objectives. As usable data are collected from each participant, fewer participants are needed (Morse, 2000). Consequently, data saturation may be achieved with fewer than 10 parent-adolescent dyads.

Measures

To achieve the study aims, a semi-structured interview guide (Appendix 1), guided by Holmbeck and Devine's (2010) bio-neuropsychosocial model will be used by PI to explore adolescents' perceptions and expectations of their social functioning and their parents' perceptions and expectations of social functioning for their adolescent with SB. In addition, interview questions about adolescents' and parents' perceptions of facilitators and barriers to social functioning will be included. The interview guide includes open-ended questions and accompanying probes based on the two components of bio-neuropsychosocial model: social factors (family/parenting, peers) and adolescents adjustment (social adjustment, quality of life, functional status) (Holmbeck & Devine, 2010).

A demographic questionnaire (Appendix B) will be completed verbally by the PI at the beginning of the interview by asking the parent and adolescent in each parent-adolescent dyad for this information. Demographic characteristics addressed in the questionnaire will include age, sex, race/ethnicity, education level for the parent and adolescent; marital status for the parent; diagnosed health conditions and the ambulation level for the adolescent.

Procedures

The PI will first obtain study approval from the Spina Bifida Association and from the University of Illinois (UIC) Institutional Review Board, and request permission for data collection online from the National Spina Bifida Association. The PI will display an announcement about the study on the SBA web page and/or SBA social media, including the PI's contact information and a requested that interested persons who think they would qualify to contact the PI. Once the participants contact the PI indicating their interests; the PI will screen for eligibility and provide more detailed information about the study purpose, procedures, and risks and benefits of participation. If they agree to participate, the PI will schedule them for the interview. The PI will select parent-adolescent dyads who meet the inclusion criteria and represent different ages and gender.

Before the scheduled interview, the PI will send via email copies of consents (parent consent, parent permission for adolescent, and adolescent assent) for review and explain the need for the three consents. At the time of and prior to the interview, the PI will discuss and clarify any questions or concerns from adolescents and parents related to the consent documents. Once questions and concerns are resolved, adolescents and parents will sign the consents and send them to the PI via email. No study activities will be conducted until the written consent forms are returned to the PI via email before starting the interview. After the consents are signed, parents will complete the demographic questionnaire. Interviews will be conducted via an electronic mechanism (Zoom, Skype, Facebook). To ensure the confidentiality, the study participants name will be assigned a code and a list matching participants' names to their codes will be kept in a secure location separate from study data. I will inform the participants if this plan to protect their confidentially

Following the interview guide (Appendix A), the PI will interview adolescents alone without the parent present, and parents will be interviewed alone without the adolescent present, in no specific order. Each interview is anticipated to last for 45 to 60 minutes. To provide an accurate verbatim record, the interview will be audio-recorded. The PI will also record relevant observations in field notes. After the interview, a $20 gift card will be sent to each participant (adolescent and parent) via email as a token of appreciation.

Data Management and Analysis

The interviews will be transcribed verbatim from the platform session into a Word computer file. The transcript will then be checked against the recording to confirm transcription accuracy and any errors will be corrected. After completion of the interviews, the transcripts will be subjected to directed content analysis process, which will be used to describe the phenomena of interest in conceptual form.

Directed content analysis is used when a study aims to describe a phenomenon (Hsieh & Shannon, 2005), and this study is intended to describe adolescent's and parent's perceptions of facilitators and barriers to social functioning, adolescents' perceptions and expectations of their social functioning and their parents' perceptions and expectations of social functioning for their adolescent with SB. The approach to content analysis will be based on the bio-neuropsychosocial model, which serves as the theoretical framework for the study. Use of an existing theory can support formulation of the research questions of a study as well as prediction of the variables, thus helping to determine the initial coding scheme (Hsieh & Shannon, 2005). This process of directed content analysis begins with identification of the initial codes based on the theory; then operational definitions for each thematic category are determined using the theory. The directed content analysis depends on the research question and involves identifying and categorizing all instances of specific phenomena, followed by coding of all the identified passages using predetermined codes. Any text that cannot be categorized using the initial coding scheme is assigned a new code (Hsieh & Shannon, 2005). Finally, descriptive

data will be compiled for each thematic category and subcategory, and each will be described in detail.

After all data have been processed as described above, a descriptive summary from both interviews (adolescent and parent) will be constructed for each category and subcategory. Contents of each category and subcategory will be described. Data will be described about adolescent's and parent's perceptions of facilitators and barriers to social functioning, adolescents' perceptions and expectations of their social functioning and their parents' perceptions and expectations of social functioning for their adolescent with SB.

Throughout the study, the privacy and confidentiality of study participants will be maintained by means of appropriate security measures. All electronic study data, including the interview recorded via zoom or audio-recordings, all electronic informed consents, interview guide, all advertisement materials and transcripts, will be saved in my computer and accessed via a password known only to the PI and the committee members.

Study Rigor

Demonstration of the quality of the research process and the data collected is essential (Creswell & Creswell, 2017; Morse et al., 2002). First, the PI will establish trustworthiness and credibility by developing a rapport with each participant prior to the interview. To accomplish this rapport, the PI will introduce herself and her study to the participant, describe the exact role and intentions of the PI, maintain a relaxed posture and employ open body language, and show personal interest in the participant's well-being (Creswell & Creswell, 2017; Morse et al., 2002). The PI will provide thick description of the data to ensure credibility. In addition, the PI will ensure study confirmability and dependability by maintaining a detailed audit trail. Specifically, the PI will carefully document the data collection, analysis, and interpretation processes by noting unique topics of interest during the interviews, recording her thought process during coding, writing a rationale for each merging of codes, and ultimately writing a detailed explanation of the meaning and significance of each theme (Creswell & Creswell, 2017; Morse et al., 2002). Furthermore, to verify interview data accuracy, the PI will use a member-checking process in which a descriptive summary of three interview's results will be reviewed for accuracy by the participant, who will then provide any needed corrections (Creswell & Creswell, 2017; Morse et al., 2002). Finally, the transferability of the study will be ensured by providing a detailed explanation of how the study aims were met (Creswell & Creswell, 2017; Morse et al., 2002). Using purposive sampling including different ages and genders increase transferability of the research study.

Feasibility

Feasibility

Spina Bifida Association (SBA) has expressed interest in facilitating the study, I have been informed by the SBA that to participate in research and recruit study participants, I am required to submit the following documents: IRB approval, all informed consent/assent materials, abstract/detailed description of the study, copy of interview guide, all advertisement materials to be used for recruitment, and agreement to share study outcomes at completion of study. I may also seek to recruit participants from Spina Bifida Wisconsin (SBWIS) and Illinois Spina Bifida Association (ISBA) if needed.

Strengths and Weaknesses

Strengths. The study will be conducted online through electronic mechanism (Zoom, Skype, Facebook), helping to ensure participants' comfort and thus facilitate their willingness to express themselves openly. In addition, the study's use of a single interviewer (the PI) will support accurate and consistent performance of study procedures throughout the interview process. To ensure rigors of the research study, the PI will provide thick description of the data and use a member-checking process in which a descriptive summary of three interview's results will be reviewed for accuracy by the participant, who will then provide any needed corrections. Finally, findings from this study are expected to provide foundational knowledge for future research addressing development of interventions to assist adolescents with SB in achieving greater social engagement with others.

Limitations. One potential study limitation is the risk of selection bias due to the use of purposive sampling. Specifically, the parents who are willing to volunteer to participate may have atypically high goals and expectations for their adolescent children's social functioning. In addition, parent participants may be prone to social desirability bias that could affect the nature of their interview responses. Another potential study limitation is the risk of researcher bias on the part of the PI, whose preconceptions and opinions could influence the data collection, analysis, and reporting processes. To overcome bias the PI will use a member-checking process in which a descriptive summary of three interview's results will be reviewed for accuracy by the participant. Furthermore, the PI will maintaining a detailed audit trail during interview. To ensure the confidentiality, the study participants name will be assigned a code and a list matching participants' names to their codes will be kept in a secure location separate from study data. I will inform the participants if this plan to protect their confidentially.

Timeline

Years	Spring 2020	Summer 2021	Fall 2021	Spring 2022
Proposal Defense and IRB Approval	✓			
Recruitment and Data Collection		✓	✓	
Data Analysis and Coding			✓	
Manuscript preparation				✓
Dissertation Defense				✓

PROTECTION OF HUMAN SUBJECTS

1-RISKS TO HUMAN SUBJECTS

Human Subject Involvement, Characteristics, and Design

Up to 20 participants (10 adolescents with SB and 10 of their parents) will be recruited from Spina Bifida Association for this study. For those indicating interest, the researcher will determine whether they meet the inclusion criteria of the study. The parents and adolescents will receive a copy of the consents/assent two weeks prior to the interview to have sufficient time to review. Then, the parents then provide written informed consent and give permission for their adolescent to participate in the study; the adolescent will provide assent for their adolescents to participate in the study. To ensure the confidentiality, the study participants name will be assigned codes and I will tell the participants that I will use the code assigned through research process and I will not use any identifying information.

Sources of Materials

All study data will be collected by the primary researcher. The interviews will take place online from Spina Bifida Association via electronic mechanism (Zoom, Skype, Facebook). Before interviews begin, participating parents will be asked to complete a demographic questionnaire addressing characteristics of both the parents and adolescents. An audio-recorder will be used during each interview to provide an accurate account of the verbatim comments of the participant. In addition, the researcher will record interview observations in field notes. The privacy and confidentiality of participants will be maintained by safeguarding the interview recordings in a locked computer secured using a password known only to the researcher. The demographic questionnaires, the field notes, and the device used to record the interviews will be kept in a locked cabinet in a locked office. As

interviews are completed, the researcher will transcribe the contents of the audio-recordings into Word files. Again, these files will be stored in a locked computer secured using a password known only to the researcher.

Potential Risks

During the interviews, participants may experience fatigue due to the anticipated complexity of their responses. The researcher will ensure that participants are not overly taxed by allowing them to take rest breaks as needed. Moreover, the adolescent participants may have bowel and bladder issues that restrict their ability to stay for a full 45 to 60 minutes; thus, the researcher will offer restroom breaks as often as necessary. During the interviews, the researcher will monitor participants for signs of emotional distress and will again offer rest breaks as necessary. Also, the researcher will remind participants that they need not answer any questions that they find overly upsetting. Possible risk is breach of confidentiality, the PI will ensure that all electronic study data, including the interview recorded via zoom or audio-recordings, all electronic informed consents, interview guide, all advertisement materials and transcripts, will be saved in my computer and accessed via a password known only to the PI and the committee members.

2. ADEQUACY OF PROTECTION AGAINST RISKS

Recruitment and Informed Consent

Those invited to participate will receive a copy of the consent to review one week prior to tentatively scheduled the interview. Additionally, the PI will discuss and clarify any questions or concerns related to the informed consents prior to starting the interview to ensure clarity. Then, the parents will then provide written informed consent, the parents will give permission for their child to participate, the adolescents will provide assent to participate, and will complete the demographic questionnaire. No study activities will be conducted until the written consent forms are returned to the PI via email before starting the interview. The interview will be conducted via an electronic mechanism (Zoom, Skype, Facebook). To ensure the confidentiality, the study participants name will be assigned a code and a list matching participants' names to their codes will be kept in a secure location separate from study data. I will inform the participants if this plan to protect their confidentially.

Protections Against Risk

Special consideration will be given to adolescents with SB who may experience fatigue during the interview due to the complexity of their health condition. As stated above, during the interviews, the researcher will ensure that participants are not overly fatigued by allowing them to take rest breaks as needed. Recognizing that adolescent participants may have bowel and bladder issues, the researcher will offer restroom breaks as often as necessary. In addition, given the potential for participants to experience emotional upset during the interviews, the researcher will monitor participants for signs of emotional distress and will again offer rest breaks as necessary. Finally, the researcher will remind participants that they need not answer any questions that they find overly upsetting. Overall, throughout each interview, breaks will be taken as often as necessary to avoid participant discomfort.

3. POTENTIAL BENEFITS OF THE PROPOSED RESEARCH TO HUMAN SUBJECTS AND OTHERS

Participation will offer no direct benefits to the study participants. However, they will be informed that the information they share may benefit future families having adolescents with SB.

4. IMPORTANCE OF THE KNOWLEDGE TO BE GAINED

Study findings will increase awareness and understanding of the nature of parents' and adolescents' perceptions and expectations of social functioning. The study is expected to provide foundational knowledge for future research and development of interventions to assist adolescents with SB to maximize their social functioning which has been associated with positive health outcomes and better quality of life.

5. INCLUSION OF WOMEN AND MINORITIES

The study participants are expected to include adolescents with SB and one of their parents (one mother or father of each adolescent). Inclusion of minorities in the study may occur but is not a study goal.

6. INCLUSION OF CHILDREN

The researcher will recruit up to 10 adolescents with SB aged 12 to 18 years to make up the study participants. Each adolescent participant will have the ability to speak English as well as the cognitive ability and stamina to participate fully in a semi-structured, in-depth interview anticipated to last for 45 to 60 minutes.