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Associations Between Neighborhood Factors and Adherence in Youth with Spina Bifida: The Mediating Role of Parental Stress and Youth Internalizing Symptoms

Breana Lyn Bryant
Loyola University of Chicago Graduate School

LOYOLA UNIVERSITY CHICAGO

ASSOCIATIONS BETWEEN NEIGHBORHOOD FACTORS AND ADHERENCE IN YOUTH WITH SPINA BIFIDA: THE MEDIATING ROLE OF PARENTAL STRESS AND YOUTH INTERNALIZING SYMPTOMS

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BREANA L. BRYANT

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ABSTRACT

Spina bifida (SB) is a birth defect that impacts physical, medical, and neuropsychological functioning. Physical complications like hydrocephalus and bladder dysfunction require daily adherence to complex medical regimens. Additionally, youth with SB are more likely to have symptoms of anxiety and depression which can impact their ability to master their regimens. Evidence in other pediatric populations have examined the impact of family factors, like parental stress, and individual-level predictors of self-management outcomes, yet few have examined how the broader context, like neighborhoods, impact outcomes. Therefore, the current study examined (1) the level of the neighborhood vulnerability and acute healthcare services within the sample, (2) associations between neighborhood factors and parental stress and youth internalizing symptoms, (3) associations between parental stress and youth internalizing symptoms and medical adherence, (4) the degree to which neighborhood factors predict medical adherence, and (5) the mediating role of parental stress and youth internalizing symptoms on associations between neighborhood factors medical adherence in youth with SB.

One hundred and thirty youth with SB were enrolled in a larger longitudinal study (Kayle et al., 2020). The current study included youth home addresses and parent report of experiences of stress. Youth internalizing symptoms were assessed via youth-, parent- and teacher-report and medical adherence was assessed via parent-report.

Results indicated that a majority of youth with SB live in a mid to high vulnerable neighborhood with no hospitals. Neighborhood factors were not significant predictors of parental

stress or youth internalizing symptoms. Parental stress and youth internalizing symptoms were not significant predictors of youth medical adherence. Similarly, neighborhood factors were not significant predictors of youth medical adherence. This study highlights the need for providers to consider larger contexts, including neighborhoods, when supporting youth with SB and their families and the need for additional research to explore other outcomes like neuropsychological and academic functioning that may be impacted by neighborhood factors.

CHAPTER ONE

INTRODUCTION

Spina bifida (SB) is a common birth defect affecting the central nervous system and is associated with physical, medical, and neuropsychological complications (Copp et al., 2015). Because of physical complications like hydrocephalus and bladder and bowel dysfunction, youth with SB and their families have to manage complex medical regimens including catheterization, skin checks, and bowel programs (Fletcher et al., 2004; O'Hara & Holmbeck, 2013). Additionally, adolescents with SB are at an increased likelihood of anxiety and depression, which can influence their ability to master the skills needed for self-management of these tasks (Appleton et al., 1997; Bellin et al., 2010; Coakley et al., 2006; Holmbeck & Devine, 2010; Iddon et al., 2004). Although considerable research in pediatric psychology has focused on family predictors (including parental stress) as well as individual-level predictors of mental health and self-management outcomes (Friedman et al., 2004; Simpson et al., 2020), few have focused on context-related constructs such as neighborhood factors.

Therefore, the current study examined the models that are presented in Figure 1, which are consistent with socioecological theory (Bronfenbrenner, 1979). Specifically, the models included parental stress and youth internalizing symptoms as mediators of the relationship between neighborhood factors and medical adherence in youth with SB. To examine the models in Figure 1, the current study utilized a longitudinal research design, data from multiple informants, and geocoded neighborhood factors. The following sections include a review of current research on the influence of neighborhood factors on parent and youth outcomes, a

summary of current literature regarding parental stress, an overview of internalizing symptoms and medical adherence, and a justification for the mediation models. A description of the current study, including objectives and specific hypotheses, is also included.

CHAPTER TWO

REVIEW OF RELEVANT LITERATURE

Neighborhood Factors

Social determinants of health (SDOH), which include neighborhood factors, are "the conditions in the environments where people are born, live, learn, work play, worship and age" (*Social Determinants of Health - Healthy People 2030 | Health.Gov*, n.d.). Socioecological theory shows how children develop in the context of several environments, including family and home environments, neighborhoods and schools, and the broader society (Bronfenbrenner, 1979). Therefore, neighborhoods are key contexts in which children develop, and the features of neighborhoods tend to be interrelated and interact with other family- and individual- level characteristics (Alderton et al., 2019; Leventhal & Brooks-Gunn, 2000). Several factors, including poverty, lack of access to transportation, and crowded housing may weaken a neighborhood's ability to prevent negative health outcomes. For centuries, structural racism in the United States housing system has contributed to persistent racial disparities in well-being, especially between Black and White households (Dickerson, 2020). Such factors comprise a higher order construct referred to as "social vulnerability," which can also include socioeconomic status, household composition/disability, and people of color/those who speak English "less than well" (Flanagan et al., 2011). The complex and nuanced definitions of SDOH and neighborhood factors are typically represented only by a small number of socioeconomic indicators, such as income and education. There are many ways to measure neighborhood

factors, but utilizing comprehensive objective measures (e.g., census data) allows us to enhance the content validity of our assessments, which is beyond what one single measure can evaluate.

Neighborhoods impact the health and wellbeing of its residents but can also contribute to health inequalities (Diez Roux & Mair, 2010; Leventhal & Brooks-Gunn, 2000). Residential segregation and inequalities in resource distribution influence neighborhood physical and social environments, which contribute to behavioral and stress-related reactions that ultimately affect the physical and mental health of residents (Diez Roux & Mair, 2010). Such links highlight the importance of considering not only individual characteristics, but also characteristics of the groups or contexts in which individuals belong (Diez Roux, 2015; Subramanian et al., 2003; Susser, 1994). Neighborhoods are relevant contexts because they possess both physical and social characteristics that affect the health of individuals.

Neighborhood research in pediatric populations mainly focuses on socioeconomic status (SES), which can include multiple subcomponents (Papadakis & Holmbeck, 2021). In pediatric asthma and obesity research, lower neighborhood SES is associated with more frequent hospitalizations, more emergency room visits, and greater asthma symptoms due to environmental pollution (Schreier & Chen, 2013). Further, neighborhood SES has been linked to self-reported pain severity and disability in youth with functional abdominal pain (Morris et al., 2022). In the context of SB, the impact of neighborhood factors has not been explored. Further, despite knowing that a variety of neighborhood factors can impact health and wellbeing (Diez Roux & Mair, 2010) the impact of health-specific neighborhood factors (i.e., health insurance coverage, disability status-hearing, visual, cognitive, ambulatory or self-care/independent living difficulty, and location of hospitals) on physical and mental health has not been evaluated.

Parental Stress

Family-based research has shown that parent functioning has a significant impact on youth outcomes. Parenting stress encompasses stress reactions to the demands of being a parent, which can include the demands for food, comfort, and attention (Deater-Deckard, 1998). Parents of children with chronic illness have additional stressors that can impact the parents' individual functioning (e.g., emotionally being affected by diagnosis and caretaking burdens) (Kazak et al., 1995). Chronic disorders, including SB, represent significant life events in the life of a family that have a sudden impact (e.g., diagnosis and high-risk surgery) as well as repetitive, daily medical tasks that can have chronic impacts (e.g., taking medication, incontinence, and ambulation challenges). Raising a child with SB can place substantial demands on parents, which have been shown to lead to less parental satisfaction, feeling less competent in their parenting skills, and greater parenting stress (Friedman et al., 2004; Holmbeck et al., 1997; Kazak & Marvin, 1984; Wallander & Varni, 1998). Mobility and bladder and bowel dysfunctions in children with SB are ongoing stressors for parents (Vermaes et al., 2008), with parental stress in families who have children with SB being higher than in the general population, particularly among economically disadvantaged and culturally diverse parents (Holmbeck et al., 1997).

Besides illness related stressors, other major life events and daily medical tasks add to the demands on parents. Excessive changes tax the body's capacity for readjustment and therefore produce stress (McCubbin et al., n.d.). Life events are stressors which require change in the individual's ongoing pattern of life (Holmes & Rahe, 1967). Specifically, stress occurs when there is a perceived imbalance between life changes and the individual's ability to meet the demands of these changes (McCubbin et al., n.d.). The cumulative risk theory suggests that if a family's resources to cope with stressors are already exhausted in dealing with other life

changes, whether normative or situational, family members may be unable to make further adjustments if additional stress arises (Sameroff, 2000). This can include the stress of coping with living in a neighborhood that has been systemically excluded from resources (e.g., higher poverty and not having needs met; having to rely on public modes of transportation due to limited access to cars; (Blumenberg, 2004)). Similarly, allostatic load research has illustrated that an overload of chronic stress and life events are highly associated with negative health outcomes. Allostatic load is also increased by living in impoverished neighborhoods and caregiving related stress (Guidi et al., 2020).

Lastly, the family stress model shows how available resources outside the family context influence behavior (Conger et al., 2000; Masarik & Conger, 2017). The lack of neighborhood resources can shape parenting, with neighborhood/community influences either exacerbating or mitigating the family stress process (Chung & Steinberg, 2006; Masarik & Conger, 2017). There currently is no research on how the stress of parents of SB children interacts with neighborhood factors.

Youth Internalizing Symptoms

Depression and Anxiety

Adolescents with SB are at an elevated risk for depressive and anxiety symptoms, due in part to the variety of challenges that such youth face across multiple spheres of their lives (Appleton et al., 1997; Bellin et al., 2010; Coakley et al., 2006; Holmbeck et al., 2006; Iddon et al., 2004). Moreover, anxiety and depression have been shown to restrict the ability of populations with chronic illness and/or disabilities to achieve self-management of their health condition (Gadalla, 2008). At the most extreme, adolescent depression and anxiety could lead to

early mortality and greater risk of suicide in adulthood (Archer et al., 2018; Brière et al., 2014; Gilman et al., 2017).

Neighborhood factors also play a role in exacerbating internalizing symptoms. Depressive symptoms are linked with living in more under-resourced neighborhoods (Diez Roux & Mair, 2010; Rollings et al., 2017) and stressful family environments (Mair et al., 2008). For example, in youth with asthma, the link between neighborhood and health was partially explained by symptoms of depression being associated with difficulties experiencing pleasure and motivation. That is, individuals living in neighborhoods that have been systemically excluded from resources may be less motivated to engage with their environment because of lack of pleasure, interest or safety in the options available to them (Tobin et al., 2016). Despite some research on typically developing populations and some pediatric populations, there are few studies that focus on how neighborhood factors influence internalizing symptoms (Katon et al., 2007).

Medical Adherence

In the context of SB, medical adherence is viewed as a medically-related adjustment outcome that is intertwined with family processes, specifically during the period of development when medical responsibilities are shared between parent and child (Holmbeck et al., 2006). Youth with SB may have a multitude of medical challenges including urinary, bowel, orthopedic and neurological difficulties—all of which require adherence with separate medical regimens (Psihogios et al., 2017). In pediatric populations, nonadherence to medical regimens can lead to long-term consequences, including increased morbidity and mortality and higher rates of healthcare utilization (Kennard et al., 2004; Piecoro et al., 2001; Rapoff, 1999).

Neighborhood and parental factors also influence adherence. Individual and family self-management theory illustrate how physical/social factors (e.g., access to healthcare, transportation, neighborhoods) and family functioning (e.g., parent stress) can either enhance or diminish self-management behaviors (Ryan & Sawin, 2009). Further, individuals living in neighborhoods that have been systemically excluded from resources due to racism and redlining segregation tend to have less access to pharmacies, thus lowering their rates of medication adherence (Beck et al., 2017; Qato et al., 2014).

Justification for the Mediation Models and the Current Study

Proximal risk and protective factors are considered to exert a greater influence on developmental trajectories than do more distal environmental factors (e.g., neighborhood; Friedman et al., 2004). Put another way, and adopting an ecological perspective, microsystemic factors such as family experiences and functioning may have a direct impact on a child's development, while mesosystemic (e.g., the connection between families and their neighborhood) and macrosystemic (e.g., the social/economic resources available within a given neighborhood) factors may have indirect effects on child outcomes (Bronfenbrenner, 1979). Importantly, the home environment is considered to be the most influential setting in which parent and family interactions affect the developmental transition from childhood to adolescence (Belsky et al., 1991). There are also mixed findings on how neighborhoods and parenting constructs interact, with differing associations and direction of the effects, thus highlighting the need for further investigation (Cuellar et al., 2015). Finally, despite knowing the importance of the neighborhood environment on physical and mental health, there is no specific model illustrating how the neighborhood has an influence on outcomes in pediatric populations.

The current study aimed to expand existing literature by characterizing the influence of neighborhood factors on parents and youth with SB. This study examined neighborhood factors as potential predictors of parental stress. Further, the mediating effects of parental stress and youth internalizing symptoms on associations between neighborhood factors and internalizing symptoms and adherence in youth with SB were examined (see Figure 1). Having a deeper understanding of the influence of neighborhood factors on parent and youth outcomes is essential to identify and address health inequities that are likely to be modifiable.

This study included several methodological strengths; it utilized a multi-method (i.e., geocoding, questionnaires), multi-informant (i.e., parents and youth) approach, spanning three time points (across four years) and offers a deeper examination of neighborhood factors in this population than has been provided in past research. While studies about the influence of neighborhood factors on health in the typically developing population are somewhat common (Diez Roux & Mair, 2010), there is an absence of research pertaining to this subject in youth with SB. Extending this research to pediatric populations, specifically SB, is important for preventing internalizing symptoms for youth and improving medical adherence.

With respect to measurement, different strategies have been employed to assess neighborhood factors, with objective measures that examine neighborhood impact on health typically relying on a single or multiple item measures of SES only (Weden et al., 2008; Weller et al., 2021). Further, these measures do not include any health-related components of a neighborhood, which may play an especially important role in health-related outcomes in youth with SB. This study utilized census and American Community Survey data to assess many neighborhood characteristics that are known to impact health, including SES (e.g., household composition, disability status, insurance access, transportation access).

Study Objectives and Hypotheses

The current study had five objectives. The first objective was to adopt an exploratory approach in determining the level of the neighborhood vulnerability and acute healthcare services in a sample of youth with SB *(Exploratory)*.

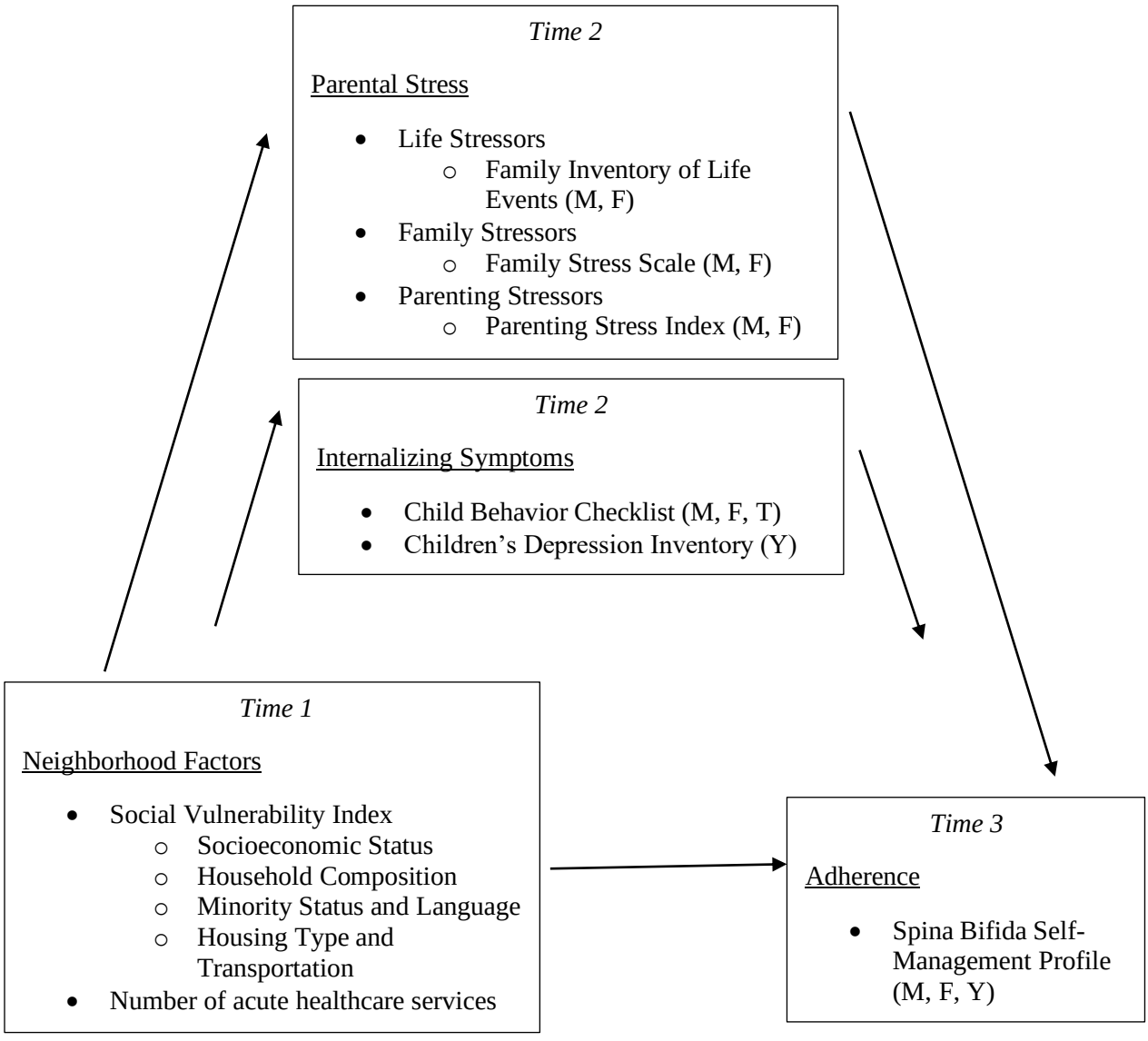
The second objective was to examine associations between neighborhood factors and parental stress and youth internalizing symptoms (see Figure 1). Living in more vulnerable neighborhoods and neighborhoods with no hospitals in zip code was hypothesized to be predictive of an increase in parental stress and internalizing symptoms (Hypotheses 1 and 2, respectively). Further, it was hypothesized that lower neighborhood SES will be most predictive of an increase in parental stress and internalizing symptoms, above and beyond other neighborhood characteristics (Hypotheses 3 and 4).

The third objective was to examine associations between parental stress and youth internalizing symptoms and medical adherence. It was hypothesized that greater parental stress and internalizing symptoms will be predictive of decreased adherence (Hypotheses 5 and 6).

The fourth objective was to examine the degree to which neighborhood factors predict medical adherence. Living in more socially vulnerable neighborhoods was hypothesized to be associated with a decrease in medical adherence (Hypothesis 7). Additionally, lower levels of hospitals per zip code were hypothesized to be predictive of lower adherence (Hypothesis 8).

The fifth objective of this study was to separately examine the mediating role of parental stress and youth internalizing symptoms on associations between neighborhood factors medical adherence in youth with SB. It was hypothesized that increased neighborhood vulnerability at T1 will be associated with an increase in parent stress from T1 to T2, which will be associated with decreases in adherence from T2 to T3 in youth with SB (Hypothesis 9). Similarly, it was

hypothesized that increased neighborhood vulnerability at T1 will be associated with an increase in internalizing symptoms from T1 to T2, which will be associated with decreases in adherence from T2 to T3 in youth with SB (Hypothesis 10).



Note. Reporters for each measure denoted by the following letters: M = mother, F = father, T = teacher Y = youth-self report.

Figure 1. Mediating Role of Parental Stress and Internalizing Symptoms on the Association Between Neighborhood Factors and Adherence

CHAPTER THREE

METHODS

Participants

Participants were a part of a larger longitudinal study examining physical, neurocognitive, psychological, and social functioning among youth with SB, "The Chicago Healthy Adolescent Transition Study," CHATS (Kayle et al., 2020). Families were recruited from hospitals in the Midwest and from a statewide SB association during clinic visits and using mailed recruitment letters. Inclusion criteria for initial participation included: (1) 8-15 years old, (2) diagnosis of SB (including myelomeningocele, lipomeningocele, and myelocystocele), (3) ability to read and speak in English or Spanish, (4) at least one caregiver involved in the study, and (5) residence within 300 miles of Chicago. For this study, included participants were living in Illinois, due to American Community Survey data and mapping access.

Two hundred forty-six youth and families were invited to participate and 163 agreed. Twenty-one declined participation or were unable to be contacted and two did not meet inclusion criteria. The final sample included 140 youth with SB and their families who completed baseline assessments. Families were contacted for follow-up time points every two years. Of the total sample of 140, 130 participants lived in two Midwestern states.

The study included data from the first three time points of the CHATS study (T1-3). T1 is considered baseline, and T2 and T3 occurred at two and four year follow ups, respectively. Parents completed questionnaires at each time point until their child participants turned 18.

Twenty-five percent of the sample turned 18 at the beginning of T3, resulting in fewer parent participants at T3.

Table 1. Youth Demographic and Condition-Related Information Reported at Time 1

	Total M(SD) or N (%)
Participants	130 (100%)
Age	11.48 (2.49)
Gender (Female)	70 (53.8%)
Race	
Caucasian	67 (51.5%)
African American/Black	18 (13.8%)
Hispanic/Latino	37 (28.5%)
Asian	2 (1.5%)
Biracial	6 (4.6%)
SB Type	
Myelomeningocele	113 (86.9%)
Lipomeningocele	14 (10.7%)
Myelocystocele	2 (1.5%)
Unknown/Not Reported	1 (0.8%)
Lesion Level	
Thoracic	20 (15.4%)
Lumbar	67 (51.5%)
Sacral	37 (28.5%)
Unknown/Not Reported	6 (4.6%)
Shunt Present	101 (77.7%)
IQ	85.24 (19.77)
Family SES	39.36 (16.00)

Note: Demographic information is based on the sample of 130 youth with spina bifida (SB) who participated in study tasks at T1 and lived in the selected Midwestern states.

Procedure

The study utilized data from the CHATS study which was approved by relevant university and hospital Institution Review Boards. Members of the research team obtained informed consent from parents and assent from children under 18 years old. A release of

information was also signed by the parent to obtain data from medical providers and medical records. Trained research assistants collected questionnaire data during home visits, lasting about three hours. There were two visits for T1 and one for each subsequent time point. Families received compensation for participating ($150, a T-shirt, and a pen at each time point).

Questionnaires were completed in English or Spanish, depending on family preference. If questionnaires were not already translated, Spanish speaking research assistants translated them. If requested by the participant, research assistants also read questionnaires out loud. The current study utilized parent-, teacher- and youth- report questionnaire data at T1, T2, and T3 as well as parent/youth current primary address at T1.

Measures

Demographics

At T1, parents reported family demographics, including child age, gender, race, current address, as well as parent education, income, and occupation, used to calculate socioeconomic status (SES) with the Hollingshead Index of Socioeconomic Status (Hollingshead, 1975).

Youth Illness Characteristics

Condition-related data was collected at T1 using the Medical History Questionnaire (MHQ; (Holmbeck et al., 2003)) and medical chart reviews, which included type of SB, lesion level and ambulation ability.

Youth Intelligence

The Vocabulary and Matrix Reasoning subtests of the Weschler Abbreviated Scale of Intelligence (WASI) were administered to youth at T1 (Wechsler, 1999). The WASI is a valid and reliable measure of intellectual functioning in children. Vocabulary (42-items assessing verbal knowledge and expressive vocabulary; $\alpha = .89$) and Matrix Reasoning (35-items assessing

nonverbal fluid reasoning and general intellectual ability; $\alpha = .92$) subtests were used to calculate an abbreviated Full-Scale IQ.

Neighborhood Factors

Neighborhood Vulnerability. The Social Vulnerability Index (SVI), created by the Centers for Disease Control and Prevention (CDC), is a percentile ranked measure used to identify neighborhoods that may be disproportionately burdened before, during, and after public health emergencies (Flanagan et al., 2011, 2018). This measure was chosen for this study because it combines the many factors that have been shown to influence physical and mental health (Diez Roux & Mair, 2010). The SVI uses 15 census variables to rank census tracks from 0 to 1, with larger numbers indicating a higher level of social vulnerability. Scores include an overall composite rank score and scores for four themes, including the following: (1) Socioeconomic status (poverty, unemployment, income, no high school diploma), (2) Household Composition and Disability (aged 65 or older, aged 17 or younger, disability, single-parent households), (3) Minority Status and Language (racial or ethnic minority group, speak English "less than well"), and (4) Housing Type and Transportation (multi-unit housing, mobile homes, crowded housing, vehicle access, group quarters). SVI 2010 data for all census tracks in a Midwestern state will be obtained from CDC/ATSDR's Geospatial Research, Analysis, and Services Program's (GRASP) publicly available database (*CDC/ATSDR Social Vulnerability Index [SVI],* 2022).

Hospitals. The number of hospitals per zip code was utilized as a proxy for acute healthcare services, hospitals that provides inpatient medical care and other related services for surgery, acute medical conditions, or injuries. This was determined using the Center for

Medicare and Medicaid Services' Cost Report for short term acute care hospitals (i.e., pediatric and Critical Access hospitals) that were open in 2011 and onward (*Cost Reports | CMS*, n.d.).

Parental Stress

Parenting Stress. Parents completed the Parenting Stress Index at T2 (PSI; Abidin, 1990), which was used to measure stress in the parenting role. The current study used three subscales: perceived parental competence (11 items; e.g., "I have had more problems raising my children than expected"; reverse-scored- higher scores indicate higher parental competence), restriction of role (7 items; e.g., "I feel trapped by my responsibilities as a parent"; higher scores indicate higher restriction), and social isolation (6 items; e.g., "Since having children, I have a lot fewer chances to see my friends and make new friends"; higher scores indicate higher social isolation). When combining the three subscales due to high correlations, adequate internal consistency was found, with $\alpha = .89$ for mother's report and $\alpha = .83$ for father's report (Friedman et al., 2004).

Family Stress. Parents also completed the Family Stress Scale at T2 (FSS; (Quittner et al., 1990), a 19-item questionnaire assessing common stressors in families with a child with SB. Thirteen items are non-disease specific (e.g., outings in the community) and six items are disease-specific (e.g., catheterization), each rated on a five point scale. Higher total (i.e., both scales combined) scores indicate higher stress. In populations with a chronic illness, the FSS has shown adequate internal consistency (.81 to .85) (Quittner et al., 1998).

Life Stress. Mothers and fathers reported on life stressors at T2 using the Family Inventory of Life Events (FILE; (McCubbin et al., n.d.). The 71 item self-report measure assesses the occurrence of normative and non-normative life events and stressors. These areas include (1) intra-family strains, (2) marital strains, (3) pregnancy and childbearing strains, (4) finance and business strains, (5) work-family transitions and strains, (6) illness and family care

strains, (7) losses, (8) transition in and out, and (9) family legal violations. Parents indicate if that event has ever happened to them and a total score is calculated by adding the "yes" responses, with higher scores indicating more potentially stressful events. Internal consistency for the FILE ranges from .79 to .82 (McCubbin et al., n.d.).

Internalizing Symptoms

Internalizing symptoms, specifically anxiety and depression, were assessed at T3 with parent and teacher report on the Child Behavior Checklist (CBCL; (Achenbach & Rescorla, 2001). The CBCL includes 118 items with several subscales; for the purposes of this study, scores from the Anxiety/Depressed and Withdrawn/Depressed subscales will be included in the analyses. The Internalizing Problems second-order problem scale and Affective and Anxiety Problems DSM-oriented scale will also be examined. Parents rate each item on a three-point scale (0=not true, 1=somewhat or sometimes true, 2=very true or often true). T-scores above 70 fall in the clinical range and indicate significant deviation from the normative sample and T-scores within 65-70 are borderline clinical. A previous study found that 23.5% of the sample of youth with SB had mean T-scores of 60 or above on the Internalizing Problems scale (Holmbeck et al., 2003).

Depression was also assessed at T3 using the Children's Depression Inventory, a 27-item self-rated measure for children (CDI; Kovacs, 1992). Each item has three choices, keyed 0, 1, or 2, with higher scores indicating increased depression severity. In a sample of youth with SB, internal consistency was .81 (Friedman et al., 2004).

Medical Adherence

Parents completed the Spina Bifida Self-Management Profile at T3 (SBSMP; (Wysocki & Gavin, 2006). Originally developed as a structured interview, the current study administered

the SBSMP as a 14-item questionnaire that covers seven dimensions of the SB regimen- (1) appointment keeping, (2) bowel control program, (3) skin and wound care, (4) exercise, (5) medications, (6) clean intermittent catheterization, and (7) dealing with urinary tract infections. Higher scores indicate more optimal treatment adherence. The measure has acceptable internal consistency, with $\alpha = .66$ for mothers of children with SB (Wysocki & Gavin, 2006).

Planned Analyses

Preliminary Analyses

Before conducting the primary analyses, the psychometric properties of all measures were evaluated, and skewness and outliers were determined and dealt with on a case-by-case basis. Pearson correlations were used to examine associations between mother and father reporters and measures were collapsed across the two if all correlations were larger than .40 (Holmbeck et al., 2002). If not correlated, analyses were conducted separately for each measure.

Primary Analyses

Some families who enrolled and participated at T1 declined participation in some or all of the following time points, which led to sample attrition across the three time points. Participants with incomplete data were retained in analyses to maintain the largest possible sample size for analyses. The current sample size of 130 has sufficient power (.80) in detecting medium and large effects for the planned analyses (Cohen, 1992). All analyses were conducted in SPSS v.28

Analytic Plan for Objective 1. The first objective was to adopt an exploratory approach to determine the level of the neighborhood vulnerability and acute healthcare services in the sample. For neighborhood vulnerability, participant addresses were geocoded using ArcMap v10.8 to identify which census tracks they lived in at T1. Each participant's census track ID was matched to the SVI database. For health-related neighborhood factors, the number of acute

healthcare service locations of all zip codes in Illinois were imported into an Access database and directly linked to each participant's address. Descriptive statistics were generated to identify the average level of neighborhood vulnerability and acute healthcare services in the sample of youth with SB. Additionally, scores on the four themes within the SVI were examined to determine the percentage of the sample who are at a higher vulnerability on each theme using established quartiles (An & Xiang, 2015).

Analytic Plan for Objective 2. The second objective was to determine the ability of neighborhood factors to predict parental stress and youth internalizing symptoms. First, a hierarchical multiple regression was conducted, with the dependent variable from the previous time point (i.e., T1 or T2) entered first (to permit the examination of residual change over time in the dependent variable), covariates (i.e., symptom severity, age, and IQ) entered second, and the overall SVI entered third. The second analysis was a hierarchical stepwise regression, with the dependent variables from the previous time point entered first, covariates entered second, followed by the four themes of the SVI, to determine if any are significantly associated with the parental stress variables. The above regressions were run separately across the parenting stress, family stress, life stress and internalizing symptoms variables.

Analytic Plan for Objective 3. The third objective was to determine the ability of parental stress and youth internalizing symptoms to predict youth medical adherence and was tested using hierarchical forward regressions. For the first regression, youth medical adherence from the previous time point was entered first, covariates were entered second, and each of the parental stressors (i.e., parenting stress, family stress and life stress) entered third. A second regression was conducted in the same manner, with internalizing symptoms entered third and medical adherence as the dependent variable.

Analytic Plan for Objective 4. The fourth objective was to determine the ability of neighborhood factors to predict adherence. The analyses were conducted in the same manner as will be done for Objective 2, with adherence as the dependent variable.

Analytic Plan for Objective 5. Finally, two mediation analyses were conducted to examine the mediating role of parental stress and youth internalizing symptoms on associations between neighborhood factors and adherence in youth with SB. The model was run in PROCESS v4.2 (Hayes, 2017) using bootstrapping.

CHAPTER FOUR

RESULTS

Preliminary Analyses

To reduce the number of analyses, bivariate correlations were conducted to determine if mother and father reports of parental stress, child internalizing symptoms and youth medical adherence could be combined into composite scores. With parenting stress and child internalizing symptoms, mother and father reports were not significantly correlated (see Tables 2 to 6) and, therefore, were not combined. All other variables (e.g., family stress, life stress, and medical adherence) were combined. Teacher ratings of child internalizing symptoms remained separate. Descriptives of parental stress, child internalizing symptoms, and youth medical adherence are reported in Table 7.

Table 2. Parent Measures of Parenting Stress

	1	2	3	4	5	6
1. Mother Report of Parental Competence	1					
2. Father Report of Parental Competence	**.103**	1				
3. Mother Report of Restriction of Role	-.532**	-.343**	1			
4. Father Report of Restriction of Role	.030	-.535**	**.128**	1		
5. Mother Report of Social Isolation	-.409**	-.307*	.454**	.165	1	
6. Father Report of Social Isolation	-.048	-.295*	.155	.516**	**.262***	1

Note. Table 3 presents correlations for measures of family stress across reporters. *p<.05, **p<.01.

Table 3. Parent Measures of Family Stress

	1	2
1. Mother Report of Family Stress	1	
2. Father Report of Family Stress	.424**	1

Note. Table 2 presents correlations for measures of parenting stress across reporters. **p <.01.

Table 4. Parent Measures of Life Stress

	1	2
1. Mother Report of Life Stress	1	
2. Father Report of Life Stress	.424**	1

Note. Table 4 presents correlations for measures of life stress across reporters. **p<.01.

Table 5. Parent Measures of Child Internalizing Symptoms

	1	2	3	4	5	6
1. Mother Report of Anxiety/Depression in Child	1					
2. Father Report of Anxiety/Depression in Child	**.243**	1				
3. Mother Report of Withdrawn/Depressed in Child	.672**	.137	1			
4. Father Report of Withdrawn/Depressed in Child	.221	.607*	**.361***	1		
5. Mother Report of Child's Internalizing Symptoms	.760**	.165	.792**	.235	1	
6. Father Report of Child's Internalizing Symptoms	.287*	.689**	.334**	.719**	**.293***	1

Note. Table 5 presents correlations for measures of child internalizing symptoms across reporters. *p<.05, **p<.01.

Table 6. Parent Measures of Child Medical Adherence

	1	2
1. Mother Report of Adherence	1	
2. Father Report of Adherence	.635**	1

Note. Table 6 presents correlations for measures of child medical adherence across reporters. **p<.01.

Table 7. Descriptives of Parental Stress, Child Internalizing Symptoms, and Youth Medical Adherence

Variable	M(SD), Skew	Possible Range
T2 Parenting Stress		
Mother Report of Parental Competence	4.00(.42), -.01	1.25-5
Father Report of Parental Competence	3.88(.53), -1.09	1.25-5
Mother Report of Restriction of Role	2.54(.63), .02	1.25-5
Father Report of Restriction of Role	2.49(.59), -.04	1.25-5
Mother Report of Social Isolation	2.29(.64), .26	1.25-5
Father Report of Social Isolation	2.37(.55), -.28	1.25-5
T2 Mother and Father Composite Report of Family Stress	1.82(.58), .96	1-5
T2 Mother and Father Composite Report of Life Stress	10.37(7.18), .79	0-90
T2 Internalizing Symptoms		
Mother Report of Anxiety/Depression in Child	54.23(5.88), 1.47	0-100
Father Report of Anxiety/Depression in Child	53.38(5.34), 1.71	0-100
Teacher Report of Anxiety/Depression in Child		0-100
Mother Report of Withdrawn/Depressed in Child	55.43(6.41), 1.64	0-100
Father Report of Withdrawn/Depressed in Child	54.80(5.68), 1.06	0-100
Teacher Report of Withdrawn/Depressed in Child		0-100
Mother Report of Child's Internalizing Symptoms	53.95(9.82), .21	0-100
Father Report of Child's Internalizing Symptoms	51.75(10.06), -.14	0-100
Teacher Report of Child's Internalizing Symptoms		0-100
Youth Report of Depressive Symptoms	1.27(.19), .82	1-3
T3 Mother and Father Composite Report of Youth Medical Adherence	4.35(.44), -1.06	1-6

Hypothesis Testing

Descriptive statistics were generated to characterize the level of neighborhood social vulnerability and acute healthcare services in the sample (objective 1). Regression analyses were used to determine whether neighborhood factors predicted parental stress and youth internalizing symptoms (objective 2). Further, regression analyses were also used to determine whether parental stress or youth internalizing symptoms predicted medical adherence (objective 3). Additional regression analyses were conducted to determine which neighborhood factors predicted medical adherence (objective 4). Finally, mediation models were used to determine whether parental stress or youth internalizing symptoms mediated the association between neighborhood factors and medical adherence (objective 5). Given variability in age, intelligence and SB symptom severity in the sample, all analyses were run with age, IQ, and lesion level included as covariates.

Objective 1. Adopt an exploratory approach to determine the level of neighborhood vulnerability and neighborhood hospitals in youth with SB.

First, participant addresses from T1 were geocoded to determine census-track SVI scores and number of hospitals per zip code (see Table 8). The overall sample neighborhood vulnerability was .52, falling within the mid-high vulnerability range. Additionally, over 30% of the sample fell in the high vulnerability range (Flanagan et al., 2011, 2018). Because all variables within the SVI were highly correlated (r >.7), only overall SVI scores were used in subsequent analyses.

Looking at hospitals per zip code, 62% of participants did not have a hospital in their neighborhood (see Table 7). Because of the skewed distribution for the hospital data, hospitals

were examined as a categorical variable in all analyses (at least one hospital in zip code [1] vs. no hospital in zip code [0]).

Table 8. Neighborhood Factors

	M(SD) or N (%)
SVI: Overall	.52 (.31)
Theme 1: Socioeconomic Status	.50 (.31)
Theme 2: Household Composition/Disability	.53 (.29)
Theme 3: Minority Status/Language	.62 (.28)
Theme 4: Housing Type/Transportation	.52 (.31)
SVI: Quartiles	
Low Vulnerability (0-.2500)	35 (26.9%)
Mid-Low Vulnerability (.2501-.5000)	21 (16.2%)
Mid-High Vulnerability (.5001-.7500)	34 (26.2%)
High Vulnerability (.7501-1.0)	40 (30.8%)
Hospitals per Zip Code	
0	80 (62.0%)
1	37 (28.7%)
2	8 (6.2%)
3	2 (1.6%)
4	2 (1.6%)

Objective 2. Examine neighborhood factors as predictors of parental stress and youth internalizing symptoms.

Next, regressions were used to assess the predictive ability of neighborhood factors at T1 on parental stress and youth internalizing symptoms at T2. Results indicated that when controlling for youth age, intelligence and symptom severity, neighborhood factors (e.g., neighborhood vulnerability and presence of hospitals) were not significant predictors of any of the measures of parental stress (i.e., parenting, family, or life stress) or youth internalizing symptoms (see Tables 9-16).

Table 9. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Mother's Parenting Stress

	T2 Parental Competence			T2 Restriction of Role			T2 Social Isolation		
Variable	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$
T1 Parental Competence	1	.54	.29**	-	-	-	-	-	-
T1 Restriction of Role	-	-	-	1	.46	.21**	-	-	-
T1 Social Isolation	-	-	-	-	-	-	1	.59	.34**
T1 Youth age	2	.17	.04	2	-.24	.08*	2	-.10	.01
T1 Youth IQ	2	-.04		2	.12		2	-.07	
T1 Youth SB severity	2	.03		2	.04		2	-.00	
T1 Neighborhood Vulnerability	3	.10	.01	3	-.11	.01	3	.06	.00
T1 Parental Competence	1	.54	.29**	-	-	-	-	-	-
T1 Restriction of Role	-	-	-	1	.46	.21**	-	-	-
T1 Social Isolation	-	-	-	-	-	-	1	.59	.34**
T1 Youth age	2	.17	.04	2	-.24	.08*	2	-.10	.01
T1 Youth IQ	2	-.04		2	.12		2	-.07	
T1 Youth SB severity	2	.03		2	.04		2	-.00	
T1 Hospitals	3	-.03	.00	3	.05	.00	3	.04	.00

**p<.001 * p<.05

Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 10. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Father's Parenting Stress

	T2 Parental Competence			T2 Restriction of Role			T2 Social Isolation		
Variable	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$
T1 Parental Competence	1	.46	.21**	-	-	-	-	-	-
T1 Restriction of Role	-	-	-	1	.50	.25**	-	-	-
T1 Social Isolation	-	-	-	-	-	-	1	.54	.29**
T1 Youth age	2	-.02	.04	2	.03	.01	2	.03	.05
T1 Youth IQ	2	-.23		2	-.04		2	.20	
T1 Youth SB severity	2	-.06		2	-.08		2	.18	
T1 Neighborhood Vulnerability	3	-.17	.02	3	-.05	.00	3	-.20	.04
T1 Parental Competence	1	.46	.21**	-	-	-	-	-	-
T1 Restriction of Role	-	-	-	1	.50	.25**	-	-	-
T1 Social Isolation	-	-	-	-	-	-	1	.54	.29**
T1 Youth age	2	-.02	.04	2	.03	.01	2	.03	.05
T1 Youth IQ	2	-.23		2	-.04		2	.20	
T1 Youth SB severity	2	-.06		2	-.08		2	.18	
T1 Hospitals	3	-.22	.05	3	-.08	.01	3	-.09	.01

**p<.001

Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 11. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Mother and Father Composite Report of Family Stress

	T2 Family Stress		
Variable	Step	β	$\triangle R^2$
T1 Family Stress	1	.56	.32**
T1 Youth age	2	-.15	.04
T1 Youth IQ	2	.05	
T1 Youth SB severity	2	-.06	
T1 Neighborhood Vulnerability	3	-.13	.02
T1 Family Stress	1	.56	.32**
T1 Youth age	2	-.15	.04*
T1 Youth IQ	2	.05	
T1 Youth SB severity	2	-.06	
T1 Hospitals	3	.06	.00

**p<.001
Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 12. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Mother and Father Composite Report of Life Stress

	T2 Life Stress		
Variable	Step	β	$\triangle R^2$
T1 Life Stress	1	.63	.40**
T1 Youth age	2	-.07	.04
T1 Youth IQ	2	.18	
T1 Youth SB severity	2	-.02	
T1 Neighborhood Vulnerability	3	-.14	.02
T1 Life Stress	1	.63	.40**
T1 Youth age	2	-.07	.04
T1 Youth IQ	2	.18	
T1 Youth SB severity	2	-.02	
T1 Hospitals	3	-.05	.00

**p<.001 * p<.05
Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 13. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Mother-report of Youth Internalizing Symptoms

	T2 Anxiety/Depressed			T2 Withdrawn/Depressed			T2 Internalizing Symptoms		
Variable	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$
T1 Anxiety/Depressed	1	.51	.26**	-	-	-	-	-	-
T1 Withdrawn/Depressed	-	-	-	1	.48	.23**	-	-	-
T1 Internalizing Symptoms	-	-	-	-	-	-	1	.66	.44**
T1 Youth age	2	-.08	.01	2	.07	.01	2	.08	.01
T1 Youth IQ	2	.04		2	.01		2	.08	
T1 Youth SB severity	2	.00		2	.05		2	.06	
T1 Neighborhood Vulnerability	3	.12	.01	3	.01	.00	3	.80	.00
T1 Anxiety/Depressed	1	.51	.26**	-	-	-	-	-	-
T1 Withdrawn/Depressed	-	-	-	1	.48	.23**	-	-	-
T1 Internalizing Symptoms	-	-	-	-	-	-	1	.66	.44**
T1 Youth age	2	-.08	.01	2	.07	.01	2	.08	.01
T1 Youth IQ	2	.04		2	.01		2	.08	
T1 Youth SB severity	2	.00		2	.05		2	.06	
T1 Hospitals	3	.06	.00	3	.06	.00	3	-.02	.00

**p<.001

Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 14. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Father-report of Youth Internalizing Symptoms

	T2 Anxiety/Depressed			T2 Withdrawn/Depressed			T2 Internalizing Symptoms		
Variable	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$
T1 Anxiety/Depressed	1	.43	.19**	-	-	-	-	-	-
T1 Withdrawn/Depressed	-	-	-	1	.37	.14*	-	-	-
T1 Internalizing Symptoms	-	-	-	-	-	-	1	.40	.16*
T1 Youth age	2	.05	.01	2	.00	.05	2	-.03	.03
T1 Youth IQ	2	-.03		2	-.07		2	-.05	
T1 Youth SB severity	2	.06		2	.20		2	.15	
T1 Neighborhood Vulnerability	3	.18	.03	3	.16	.02	3	.18	.03
T1 Anxiety/Depressed	1	.43	.19**	-	-	-	-	-	-
T1 Withdrawn/Depressed	-	-	-	1	.37	.14*	-	-	-
T1 Internalizing Symptoms	-	-	-	-	-	-	1	.40	.16*
T1 Youth age	2	.05	.01	2	.00	.05	2	-.03	.03
T1 Youth IQ	2	-.03		2	-.07		2	-.05	
T1 Youth SB severity	2	.06		2	.20		2	.15	
T1 Hospitals	3	.20	.04	3	.13	.02	3	.13	.02

**p<.001 *p<.05

Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 15. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Teacher-report of Youth Internalizing Symptoms

	T2 Anxiety/Depressed			T2 Withdrawn/Depressed			T2 Internalizing Symptoms		
Variable	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$	Step	β	$\triangle R^2$
T1 Anxiety/Depressed	1	.27	.07*	-	-	-	-	-	-
T1 Withdrawn/Depressed	-	-	-	1	.44	.14**	-	-	-
T1 Internalizing Symptoms	-	-	-	-	-	-	1	.41	.17*
T1 Youth age	2	.06	.08	2	-.10	.05	2	-.03	.09
T1 Youth IQ	2	-.25		2	-.22		2	-.31	
T1 Youth SB severity	2	.02		2	.03		2	.03	
T1 Neighborhood Vulnerability	3	-.14	.02	3	.00	.00	3	-.04	.00
T1 Anxiety/Depressed	1	.27	.07*	-	-	-	-	-	-
T1 Withdrawn/Depressed	-	-	-	1	.44	.20**	-	-	-
T1 Internalizing Symptoms	-	-	-	-	-	-	1	.41	.16**
T1 Youth age	2	.06	.08	2	-.10	.05	2	-.03	.09
T1 Youth IQ	2	-.25		2	-.22		2	-.31	
T1 Youth SB severity	2	.02		2	.03		2	.03	
T1 Hospitals	3	-.03	.00	3	.02	.00	3	-.03	.00

**p<.001 *p<.05

Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Table 16. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T2 Youth-report of Depressive Symptoms

	T2 Depression		
Variable	Step	β	$\triangle R^2$
T1 Life Stress	1	.24	.06*
T1 Youth age	2	.11	.04
T1 Youth IQ	2	-.12	
T1 Youth SB severity	2	-.15	
T1 Neighborhood Vulnerability	3	.13	.01
T1 Life Stress	1	.24	.06*
T1 Youth age	2	.11	.04
T1 Youth IQ	2	-.12	
T1 Youth SB severity	2	-.15	
T1 Hospitals	3	.07	.00

**p<.001 * p<.05
Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Objective 3. Examine parental stress and youth internalizing symptoms as predictors of youth medical adherence.

Regressions were also used to assess the predictive ability of parental stress and youth internalizing symptoms at T2 on youth medical adherence at T3. Results indicated that when controlling for youth age, intelligence and symptom severity, parental stress and youth internalizing symptom variables were not significant predictors of youth medical adherence (see Table 17).

Table 17 Summary of Regression Analyses Showing Associations between T2 Mother and Father Stress, T2 Youth Internalizing Symptoms, and T3 Mother and Father Composite Report of Youth Medical Adherence

	T3 Medical Adherence		
Variable	Step	β	$\triangle R^2$
T2 Medical Adherence	1	.65	.43**
T1 Youth age	2	.00	.09
T1 Youth IQ	2	-.05	
T1 Youth SB severity	2	.30	
T2 Medical Adherence	1	.64	.41**
T1 Youth age	2	-.00	.07
T1 Youth IQ	2	-.03	
T1 Youth SB severity	2	.27	

**p<.001 * p<.05

Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set. No parental stress (first regression listed) or internalizing symptoms (second regression listed) variables at step 3 were entered.

Objective 4. Examine neighborhood factors as predictors of youth medical adherence.

Next, regressions were used to assess the predictive ability of neighborhood factors at T1 on youth medical adherence at T3. Results indicated that when controlling for youth age, intelligence and symptom severity, neighborhood factors (e.g., neighborhood vulnerability and presence of hospitals) were not significant predictors of youth medical adherence (see Table 18).

Table 18. Summary of Regression Analyses Showing Associations between T1 Neighborhood Factors and T3 Mother and Father Composite Report of Youth Medical Adherence

	T3 Medical Adherence		
Variable	Step	β	$\triangle R^2$
T2 Medical Adherence	1	.64	.41**
T1 Youth age	2	-.01	.05
T1 Youth IQ	2	-.00	
T1 Youth SB severity	2	.23	
T1 Neighborhood Vulnerability	3	.02	.00
T2 Medical Adherence	1	.64	.40**
T1 Youth age	2	-.01	.05
T1 Youth IQ	2	-.00	
T1 Youth SB severity	2	.23	
T1 Hospitals	3	-.03	.00

**p<.001 * p<.05
Note: $\triangle R^2$ at step 2 is for all 3 covariates as a set.

Objective 5. Separately examine the mediating role of parental stress and youth internalizing symptoms on associations between neighborhood factors and youth medical adherence.

Due to the lack of significant findings in relation to Objectives 2-4, mediation analyses were not conducted.

CHAPTER FIVE

DISCUSSION

Youth with SB experience physical, medical, and neuropsychological complications that require daily medical management tasks like catheterization, bowel program management, and skin checks for pressure injuries (Copp et al., 2015; Fletcher et al., 2004). Further, mental health factors like depression and anxiety can influence a youth's ability to adhere to these daily self-management tasks (Appleton et al., 1997; Bellin et al., 2010; Coakley et al., 2006; Holmbeck & Devine, 2010; Iddon et al., 2004). Evidence from other chronic illness populations have identified family and individual-level predictors (e.g., internalizing symptoms, parental stress) of self-management outcomes (Friedman et al., 2004; Simpson et al., 2020), yet few have looked at the impact of neighborhood factors despite knowing the impact it has on a variety of health outcomes (Diez Roux & Mair, 2010; Leventhal & Brooks-Gunn, 2000).

This study attempted to understand these constructs and their associations in the SB population via a longitudinal design examining the influence of neighborhood factors on parents and youth with SB. Considering prior research, it was hypothesized that living in more vulnerable neighborhoods and neighborhoods with no hospitals would predict an increase in parental stress and youth internalizing symptoms. In addition, this study examined associations between parental stress and youth internalizing symptoms and medical adherence. Because parents of youth with SB experience higher stress than the general population (Holmbeck et al., 1997), which can impact adherence (Ryan & Sawin, 2009), it was hypothesized that greater parental stress and internalizing symptoms would be predictive of decreased medical adherence.

Further, extant literature also suggests that physical/social factors (e.g., access to healthcare, transportation, neighborhoods) impact medical adherence (Ryan & Sawin, 2009). Thus, this study sought to examine associations between neighborhood factors and medical adherence. It was hypothesized that living in more socially vulnerable neighborhoods would be associated with a decrease in medical adherence and lower levels of hospitals per zip code were hypothesized to be predictive of lower adherence. Finally, we sought to examine parental stress and youth internalizing symptoms as mediators, such that increased neighborhood vulnerability would be associated with an increase in parent stress, which would be associated with decreases in adherence. Similarly, it was hypothesized that increased neighborhood vulnerability would be associated with an increase in internalizing symptoms, which would be associated with decreases in adherence.

Level of Neighborhood Vulnerability and Hospitals in Sample

Findings illustrated that the overall sample fell within the mid-high vulnerability range, meaning participants were living in neighborhoods that are more likely to be impacted by external stressors on human health ((Flanagan et al., 2011, 2018). With over 30% of the sample falling in the high vulnerability range, this suggests that participants in these vulnerable neighborhoods are at the highest need for resources so they can prepare for, respond to, and/or recover from any public health crises. Similarly, a majority of the sample did not have a hospital in their zip code. This may be tied to the level of zip code vulnerability, with there being a large increase in hospital closures in lower-income neighborhoods (*Mercy Hospital's Slated Closure among Wave of Medical Centers Vanishing from Chicago Area*, 2020).

Impact of Neighborhood Factors on Parental Stress, Youth Internalizing Symptoms, and Youth Medical Adherence

Neighborhood vulnerability and presence of hospitals at T1 were not significant predictors of any parental stress or youth internalizing symptoms at T2. These findings were contrary to hypotheses and not consistent with previous work that had demonstrated the impact of neighborhood lack of resources on parental stress and youth internalizing symptoms. Similarly, neighborhood vulnerability and presence of hospitals at T1 were also not a significant predictor of youth medical adherence at T3. These findings were inconsistent with hypotheses and the individual and family self-management theory that posits that the physical/social environment can also impact self-management (Ryan & Sawin, 2009).

Impact of Parental Stress and Youth Internalizing Symptoms on Youth Medical Adherence

Contrary to hypotheses, parental stress, and youth internalizing symptoms at T2 were not significant predictors of youth medical adherence at T3. These findings were also contrary to the individual and family self-management theory which illustrated how negative family behaviors (e.g., high parental stress) and anxiety and depressive symptoms can diminish self-management behaviors (Ryan & Sawin, 2009; Gadalla, 2008).

Assessing the Influence of Neighborhood Factors

The lack of findings illustrates that youth with SB may be less influenced by neighborhood factors because they are not actively engaging in it. For instance, youth with physical disabilities participate in fewer activities and less often than youth without disabilities (King et al., 2009). While more research needs to be done in the SB population, it is possible that youth are outside less and are not interacting with the surrounding neighborhood and community.

As evidenced in other populations with disabilities (Krahé & Altwasser, 2006; Meyers et al., 2002; Park et al., 2003), this lack of engagement could be due to a variety of factors including inaccessibility of the built environment and stigma from individuals without disabilities.

Additionally, with the impact of neighborhood factors on individuals with SB never being explored before, it is possible that the themes within the SVI (i.e., SES, Household Composition/Disability, Minority Status/Language and Housing Type/Transportation) do not impact these youth and their families and other factors might be more relevant. Recent research illustrated the nuances between neighborhood indices and how there is no one-size-fits all approach to capturing neighborhood factors (Kaalund et al., 2022). The SVI centers on the economic, education, and community domains of the social determinants of health, not including other factors like environmental health or healthcare access that have been shown to also impact health outcomes (Brender et al., 2011; Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2003).

Knowing this, neighborhood indices like the Child Opportunity Index (COI) (*Child Opportunity Index (COI) | Diversitydatakids.Org*, n.d.) and COVID-19 Community Vulnerability Index (CCVI) (*Bringing Greater Precision to the COVID-19 Response*, n.d.) may be better suited for capturing neighborhood conditions that may be more relevant to youth with SB. The COI is the first child specific neighborhood metric that covers economic and educations domains in addition to an environmental domain that reflects features of healthy environments, such as access to green space, and features that are toxic, such as pollution and exposure to extreme heat. These environmental factors may especially impact youth with SB, as safety of an environment has been shown as a barrier to parents having their child with SB engage in outside activities (Bloemen et al., 2015). Originally designed to measure how well a community

responds to a COVID-19 outbreak, the CCVI covers economic, education, and community domains like the SVI, with the addition of a health care domain that includes healthcare accessibility (e.g., percent of population with a primary care provider) and health system strength (e.g., health spending and aggregate cost of medical care). This domain may be relevant to youth with SB and their families, given that the management of SB involves consistent health care utilization; a lack of accessibility may contribute to a decrease in medical adherence (Beck et al., 2017; Qato et al., 2014).

It is also possible that the number of hospitals in a neighborhood might not be relevant to the medical care of youth with SB. These youth have complex medical care that requires treatment and ongoing management of challenges including hydrocephalus and bladder and bowel incontinence (Fletcher et al., 2004; O'Hara & Holmbeck, 2013). Because of this, the clinical model most commonly used to provide care to individuals with SB involves multiple healthcare provider specialties seeing patients in the same clinical space on the same day (Thibadeau et al., 2020). Given that there are only 104 multidisciplinary SB clinics in the US, it is possible that youth with SB are not being seen at local hospitals but instead are traveling to be seen at a specialized location that is familiar with their care. Therefore, the presence of hospitals in their neighborhood would have little to no impact on their health outcomes.

Strengths, Limitations, and Future Directions

This study had several strengths. It addressed notable gaps in the pediatric literature and added to knowledge about the role of neighborhood factors on parental and youth functioning. Notably, this study utilized a multi-method approach (i.e., geocoding and questionnaires) and data from multiple sources (i.e., parents, teachers, and youth) to evaluate youth outcomes across multiple contexts (i.e., neighborhood and home). Additionally, the study's longitudinal design

spanned across three time points (across 4 years) to offer a deeper examination of how neighborhood factors impact the SB population across time.

Importantly, the study also had limitations. The SBSMP may have not have fully captured adherence in this population. The measure was adapted from the Diabetes Self-Management Profile, which was a validated semi-structured interview to measure adherence of individuals with type one diabetes (Harris et al., 2000). The measure was then adapted as an interview for individuals with SB (Wysocki & Gavin, 2006) and then further adapted as a questionnaire for the purposes of this study. Knowing this, it is possible that, due to differences across chronic illnesses (i.e., type 1 diabetes to SB) and methods (i.e., interview to questionnaire), the SBSMP may not yield an accurate assessment of adherence in youth with SB. Future research should explore other methods of capturing adherence, like utilizing the SBSMP as an interview or a health care provider report to assess rates of compliance to specific medical tasks.

Additionally, given that the SVI may not have captured the neighborhood characteristics that are most relevant to youth with SB and their families, future research is needed to explore how different indices like the COI and CCVI impact these youth, in addition to how these neighborhood indices can be used to identify health inequities and accurately capture the impact of structural racism and discrimination that influence social disadvantage.

Due to the lack of findings in the regression analyses, the mediation model was not run. Further, to reduce the number of analyses, some mother and father reports were combined. Despite the reporters being significantly correlated prior to creating composite scores, looking at mother and father reports separately may impact findings. Lastly, given that the study utilized a sample located in two Midwestern states, the findings are unable to be generalized to other

regions or states. A dataset collected from multiple sites across the nation would provide not only a larger sample size but would likely further our understanding of the associations of neighborhood factors on youth and parent outcomes.

Conclusions and Clinical Implications

Overall, findings from this study addressed gaps in the existing SB literature. Results suggest that, despite living in moderately to highly vulnerable neighborhoods with a lack of hospitals, these factors do not appear to impact parental stress, youth internalizing symptoms, or youth medical adherence. Despite the lack of significant findings, this study still has clinical implications. Providers should continue to consider larger contexts, including neighborhoods, when supporting youth with SB and their families. Providers could utilize existing neighborhood indices like the SVI or social needs screening to better understand the family's barriers to care (e.g., transportation and safe housing). This type of screening has been successfully integrated into many US healthcare systems (Yan et al., 2022). Given the need for clinicians to screen for contextual barriers that impact care and health outcomes, it is also important that clinicians recognize the role of larger systems (e.g., systemic racism, redlining) that may impact how client functions within their neighborhood environment. Tools like the SVI can also be used inform more equitable policies that prioritize vulnerable neighborhoods, highlighting the importance of clinicians engaging in local, state, and federal advocacy.

Future research should also examine how neighborhood factors impact neuropsychological, academic, and social functioning. To date, this relationship between neighborhood factors and functioning has not been explored in pediatric populations but research in typically developing populations have found that neighborhoods significantly impact these domains (Muñoz et al., 2020; Nieuwenhuis & Hooimeijer, 2016; Warner & Settersten, 2017).

Evaluating these clinically significant outcomes within the SB population is needed to provide the best well-rounded and contextually informed care for youth with SB and their families.

APPENDIX A

MEASURES

ASEBA

Please print **CHILD BEHAVIOR CHECKLIST FOR AGES 6-18**

For office use only ID #

CHILD'S FULL NAME: First Middle Last

CHILD'S GENDER ☐ Boy ☐ Girl | CHILD'S AGE | CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo._____ Date _____ Yr. _____ | CHILD'S BIRTHDATE Mo._____ Date _____ Yr. _____

GRADE IN SCHOOL _____

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the space provided on page 2. ***Be sure to answer all items.***

PARENTS' USUAL TYPE OF WORK, even if not working now. *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK _____

MOTHER'S TYPE OF WORK _____

THIS FORM FILLED OUT BY: (print your full name)

_____

Your gender: ☐ Male ☐ Female

Your relation to the child:

☐ Biological Parent ☐ Step Parent ☐ Grandparent
☐ Adoptive Parent ☐ Foster Parent ☐ Other (specify)_____

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average	Don't Know
a. _____	☐	☐	☐	☐	☐	☐	☐	☐
b. _____	☐	☐	☐	☐	☐	☐	☐	☐
c. _____	☐	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, computers, singing, etc. (Do ***not*** include listening to radio or TV.)

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average	Don't Know
a. _____	☐	☐	☐	☐	☐	☐	☐	☐
b. _____	☐	☐	☐	☐	☐	☐	☐	☐
c. _____	☐	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to others of the same age, how active is he/she in each?			
	Less Active	Average	More Active	Don't Know
a. _____	☐	☐	☐	☐
b. _____	☐	☐	☐	☐
c. _____	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

	Compared to others of the same age, how well does he/she carry them out?			
	Below Average	Average	Above Average	Don't Know
a. _____	☐	☐	☐	☐
b. _____	☐	☐	☐	☐
c. _____	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

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Please print. Be sure to answer all items.

V. 1. About how many close friends does your child have? (Do *not* include brothers & sisters)

☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work alone?	☐	☐	☐	

VII. 1. Performance in academic subjects. ☐ Does not attend school because _____

Check a box for each subject that child takes	Failing	Below Average	Average	Above Average
a. Reading, English, or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
e. _____	☐	☐	☐	☐
f. _____	☐	☐	☐	☐
g. _____	☐	☐	☐	☐

Other academic subjects–for example: computer courses, foreign language, business. Do *not* include gym, shop, driver's ed., or other nonacademic subjects.

2. Does your child receive special education or remedial services or attend a special class or special school?
☐ No ☐ Yes—kind of services, class, or school:

3. Has your child repeated any grades? ☐ No ☐ Yes—grades and reasons:

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes—please describe:

When did these problems start?_____
Have these problems ended? ☐ No ☐ Yes–when?

Does your child have any illness or disability (either physical or mental)? ☐ No ☐ Yes---please describe:

What concerns you most about your child?

Please describe the best things about your child.

Be sure you answered all items.

Please print. Be sure to answer all items. 16

Below is a list of items that describe children and youths. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. Acts too young for his/her age
0 1 2 2. Drinks alcohol without parents' approval (describe):_____
_____
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5. There is very little he/she enjoys
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate; can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
_____
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Cruel to animals
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Daydreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys things belonging to his/her family or others
0 1 2 22. Disobedient at home
0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well
0 1 2 25. Doesn't get along with other kids
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Breaks rules at home, school, or elsewhere
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): _____
_____
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): _____
_____
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe): _____
_____
_____
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight

56. Physical problems ***without known medical cause:***
0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): _____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____
_____

Please print. Be sure to answer all items. 16

Below is a list of items that describe children and youths. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

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0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
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0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
_____
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
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0 1 2 27. Easily jealous
0 1 2 28. Breaks rules at home, school, or elsewhere
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): _____
_____
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): _____
_____
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe): ____
_____
_____
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight

56. Physical problems ***without known medical cause:***

0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): _____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____
_____

CDI

Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentences, pick the ***one*** sentence that describes you ***best*** for the past ***two*** weeks. After you pick a sentence from the first group, go on to the next group.

There is no right or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this ☑ next to your answer. Put the mark in the box next to the sentence that you pick.

Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you ***best***.

Example:

☐ I read books all the time.
☐ I never read books.
☐ I read books once in awhile.

Remember, pick out the sentence that describes you best in the PAST TWO WEEKS.

Remember describe how you have been in the past two weeks...	
Item 1 I am sad once in a while. I am sad many times. I am sad all the time.	*Item 8* All bad things are my fault. Many bad things are my fault Bad things are not usually my fault.
Item 2 Nothing will ever work out for me. I am not sure if things will work out for me. Things will work out for me O.K.	*Item 9* I do not think about killing myself. I think about killing myself, but I would not do it. I want to kill myself.
Item 3 I do most things O.K. I do many things wrong. I do everything wrong.	*Item 10* I feel like crying everyday. I feel like crying most days. I feel like crying once in a while.
Item 4 I have fun in many things. I have fun in some things. Nothing is fun at all.	*Item 11* Things bother me all the time. Things bother me many times. Things bother me once in a while.
Item 5 I am bad all the time. I am bad many times. I am bad once in a while.	*Item 12* I like being with people. I do not like being with people many times. I do not want to be with people at all.
Item 6 I think about bad things happening to me once in a while. I worry that bad things will happen to me. I am sure that terrible things will happen to me.	*Item 13* I cannot make up my mind about things. It is hard to make up my mind about things. I make up my mind about things easily.
Item 7 I hate myself. I do not like myself. I like myself.	*Item 14* I look O.K. There are some bad things about my looks. I look ugly.

CDI

Remember, describe how you have been in the past two weeks…	
Item 15 ☐ I have to push myself all the time to do my schoolwork. ☐ I have to push myself many times to do my schoolwork. ☐ Doing schoolwork is not a big problem.	*Item 21* ☐ I never have fun at school. ☐ I have fun at school only once in a while. ☐ I have fun at school many times.
Item 16 ☐ I have trouble sleeping every night. ☐ I have trouble sleeping many nights. ☐ I sleep pretty well.	*Item 22* ☐ I have plenty of friends. ☐ I have some friends but I wish I had more. ☐ I do not have any friends.
Item 17 ☐ I am tired once in a while. ☐ I am tired many days. ☐ I am tired all the time.	*Item 23* ☐ My schoolwork is alright. ☐ My schoolwork is not as good as before. ☐ I do very badly in subjects I used to be good in.
Item 18 ☐ Most days I do not feel like eating. ☐ Many days I do not feel like eating. ☐ I eat pretty well.	*Item 24* ☐ I can never be as good as other kids. ☐ I can be as good as other kids if I want to. ☐ I am just as good as other kids.
Item 19 ☐ I do not worry about aches and pains. ☐ I worry about aches and pains many times. ☐ I worry about aches and pains all the time.	*Item 25* ☐ Nobody really loves me. ☐ I am not sure if anybody loves me. ☐ I am sure that somebody loves me.
Item20 ☐ I do not feel alone. ☐ I feel alone many times. ☐ I feel alone all the time.	*Item 26* ☐ I usually do what I am told. ☐ I do not do what I am told most times. ☐ I never do what I am told.
	Item 27 ☐ I get along with people. ☐ I get into fights many times. ☐ I get into fights all the time.

FILE

Over the life cycle, all families experience many changes as a result of normal growth and development of members and due to external circumstances. The following list of family life changes can happen in a family at any time. A life change for any one family member affects all other persons in the family to some degree. Please read each family life change and decide whether it happened to any member of your family—including you.

First decide if the event happened in your family during the last 12 months. For those events that have happened, please indicate the extent to which the event had an impact on your life at the time the event occurred.

	Has this event happened in the **PAST** 12 months?		**IF YES,** how much impact/effect has this event had on **YOU**.		
			No effect at all	Some effect	Very big effect
1. Increase in amount of time spouse/significant other spent away from the family	Yes	No	1--------2--------3--------4--------5		
2. Increase in the amount of time you spent away from the family	Yes	No	1--------2--------3--------4--------5		
CONFLICTS					
3. Increase in conflict between you and your spouse/significant other	Yes	No	1--------2--------3--------4--------5		
4. Increase in arguments between parents(s) and child(ren)	Yes	No	1--------2--------3--------4--------5		
5. Increase in conflicts among children of the family	Yes	No	1--------2--------3--------4--------5		
6. Increased difficulty with teenage child(ren)	Yes	No	1--------2--------3--------4--------5		
7. Increased difficulty with school age child(ren) (6 to 12years)	Yes	No	1--------2--------3--------4--------5		
8. Increased difficulty with preschool age child(ren) (2 ½ to 6 years)	Yes	No	1--------2--------3--------4--------5		
9. Increased difficulty with toddler(s) (1 to 2 ½ years)	Yes	No	1--------2--------3--------4--------5		
10. Increased difficulty with infants	Yes	No	1--------2--------3--------4--------5		
11. Increased number of "outside activities" in which child(ren) are involved	Yes	No	1--------2--------3--------4--------5		
12. Increase in number of problems or issues in the family that don't get resolved	Yes	No	1--------2--------3--------4--------5		

	Has this event happened in the PAST 12 months?		IF YES, how much impact/effect has this event had on YOU.		
			No effect at all	Some effect	Very big effect
13. Increase in the number of tasks of chores that don't get done	Yes	No	1--------2--------3--------4--------5		
14. Child experienced increased conflict with peers	Yes	No	1--------2--------3--------4--------5		
15. Parent experienced increased conflict with friends	Yes	No	1--------2--------3--------4--------5		
16. A family member had problems or increased conflict with in-laws or relatives	Yes	No	1--------2--------3--------4--------5		
17. Increased conflict with a neighbor	Yes	No	1--------2--------3--------4--------5		
18. Conflict with a landlord	Yes	No	1--------2--------3--------4--------5		
19. Increased disagreement about a family member's friends or activities	Yes	No	1--------2--------3--------4--------5		
MARITAL					
20. You or your spouse/significant other separated for some time	Yes	No	1--------2--------3--------4--------5		
21. Spouse/significant other had an "affair"	Yes	No	1--------2--------3--------4--------5		
22. You and your spouse/significant other divorced	Yes	No	1--------2--------3--------4--------5		
23. A family member got engaged, married, or remarried	Yes	No	1--------2--------3--------4--------5		
24. Increased difficulty in resolving issues with a "former" or separated spouse/significant other	Yes	No	1--------2--------3--------4--------5		
25. Increased difficulty with sexual relationship between you and your spouse/significant other	Yes	No	1--------2--------3--------4--------5		
26. Married son or daughter was separated or divorced	Yes	No	1--------2--------3--------4--------5		
27. A family member "broke up" a relationship with a close friend	Yes	No	1--------2--------3--------4--------5		
BIRTHS/PREGNANCY	Yes	No			
28. An unmarried family member became pregnant	Yes	No	1--------2--------3--------4--------5		
29. A family member terminated a pregnancy	Yes	No	1--------2--------3--------4--------5		

	Has this event happened in the PAST 12 months?		IF YES, how much impact/effect has this event had on YOU.		
			No effect at all	Some effect	Very big effect
30. A family member had a miscarriage	Yes	No	1--------2--------3--------4--------5		
31. A family member had an unwanted or difficult pregnancy	Yes	No	1--------2--------3--------4--------5		
32. A family member gave birth to or adopted a child	Yes	No	1--------2--------3--------4--------5		
33. A family member is experiencing menopause	Yes	No	1--------2--------3--------4--------5		
MONEY					
34. Took out a loan or refinanced a loan to cover increased expenses	Yes	No	1--------2--------3--------4--------5		
35. The family went on welfare or food stamps	Yes	No	1--------2--------3--------4--------5		
36. Change in conditions (economic, political, weather) that hurt family investments and/or income	Yes	No	1--------2--------3--------4--------5		
37. Change in agriculture market, stock market, or land values that hurt family investments and/or income	Yes	No	1--------2--------3--------4--------5		
38. A family member started a new business	Yes	No	1--------2--------3--------4--------5		
39. Purchased or built a home	Yes	No	1--------2--------3--------4--------5		
40. A family member purchased a car or other major item	Yes	No	1--------2--------3--------4--------5		
41. Increasing financial debts due to over-use of credit cards	Yes	No	1--------2--------3--------4--------5		
42. Increase strain on family "money" for medical/dental expenses	Yes	No	1--------2--------3--------4--------5		
43. Increase strain on family "money" for food, clothing, energy, home care	Yes	No	1--------2--------3--------4--------5		
44. Increased strain on family "money" for child(ren)'s education	Yes	No	1--------2--------3--------4--------5		
45. The family had possessions repossessed or declared bankruptcy	Yes	No	1--------2--------3--------4--------5		
46. Delay in receiving child support or alimony payments	Yes	No	1--------2--------3--------4--------5		
JOBS					
47. A family member retired from work	Yes	No	1--------2--------3--------4--------5		

	Has this event happened in the **PAST 12** months?		**IF YES,** how much impact/effect has this event had on **YOU.**
			No effect at all ... Some effect ... Very big effect
48. A family member started or returned to work	Yes	No	1--------2--------3--------4--------5
49. A family member changed jobs/career	Yes	No	1--------2--------3--------4--------5
50. A family member stopped work for extended period (e.g., laid off, leave of absence, strike)	Yes	No	1--------2--------3--------4--------5
51. A family member became less satisfied with job/career	Yes	No	1--------2--------3--------4--------5
52. A family member had difficulty with boss or supervisor at work	Yes	No	1--------2--------3--------4--------5
53. A family member had increased difficulty with other people at work	Yes	No	1--------2--------3--------4--------5
54. A family member was fired from a job	Yes	No	1--------2--------3--------4--------5
55. A family member quit a job	Yes	No	1--------2--------3--------4--------5
56. A family member was promoted at work or given more responsibilities	Yes	No	1--------2--------3--------4--------5
57. Experienced difficulty in arranging for satisfactory child care	Yes	No	1--------2--------3--------4--------5
58. You or your spouse/significant other started school (or training program) after being away from school for a long time	Yes	No	1--------2--------3--------4--------5
MOVES			
59. Family moved to a different home or apartment	Yes	No	1--------2--------3--------4--------5
60. A child or adolescent member changed to a new school or started a new school in the fall	Yes	No	1--------2--------3--------4--------5
61. You or your spouse/significant other became seriously ill or injured	Yes	No	1--------2--------3--------4--------5
62. A child became seriously ill or injured	Yes	No	1--------2--------3--------4--------5
63. An ongoing illness in a family member got worse	Yes	No	1--------2--------3--------4--------5
64. Close relative or friend of the family became seriously ill	Yes	No	1--------2--------3--------4--------5
65. A family friend became physically disabled or chronically ill	Yes	No	1--------2--------3--------4--------5

	Has this event happened in the **PAST 12** months?		**IF YES,** how much impact/effect has this event had on **YOU.**		
			No effect at all	Some effect	Very big effect
66. Increased difficulty in managing a chronically ill or disabled family member	Yes	No	1--------2--------3--------4--------5		
67. A family member or close relative was committed to an institution or nursing home	Yes	No	1--------2--------3--------4--------5		
68. A family member appears to have emotional problems	Yes	No	1--------2--------3--------4--------5		
69. A family member appears to depend on alcohol or drugs	Yes	No	1--------2--------3--------4--------5		
70. A family member saw a professional for emotional problems	Yes	No	1--------2--------3--------4--------5		
71. A family member was brought to the emergency room	Yes	No	1--------2--------3--------4--------5		
72. Increased responsibility to provide direct care or financial help to your parents or spouse/significant other's parents	Yes	No	1--------2--------3--------4--------5		
DEATHS					
73. Your child's father/mother died (or your spouse significant/other died)	Yes	No	1--------2--------3--------4--------5		
74. A child family member died	Yes	No	1--------2--------3--------4--------5		
75. Death of a close relative	Yes	No	1--------2--------3--------4--------5		
76. Close friend of the family died	Yes	No	1--------2--------3--------4--------5		
77. A family pet died	Yes	No	1--------2--------3--------4--------5		
OTHER					
78. A family member started college (or post high school training)	Yes	No	1--------2--------3--------4--------5		
79. Young adult family member left home (other than for school)	Yes	No	1--------2--------3--------4--------5		
80. A family member ran away from home	Yes	No	1--------2--------3--------4--------5		
81. A family member moved back home or a new person moved into the home	Yes	No	1--------2--------3--------4--------5		
82. A family member dropped out of school or was suspended from school	Yes	No	1--------2--------3--------4--------5		

	Has this event happened in the **PAST 12** months?		**IF YES,** how much impact/effect has this event had on **YOU.**		
			No effect at all	Some effect	Very big effect
83. A family member was picked up by police or arrested	Yes	No	1--------2--------3--------4--------5		
84. A family member went to jail, prison, or juvenile detention	Yes	No	1--------2--------3--------4--------5		
85. A family member was attacked or robbed	Yes	No	1--------2--------3--------4--------5		
86. Physical or sexual abuse or violence in the home	Yes	No	1--------2--------3--------4--------5		
87. Your home was damaged or destroyed (fire, flood, tornado, etc.)	Yes	No	1--------2--------3--------4--------5		
88. Your home was robbed	Yes	No	1--------2--------3--------4--------5		
89. The family received bad news	Yes	No	1--------2--------3--------4--------5		
90. The family went on vacation	Yes	No	1--------2--------3--------4--------5		

Please list any additional events or changes that have happened to you or your family during the last 12 months:

1. _____
2. _____
3. _____
4. _____
5. _____

Please describe any positive events or changes that happened to your family, yourself, or your child(ren):

1. _____
2. _____
3. _____
4. _____
5. _____

FSS-MM

The following is a list of things that may be stressful when raising a child with spina bifida. We would like you to think of stress as meaning something that taxes your resources, or as something that is more than you can handle comfortably. Please rate the stressfulness of each item on the scale below:

1 = not at all stressful
2 = a bit stressful
3 = fairly stressful
4 = quite stressful
5 = extremely stressful

	Not at all stressful	A bit stressful	Fairly stressful	Quite stressful	Extremely stressful
1. Outings in the community	1	2	3	4	5
2. Relationships with our friends or extended family.	1	2	3	4	5
3. Discipline.	1	2	3	4	5
4. My marital/intimate relationship.	1	2	3	4	5
5. Mealtimes and bedtimes.	1	2	3	4	5
6. Educational concerns.	1	2	3	4	5
7. Safety.	1	2	3	4	5
8. Communication with my child.	1	2	3	4	5
9. My child's relations with other children.	1	2	3	4	5

	Not at all stressful	A bit stressful	Fairly stressful	Quite stressful	Extremely stressful
10. My child's behavior problems.	1	2	3	4	5
11. My child's emotional problems.	1	2	3	4	5
12. My child's relationships with his/her brother(s) and sister(s).	1	2	3	4	5
13. Financial responsibilities.	1	2	3	4	5
14. Medical care/appointments.	1	2	3	4	5
15. Catheterization.	1	2	3	4	5
16. Medications.	1	2	3	4	5
17. Bowel program.	1	2	3	4	5
18. Food/diet.	1	2	3	4	5
19. Braces/wheelchair/ambulation.	1	2	3	4	5

Medical History and Adherence Questionnaire

1. What type of spina bifida does your child have?

   _____ lipomeningocele (lipo)
   _____ myelomeningocele (MM)
   _____ not sure

2. What is the level of your child's lesion?

   _____ sacral
   _____ lumbar
   _____ thoracic
   _____ not sure

3. Does your child have a shunt? yes _____ no _____

   a. IF YES, has your child's shunt been infected? yes _____ no _____
   b. IF YES, has your child had a shunt revision? yes _____ no _____
   c. IF your child's SHUNT HAS BEEN INFECTED, how many times? _____
   d. IF your child has had a SHUNT REVISION, how many times? _____

4. Does your child have seizures or take medication to prevent seizures?
   yes _____ no _____

5. Is your child able to do independent toileting?
   yes _____ no _____

6. Is your child on a catheterization schedule? yes _____ no _____

   a. If YES, does your child do the catheterization (check one)?

      _____ independently without reminding
      _____ independently with reminding
      _____ with partial assistance
      _____ with complete assistance

   b. Has your child ever had a bladder or urinary tract infection? yes _____ no _____

   c. How many times has your child had a bladder or urinary tract infection? _____

   d. Has your child had bladder stimulation? yes _____ no_____

7. Is your child on a bowel program?
yes _____ no _____

a. If YES, what type of bowel program (suppositories, diet, enemas, digital manipulation, etc.)?
_____
_____
_____

b. If YOUR CHILD IS ON A BOWEL PROGRAM, does your child do this program (check one)?
_____ independently without reminding
_____ independently with reminding
_____ with partial assistance
_____ with complete assistance

c. Has your child had bowel stimulation? yes ____ no ____

8. Does your child use diapers? yes _____ no _____

a. If YES, where does your child use diapers (please check all that apply)?
_____ school
_____ home
_____ on outings
_____ all the time
_____ other? _____

9. Does your child use braces? yes _____ no _____

a. If YES, what type (please check all that apply)?
_____ ankle-foot
_____ knee-ankle-foot
_____ hip-knee-ankle-foot
_____ reciprocating brace
_____ full control brace
_____ swivel walker
_____ parapodium
_____ twister cables
_____ night splint
_____ back brace

10. Does your child use crutches? yes _____ no _____

11. Does your child use a walker? yes _____ no _____

    a. If YES, where does your child use a walker (please check all that apply)?
    _____ school
    _____ home
    _____ for long distance walking
    _____ on outings
    _____ all the time
    _____ other? _____

12. Does your child use a wheelchair? yes _____ no _____

    a. If YES, where does your child use a wheelchair (please check all that apply)?
    _____ school
    _____ home
    _____ for long distance travel
    _____ on outings
    _____ all the time
    _____ other? _____

13. If your child uses more than one mobility device, please write down the percentage of time that your child uses each device (please make sure that the percentages add up to 100%):

    _____ % unassisted walking (no braces)
    _____ % braces alone (no crutches or walker)
    _____ % braces with crutches or walker
    _____ % wheelchair
    = 100 %

14. Please list your child's medications (include NAME OF MEDICATION, AMOUNT, HOW OFTEN TAKEN):

	Name of Medication	Amount	How Often Taken?
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			

15. Please list your child's surgeries, since birth (include year of surgery, reason for surgery; examples include: shunt revision, shunt replacement, leg surgery, back surgery, tethered cord, etc.):

	Year of Surgery	Reason for Surgery
1.	_____	_____
2.	_____	_____
3.	_____	_____
4.	_____	_____
5.	_____	_____
6.	_____	_____
7.	_____	_____
8.	_____	_____
9.	_____	_____
10.	_____	_____
11.	_____	_____
12.	_____	_____
13.	_____	_____
14.	_____	_____
15.	_____	_____

16. What changes have occurred in your child's health OVER THE PAST YEAR?

17. What type of health insurance does your child have?

_____

18. In the past year, how many visits has your child had with a primary care physician (regular family doctor)? _____

Please describe the reason for these visits: _____

_____

_____

19. In the past year, how many visits has your child had with a urologist? _____

Please describe the reason for these visits: _____

_____

_____

20. In the past year, how many visits has your child had with a orthopedist? _____

Please describe the reason for these visits: _____

_____

_____

21. In the past year, how many visits has your child had with a neurologist? _____

Please describe the reason for these visits: _____

_____

_____

22. In the past year, how many visits has your child had with a physical or occupational therapist? (please specify which one)

_____

Please describe the reason for these visits: _____

_____

_____

23. In the past year, on how many occasions has your child visited the emergency room? _____

Please describe the reason for these visits: _____

_____

_____

24. In the past year, how many visits has your child had with any other type of health care professional? _____

Type of health professional seen: _____

_____

Please describe the reason for these visits: _____

_____

_____

25. In the past year, how many times has your child been hospitalized? _____

Length of stay _____

Please describe the reason for these hospitalizations: _____

_____

_____

PSI

These questions ask you to record an answer which best describes your feelings about being a parent to the child discussed in this questionnaire. While you may not find an answer which exactly states your feelings, please record the answer which comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Please record the degree to which you agree or disagree with the following statements by filling in the number which best describes how you feel.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

_____ 1. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.

_____ 2. Being a parent is harder than I thought it would be.

_____ 3. I feel capable and on top of things when I am caring for my child.

_____ 4. I can't make decisions without help.

_____ 5. I have had many more problems raising children than I expected.

_____ 6. I enjoy being a parent.

_____ 7. I feel that I am successful most of the time when I try to get my child to do or not do something.

_____ 8. Since I brought my child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help.

_____ 9. I often have the feeling that I cannot handle things very well.

_____ 10. Most of my life is spent doing things for my child.

_____ 11. I find myself giving up more of my life to meet my children's needs than I ever expected.

_____ 12. I feel trapped by my responsibilities as a parent.

_____ 13. I often feel that my child's needs control my life.

_____ 14. Since having this child, I have been unable to do new and different things.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

_____ 15. Since having this child, I feel that I am almost never able to do things that I like to do.

_____ 16. It is hard to find a place in our home where I can go to be by myself.

_____ 17. I feel alone and without friends.

_____ 18. When I go to a party, I usually expect not to enjoy myself.

_____ 19. I am not as interested in people as I used to be.

_____ 20. I often have the feeling that other people my own age don't particularly like my company.

_____ 21. When I run into a problem taking care of my children, I have a lot of people I can talk to for help or advice.

_____ 22. Since having children, I have a lot fewer chances to see my friends and to make new friends.

23. When I think about myself as a parent, I believe (please circle one):

A) I can handle anything that happens.
B) I can handle most things pretty well.
C) sometimes I have doubts, but I find that I handle most things without any problems.
D) I have some doubts about being able to handle things.
E) I don't think I handle things very well at all.

24. I feel that I am (please circle one):

A) a very good parent.
B) a better than average parent.
C) an average parent.
D) a person who has some trouble being a parent.
E) not very good at being a parent.

SUBJECT ID #: _____

SPINA BIFIDA SELF-MANAGEMENT PROFILE

Taking care of spina bifida means doing a lot of different things like doing clean intermittent catheterization, taking medications, handling infections, being on a bowel control program and cooperating with tests like x-rays and urologic (bladder) studies. It's not easy doing all of these things exactly the way doctors and nurses might want. Very few individuals with spina bifida do everything exactly according to plan. Sometimes there are other things that grab your attention or you might just forget to take care of these things, even though you may have wanted to.

Most individuals with spina bifida develop their own habits for taking care of it that are comfortable for them. What we're trying to learn in this questionnaire is what you usually do to take care of your spina bifida. Your answers won't be shared with anyone else, so you can feel comfortable writing exactly what you do not just what you think you're supposed to do or what you think you should say. So, try to be completely honest about what you have usually done in taking care of your spina bifida in the past 6 months.

APPOINTMENT KEEPING

Taking care of spina bifida requires lots of clinic visits. Sometimes it's hard to keep all of those appointments because you may be busy with lots of other important things. This part of the questionnaire is about what you usually do about keeping medical appointments.

1. When you have had medical appointments within the past 6 months, how often have you gone to that appointment? (please check one)

___ Arrived on time for every scheduled appointment
___ Came to every appointment but was a little late sometimes
___ Cancelled appointment more than 24 hours before the appointment and rescheduled another appointment
___ Arrived so late for an appointment that it had to be rescheduled
___ Forgot or otherwise did not come to an appointment

BOWEL CONTROL PROGRAM

Spina bifida makes it harder to have regular bowel movements and so your doctor may have given you a program to help you to develop consistent habits. This may include eating foods that contain plenty of fiber, staying away from some other foods, recording your bowel movements, and taking an enema or suppository if your bowel movements aren't frequent enough. This part of the questionnaire is about how carefully you have done these things in the past 6 months.

2. In the past 6 months, how often have you stayed within the diet recommendations that the doctor has given you? (please check one)

___ Always eat according to the recommendations (100%)
___ Usually eat according to the recommendations (80-100%)
___ Often eat according to the recommendations (50-80%)
___ Sometimes eat according to the recommendations (10-50%)
___ Rarely or never eat according to the recommendations (0-10%)

3. When you have gotten constipated in the last 6 months, how often have you taken a suppository, enema or stool-softening medication as prescribed by the doctor? (please check one)

___ No constipation in past 6 months
___ Always take the prescribed enema, suppository or stool-softening medication as instructed (100% of the time)
___ Usually take the prescribed enema, suppository or stool-softening medication as instructed (80-99% of the time)
___ Often take the prescribed enema, suppository or stool softening medication as instructed (50-79% of the time)
___ Sometimes take the prescribed enema, suppository or stool-softening medication as instructed (10-49% of the time)
___ Rarely or never take the prescribed enema or suppository as instructed (Less than 10% of the time)

SKIN AND WOUND CARE

Most individuals with spina bifida need to be careful about skin and wound care. Your care team may ask you to check the skin on a daily basis for any sores or places where the skin is breaking down. It is important to recognize the signs of these kinds of wounds quickly, as they might develop into pressure sores that are difficult to heal. This question is about your usual habits in checking skin.

4. In the past 6 months, how often did you check your skin? (please check one)

___ Check all over the body every day
___ Check certain parts of body every day
___ Check all over the body 2-3 times per week
___ Check body once in a while
___ Rarely check skin

EXERCISE

Your care team has probably explained the importance of getting some kind of exercise every day. Depending on how mobile you are, this might include anything from walking, to moving around in a wheelchair, to doing arm pushups in a chair. Sometimes individuals don't like to do this, or are busy with other things and would rather do other stuff. This question is about exercise.

5. In the past 6 months, how often do you do the exercise that is asked of you? (please check one)

___ Do exercise every day on average
___ Do exercise every other day, on average
___ Do exercise one time, per week
___ Rarely exercise

MEDICATIONS

Treatment of spina bifida also often includes taking medicines for several different purposes. Most individuals have at least some trouble taking all of these medicines in exactly the right amounts and at the scheduled times. This part of the questionnaire is about how regular you are about giving medicines as the doctor has asked you to do.

6. Many individuals with spina bifida are expected to take antibiotics every day to prevent urinary tract infections, whether they are sick or not. How regular have you been in taking this antibiotic in the past 6 months? (please check one)

___ Almost always take the prescribed amount of antibiotic on time (Miss no more than two doses per month)
___ Usually take the prescribed amount of antibiotic on time (Miss no more than 5 doses per month)
___ Often take the prescribed amount of antibiotic on time (Miss no more than 10 doses per month)
___ Sometimes take the prescribed amount of antibiotic on time (Miss no more than 20 doses per month)
___ Rarely or never take the prescribed amount of antibiotic on time (Miss at least 20 doses per month)
___ Not prescribed antibiotics

7. You may also be asked to take Ditropan or a similar medicine to keep your bladder functioning well. In the past 6 months, how often have you taken the correct dose of this medicine at the right time? (please check one)

___ Always take the prescribed amount on time.
___ Usually (Over 80%) take the prescribed amount on time
___ Often (50-80%) take the prescribed amount on time
___ Sometimes (10-50%) take the prescribed amount on time
___ Rarely or never (0-10%) take the prescribed amount on time
___ Not prescribed this type of medicine

CLEAN INTERMITTENT CATHETERIZATION

Many individuals with spina bifida must catheterize several times daily, and these procedures must be followed very carefully. Lots of things can get in the way of doing this and, even when they try their best, many individuals still struggle with doing this exactly according to the plan. For example, it might be hard to follow every step of the procedure exactly as you were taught or to do it exactly on time.

This part of the questionnaire will be asking about your habits about clean intermittent catheterization at home and away from home. Try to be as honest and accurate as you can about your catheterization habits in the past 6 months.

8. Many individuals with spina bifida need to catheterize several times daily. In the past 6 months, how often has this been done exactly according to schedule? (please check one)

___ Never or rarely miss doing catheterization as often as prescribed (Once a week or less)
___ Occasionally miss doing catheterization as often as prescribed (2-3 times a week)
___ Sometimes miss doing catheterization as often as prescribed (4-5 times a week)
___ Frequently miss doing catheterization as often as prescribed (Once a day)
___ Usually miss doing catheterization as often as prescribed (More than once a day)
___ Not asked to do clean intermittent catheterization

9. You are asked to follow some careful steps whenever you complete catheterization. This includes five steps: 1.) Having all the supplies together, 2.) Washing your hands first, 3.) Correct positioning, 4.) Inserting the catheter with slow steady pressure until urine begins to flow, and 5.) Washing the catheter in warm soapy water. In the past 6 months during catheterization, how many of these five steps do you always do? (please check one)

___ Complete all five steps.
___ Complete four steps.
___ Complete three steps.
___ Complete two steps.
___ Complete 0-1 steps.

10. If you re-use catheters, how often do sterilize the catheter by either washing it in antibacterial soap or boiling it in clean water for 10 minutes or more before you use it again? (please check one)

___ Do not re-use catheters.
___ Almost always sterilize catheter between uses. (Miss no more than once per month)
___ Usually sterilize catheter between uses. (Miss 2-5 times per month)
___ Often sterilize catheter between uses. (Miss 6-10 times per month)
___ Sometimes sterilize catheter between uses. (Miss 10-20 times per month)
___Infrequently or never sterilize catheter between uses. (Miss more than 20 times per month)

DEALING WITH URINARY TRACT INFECTIONS

Most individuals with spina bifida get urinary tract infections now and then. It is important to recognize the signs of these infections quickly, call in for treatment and take any medicines that are prescribed for this, but it isn't always easy to do these things. This part of the questionnaire is about your usual habits in recognizing urinary tract infections and the actions you take once you discover an infection.

11. In the past 6 months, what did you usually do when you first thought that you might have a urinary tract infection? (please check one)

___ No symptoms of urinary tract infection in the past 3 months
___ Call the clinic immediately to report the symptoms and get advice
___ Wait a few hours before calling to see if the symptoms went away
___ Wait until the next day before calling to see if the symptoms went away
___ Wait a few days before calling to see if the symptoms went away
___ Don't call at all

12.The last time you had a urinary tract infection, how did you do with taking the prescribed antibiotic medication <u>on time</u>? (please check one)

___ Always take the prescribed amount of antibiotic on time (100%)
___ Usually take the prescribed amount of antibiotic on time (80-100%)
___ Often take the prescribed amount of antibiotic on time (50-80%)
___ Sometimes take the prescribed amount of antibiotic on time (10-50%)
___ Rarely or never take the prescribed amount of antibiotic on time (0-10%)

13. The last time you had a urinary tract infection, how quickly did you fill the prescription for the antibiotic medication that the doctor prescribed for treating it? (please check one)

___ Within 6 hours after receiving the prescription
___ Between 6 and 12 hours after receiving the prescription
___ Between 12 and 24 hours after receiving the prescription
___ More than 24 hours after receiving the prescription
___ Did not fill the prescription

14.The last time you had a urinary tract infection, <u>how much</u> of the prescribed antibiotic medication did you actually take? (please check one)

___ Took every scheduled dose until the medicine was gone
___ Took at least 80% of scheduled doses of the medicine
___ Took 50-80% of the scheduled doses of the medicine
___ Took 10-5% of the scheduled doses of the medicine
___ Took less than 10% of the scheduled doses of the medicine
___ Did not fill the prescription

DEALING WITH SPINA BIFIDA COMPLICATIONS

Unfortunately, sometimes complications of spina bifida occur even when young adults take appropriate steps to take care of themselves. Other times, adults find that complications result from difficulties they have been having with completing certain medical tasks. The following questions ask if you have had any spina bifida-related complications in the past 6 months and if yes, how many times you have had the complication.

In the past 6 months, please circle the following if you have had…

Urinary Tract Infections (UTIs) **YES** **NO**

IF YES, how many have you had in the past 6 months? _____

Constipation **YES** **NO**

IF YES, how many times in the past 6 months? _____

Pressure sores/wounds on skin **YES** **NO**

IF YES, how many in the past 6 months? _____

Urinary accidents **YES** **NO**

IF YES, how many in the past 6 months? _____

Bowel accidents **YES** **NO**

IF YES, how many in the past 6 months? _____

Experienced kidney or bladder stones **YES** **NO**

IF YES, how many times in the past 6 months? _____

CO-OCCURING MEDICAL DISORDERS

Some young adults develop other medical conditions that may or may not be related to spina bifida. We are interested in any other medical condition that your doctors have diagnosed. Please indicate whether or not you have been diagnosed with the following conditions:

Please check the following conditions you have in addition to spina bifida…

_____ Type II Diabetes

_____ Obesity

_____ Sleep apnea

_____ Latex allergy

_____ Cardiovascular disease (i.e., heart disease)

_____ Metabolic dysfunction

_____ Osteoporosis

_____ Chronic pain

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VITA

Breana L. Bryant is a doctoral student at Loyola University Chicago studying Clinical Psychology, on the child and family track, and pursuing a Public Health certificate. She earned her B.S. in Psychology with a minor in Public Health from University of North Florida in 2020. During her time as an undergraduate, Bryant completed an honors thesis, examining the effects of imagined social support on subjective and physiological indicators of stress under the supervision of Dr. Paul Fuglestad. After graduation, Bryant worked under the mentorship of Drs. Randi Streisand and Maureen Monaghan at Children's National Hospital as a full-time research coordinator on the Behavioral Diabetes Research Team. It was during this time she developed interests in the impact of healthcare access and health communication on psychosocial functioning in pediatric populations. As a graduate student at Loyola, Bryant is a member of Dr. Grayson Holmbeck's CHATS Lab. In this position, Bryant has worked on several projects examining the impact of social determinants of health on the psychosocial functioning of youth with spina bifida and their families. Bryant's master's thesis examined associations between neighborhood factors and medical adherence in youth with spina bifida as well as the mediating role of parental stress and youth internalizing symptoms. Bryant has had the opportunity to present multiple posters at annual conferences and contribute to peer-reviewed articles through these experiences.