Psychological Functioning in Children and Adolescents living with Spinal Cord Lesions and their Caregivers in Colombia, South America

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Abstract

Psychological Functioning in Children and Adolescents living with Spinal Cord Lesions and their Caregivers in Colombia, South America

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Objective: Spinal cord lesions resulting from spinal cord injury (SCI) and spina bifida (SB) are permanent and cause significant functional impairment. High rates of impaired psychological function and lower health-related quality of life (HRQOL) have been documented in children with SB and their caregivers, but few studies have examined these issues in the pediatric SCI population. Moreover, no research has investigated mental health or HRQOL among children living with spinal cord lesions, or their caregivers, in the developing world. There is reason to suspect that lack of access to medical, rehabilitative, and psychological resources places these individuals at particular risk for compromised psychological functioning. Therefore, the goals of the present study are: 1) to compare psychological functioning and HRQOL of children with SCI or SB to an age-matched comparison group; 2) to compare the psychological functioning, HRQOL, and level of burden in caregivers of children with SCI /SB to that of caregivers of healthy age-matched children; and, 3) to determine the influence of hopefulness on anxious and depressive symptomatology and HRQOL in children with SCI or SB.

Participants: Thirty children with spinal cord lesions; 30 age-matched comparison group children; 30 caregivers of children with spinal cord lesions, and 30 caregivers of comparison group children.

Methods: Children and caregivers completed a series of questionnaires assessing depressive and anxious symptomatology and HRQOL. Children also completed a questionnaire assessing hopefulness, and caregivers completed a questionnaire assessing levels of burden.

Results: Contrary to hypotheses, significant between-group differences were not observed in terms of depressive and anxious symptoms in either children or their caregivers. However, significant differences in HRQOL were observed between children with spinal cord lesions and the comparison group. Finally, results revealed significant differences between caregiver groups on measures of HRQOL and burden.

Conclusions: Results therefore highlight the need service delivery in Colombia to children with spinal cord lesions and their caregivers. Access to improved medical, rehabilitative, and psychological care could profoundly impact quality of life in the spinal cord lesion child and caregiver population, particularly with regard to respite services and resources to improve children's ability to attend school and participate in the community. In addition, parents of Colombian children with permanent physical disabilities may not expect their children to achieve normative levels of participation as compared to their healthy peers; psychoeducation would likely assist parents to understand that their children can live full lives despite their different abilities.

CHAPTER 1: INTRODUCTION

The current introduction will be organized as follows. First, the literature will be reviewed related to pediatric spinal cord injury (SCI) and spina bifida (SB) epidemiology, physiology, mental health outcomes, and caregiver psychological functioning. It is important to note that the overwhelming majority of research pertaining to children with SCI or SB and their caregivers has been performed in the United States and Western Europe, such that little is known about these issues in developing countries. The literature review will thus consolidate data from diverse sources in an effort to present challenges to psychological and psychosocial well-being, physical recovery, and caregiver functioning among children with spinal cord dysfunction and their caregivers in low-income areas. Finally, methodology and results will be presented for the current study.

1.1 Pediatric SCI

Spinal cord injury (SCI) is diagnosed when a traumatic insult causes tearing, bruising, or crushing of the delicate nerves of the spinal cord (National Institute of Neurological Disorders and Stroke [NINDS], 2012). Because these nerves are responsible for conveying motor messages to and from the brain, SCI often results in loss of control for both voluntary and involuntary motor functions below the site of injury (NINDS, 2012). Although the degree of disability resulting from SCI can vary greatly according to the severity and level of lesion, most survivors will experience permanent impairment that can profoundly impact both physical and psychological functioning (McDonald & Sadowsky, 2002).

1.1.1 Epidemiology in the First World

Children account for as many as 11% of new SCI cases each year in the United States, while European incidence estimates range between 0.9 and 27 cases per million children (Augutis, Abel, & Levi, 2006; Proctor, 2002). The extant literature indicates children are most likely to sustain SCI by way of traffic accidents, sports injuries, falls, and firearm injuries (Agutis & Levi, 2003; Vitale, Goss, Matsumoto, & Roye, 2006). Boys and African American children are at heightened risk of sustaining an SCI in the United States, with peaks in incidence observed in very young children and again during adolescence (Parent, Dimar, Dekutoski, & Roy-Beaudry, 2010; Wade, Walz, & Bosques, 2009; Vitale et al., 2006). The epidemiology of pediatric SCI in developing countries has not been reported.

1.1.2 Physical Challenges

Although the spine of a child is more flexible and therefore more resistant to injury than the adult spine, pediatric SCI is often severe and results in particularly high rates of morbidity and mortality (Cirak et al., 2004; Proctor, 2002). For example, young children’s large head-to-body ratio creates elevated risk for more functionally devastating and life-threatening high-level, upper cervical spine injuries (DiMartino, Madigan, Silber, & Vaccaro, 2004). Moreover, the impact of such a severe injury on the growing spine means that children with SCI often experience secondary physical issues and complications requiring extensive medical care, including serious growth abnormalities (e.g., scoliosis, hip displacement) that are both painful and functionally limiting (Dearolf et al., 1990; Vogel, Hickey, Klaas, & Anderson, 2004). In addition, childhood developmental and physical limitations mean that the rigors of self-care can be difficult for youth to maintain, which is especially problematic given that failure to adhere to a strict regimen can have a major negative impact on short- and long-term health, independence, and well-being (DeVivo, Krause, & Lammertse, 1999). As a result of these factors, pediatric SCI patients often make poor recoveries and require a considerable amount of ongoing care (Proctor, 2002).

1.1.3 Psychological and Psychosocial Challenges

Numerous investigations of psychological functioning in adult SCI patients have revealed high rates of psychological morbidity, including mood and anxiety disorders, low self-esteem, hopelessness, and substance abuse problems in this population (for a systematic review, see Craig, Tran, & Middleton, 2009). Others have reported that adults who sustained SCIs as children have high rates of posttraumatic stress, as well as diminished quality of life and difficulties with social functioning (North, 1999). However, the scope of these issues in the pediatric SCI population has largely been neglected.

The lack of investigation into psychological outcomes among children with SCI is especially surprising given that pediatric SCI is a sudden injury that can cause significant adjustment problems and create a challenging psychosocial environment for young people (Augutis, Levi, Asplund, & Berg-Kelly, 2007; Wade et al., 2009). Children with SCI may have few opportunities for normative peer interaction at school, and other opportunities for socialization may be limited as well given that pediatric SCI patients may require intermittent hospitalization for their injuries and secondary complications (Anderson, 2003; Carney & Porter, 2009; Vitale et al., 2006). As children with SCI grow older, physical limitations (e.g., loss of control of bodily functions) may make it difficult to engage in typical adolescent activities, creating additional barriers to integrating with peers and the community, feelings of unattractiveness, poor body image, and embarrassment (Anderson, 1997; 2003; Potgeiter & Khan, 2005). However, few investigations have sought to examine the impact of these factors on the mental health of the child with a SCI.

In terms of findings specific to psychological functioning in children with current SCI, few studies have reported rates of depression and anxiety in children with SCI, and all have been conducted in the United States. Findings indicated that adolescents with a shorter duration of injury were more likely to experience anxiety, while those who were less functionally independent were more likely to be depressed; however, overall rates of clinically significant depression and anxiety (6% and 13%, respectively) were comparable to normative data for American youth (Anderson et al., 2009). Similarly, Kelly et al. (2012) reported that 5% of children with SCI experience clinically significant depressive symptoms and 9% experience clinically significant anxious symptomatology. However, when Kelly and Vogel (2013) investigated rates of depression and anxiety by age group, results indicated that 17.2% of adolescents (ages 16-18) report clinically significant anxiety and 9% report clinically significant depression.

1.1.4 Health-Related Quality of Life

Broadly speaking, the concept of QOL is used clinically to refer to an individual’s global evaluation of the meaning and value of his or her life, in conjunction with that individual’s personal values. In contrast, HRQOL refers to this evaluation with specific reference to the impact of health-related factors (Hammell, 2004). Quality of life and (QOL) and health-related quality of life (HRQOL) are generally considered to fall within the psychological domain secondary to their subjective, perceptual quality. Although several investigations have identified reduced HRQOL in adults with SCI (for a review, see Tate, Kalpakjian, & Forchheimer, 2004), applications of these concepts to the pediatric SCI population have generally resulted in limited interpretability.

One recent study comparing HRQOL between pediatric SCI patients and a normative sample reported that children with SCI noted significantly lower HRQOL than healthy children (Garma, Kelly, Daharsh, & Vogel, 2011). Similarly, and Kelly et al. (2013) identified poorer HRQOL compared to normative data in areas of emotional, social, and school functioning as compared to normative data. Oladeji et al. (2007) identified physical, but not emotional, social, or school functioning among children with SCI. Another investigation of HRQOL in children with SCI or SB demonstrated significant differences between children with disabilities as compared to healthy controls in the areas of school, social, and emotional functioning, although findings specific to the either sample were not reported (Abresch, McDonald, Widman, McGinnis, & Hickey, 2007). Furthermore, although greater injury severity has been associated with decrements in HRQOL and other aspects of psychological functioning in the adult SCI population (e.g., Hughes, Swedlund, Petersen, & Nosek, 2001; Tate et al., 2002), the relationship between HRQOL and injury severity is unclear among children with SCI.

1.1.5 Caregiver Psychological Functioning

All children require support from caregivers, but children with serious physical disabilities represent a particularly dependent population due to their significant healthcare needs. The demands of caring for a child with a chronic physical disability may adversely impact caregivers’ mental health, with greater caregiving needs associated with poorer psychological functioning (Raina et al., 2005). In addition , high rates of anxiety, depression, and stress are well-documented in caregivers of adults with SCI and other spinal cord dysfunction (e.g., Blanes, Carmagnani, & Ferreira, 2007; Dreer, Elliot, Shewchuk, Berry, & Rivara, 2007; Post, Bloemen, & DeWitte, 2005). Moreover, pediatric SCI caregivers may be at particular risk for psychological morbidity secondary to trauma, feelings of guilt about their child’s SCI, and anxiety about how to best care for a child with such a severe and traumatic injury (Anderson, 2003). Unfortunately, the mental health of pediatric SCI caregivers has been only minimally explored in the literature. Results of the single extant study revealed substantial levels of anxiety and depression in parents of children with SCI (16% and 21%, respectively; Kelly et al., 2011; 20% and 22%, respectively, Kelly et al., 2012). The lack of research in this area is particularly marked given that recent caregiving literature demonstrates a link between child and caregiver psychological problems among children with SCI and other disabilities (e.g., Dasch et al., 2011; Kelly et al., 2011). More specifically, adolescents with SCI report that their caregivers function as crucial resources in terms of advocacy, support, and help in dealing with negative feelings such that caregiver dysfunction could potentially adversely impact a child’s ability to effectively cope with injury (Augutis et al., 2007).

1.1.6 Caregiver Health-Related Quality of Life

Although no previous studies have investigated HRQOL among caregivers of children with SCI, there is the potential for the pediatric SCI caregiver community to experience adverse outcomes in this domain. For example, caregivers of children with chronic health conditions such as cerebral palsy have reported poor functioning in both psychological and physical health (Raina et al., 2005). Furthermore, caregivers of adults with SCI have reported poor HRQOL (Blanes et al., 2007) and low satisfaction with life, a construct encompassing health factors (Arango-Lasprilla et al., 2010).

1.1.7 Caregiver Burden

Another important caregiver psychological construct, burden, is also undocumented in the pediatric SCI caregiver population. Burden generally refers to psychological dysfunction combined with impairment in various life domains (e.g., work, relationships, physical health) specifically as a result of caregiving responsibilities (Baronet, 1999). Several studies have described burden in spousal caregivers of adults with SCI (Dreer et al., 2007; Post et al., 2005), but the presence of burden in pediatric SCI caregivers is unreported, despite the fact that caregivers of severely injured children likely represent a particularly burdened population.

1.2 Spina Bifida in the First World

Like SCI, spina bifida (SB) is a pervasive disorder involving spinal cord dysfunction wherein level and severity of lesion are closely tied to degree of disability (Fletcher & Brei, 2010). Spina bifida is the result of a birth defect (Fletcher & Brei, 2010) and is diagnosed when the caudal portion of the neural tube, which encloses the spinal cord, does not fuse successfully in utero, resulting in malformation of the spinal cord and brain (Deidrick, Grisson, & Farmer, 2009; Wallingford, Niswander, Shaw, & Finnell, 2013). The most common and severe form of SB, myelomeningocele, is diagnosed when neither the meninges nor the spinal nerves are enclosed within the spinal cord; instead, the spinal cord and meninges protrude from the child’s back in a cerebrospinal fluid-filled sac of skin and dura mater (CDC, 2013; Fletcher & Brei, 2010).

Like SCI, SB is a heterogenous disorder which, depending on the level of lesion to the spinal cord, can leave children with a range of physical and psychological challenges (Deidrick et al., 2009; Fletcher et al., 2005; Fletcher & Brei, 2010).

1.2.1 Epidemiology

SB is the most prevalent birth defect affecting the central nervous system (Fletcher & Brei, 2010). In the United States, approximately 3 per 10,000 children born each year (or 1,500 total) are diagnosed with SB (CDC, 2013; Wallingford et al., 2013; WHO, 2003). The vast majority (80-90%) are diagnosed with myelomeningocele (Fletcher & Brei, 2010). Differences in incidence by racial and ethnic group have been observed in the U.S.; the rate of SB in Hispanic American infants is 4.17 per 10,000 live births, compared to 3.22 among non-Hispanic Whites and 2.64 among African Americans (CDC, 2013). In addition, children of Hispanic descent tend to have higher-level lesions as compared to their peers of other races and ethnicities in the US (Fletcher et al., 2005). Unlike SCI, epidemiological data for SB is available in many developing countries, with generally higher incidence reported in these areas (WHO, 2003). Notably, although genetic precursors to SB have been identified (Au et al., 2010), a major risk factor for SB is maternal malnutrition (Fletcher & Brei, 2010). More specifically, inadequate maternal folate intake increases the likelihood of neural tube defects (Wallingford et al., 2013). However, between 30% and 50% of SB diagnoses are not preventable with folate; other risk factors include maternal history of insulin-dependent diabetes, obesity, and/or use of certain anticonvulsant drugs (Wallingford et al., 2013).

1.2.2 Physical Challenges

Children with SB generally require surgical intervention during infancy to repair the neural tube and/or correct protrusion of the spinal cord from the back (Wallingford et al., 2013). As in SCI, children with higher-level SB lesions experience greater degrees of muscle weakness, spasticity, and paralysis than children whose spinal malformations occur lower in the spinal cord (Heffelfinger et al., 2008; Wallingford et al., 2013). Most children with SB require braces or wheelchairs for mobility (Dicianno, Gaines, Collins, & Lee, 2009). Furthermore, SB results in malformation of both the spinal cord and the brain, most typically in the form of Chiari II malformations (Juranek & Salman, 2010), dysgenesis of the corpus callosum (Barkovich, 2005), and hydrocephalus (Wallingford et al., 2013). Children with SB with comorbid hydrocephalus and/or Chiari malformation often require additional surgical intervention to prevent the cortex from being pressed downward into the spinal canal (Fletcher & Brei, 2010; Wallingford et al., 2013). As children with SB age, a host of secondary complications and growth abnormalities may occur. Most commonly these include early puberty, obesity, bladder and bowel difficulties, skin ulcers, hip dislocation, and scioliosis, issues which require ongoing medical attention and/or surgical revision (Dosa et al., 2009; Holmbeck & Devine, 2010; Wallingford et al., 2013). Children with SB also encounter similar struggles related to the necessity for demanding self-care (e.g., bladder and bowel management) as their peers with SCI and require support from caregivers to maintain health (Rofail, Maguire, Kissner, Colligs, & Abetz-Webb, 2013).

1.2.3 Psychological and Psychosocial Challenges

Psychological challenges in SB involve not only disability-related barriers to normative psychosocial development, but also neurocognitive deficits related to malformation of the cortex. Although children diagnosed with SB exhibit generally intact intellectual functioning, those with greater cortical involvement often experience deficits in visual-spatial and visual-motor skills abilities, long-term memory retrieval, higher-order language abilities, and executive functioning (Deidrick et al., 2009; Fletcher & Brei, 2005). Greater severity of brain malformation and adverse neurocognitive outcomes in SB are associated with higher-level lesions, although most children with SB at any level fall at the low end of the average range of overall intelligence (Fletcher et al., 2005; Fletcher & Brei, 2010; Holmbeck et al., 2010). As a result of these issues, children with SB may struggle to progress academically, have problems sustaining attention in school, and earn lower grades than their peers (Deidrick et al., 2009; Holmbeck et al., 2010). Executive dysfunction, in particular, is associated with poor functional outcomes (Heffelfinger et al., 2008).

Regarding social and emotional functioning, children with SB and SCI face similar challenges in terms of negotiating the world with physical disabilities (Holmbeck & Devine, 2010). For example, children with SB report more social isolation, fewer friends, smaller social networks, lower self-esteem, and less social support as compared to their able-bodied peers (Holmbeck & Devine, 2010). In addition, some extant literature suggests youth with SB exhibit greater levels of psychological distress (Ammerman et al., 1998) and/or depressive symptoms as compared to healthy children (Appleton et al., 1997). Other studies have suggested children with SB do not fare worse than their healthy control peers in terms of depressive symptomatology (Holmbeck et al., 2003; Zurmohle et al. 1998). However, risk may increase as children age; among a sample of older adolescents and young adults with SB (ages 18-25), Bellin and colleagues (2010) identified 53% reporting clinically significant symptoms of anxiety and depression, 33.3% reporting clinically significant depression only, and 13.3% reporting anxiety only. In terms of risk factors for psychological morbidity in SB, female gender, low socioeconomic status, greater severity of disability and complexity of medical needs, and perception of inadequate health care are associated with greater levels of psychosocial adjustment difficulties, depression, and anxiety (Bellin et al., 2010; Holmbeck et al., 2003). Although parental acceptance, mental health, and support mediate the relationship between SB and internalizing symptoms in children, impairments in psychological functioning in children with SB tends to be chronic in nature (Holmbeck et al., 2010; Holmbeck & Devine, 2010; Schellinger, Holmbeck, Essner, & Alvarez, 2012).

1.2.4 Health-Related Quality of Life

Studies investigating HRQOL in children with SB generally reveal lower HRQOL as compared to developmentally normative samples (e.g., Danielsson et al., 2008; Muller-Godeffroy et al., 2008). Furthermore, echoing findings from the SCI literature, factors associated with worse HRQOL in children with SB include greater levels of disability, secondary complications, functional limitations, assistance needs, pain, psychological distress, and social isolation (Bier, Prince, Tremont, & Msall, 2005; Danielsson et al., 2008; Muller-Godeffroy et al., 2008; Oddson, Clancy, & McGrath, 2006; Padua et al., 2002). Family resources also predict HRQOL among children with SB (Cate, Kennedy, & Stevenson, 2002).

1.2.5 Caregiver Psychological Functioning

Like pediatric SCI caregivers, parents of children with SB face significant challenges. Caring for a child with SB is a time- and labor-intensive process that can adversely impact mental health and, moreover, parents of youth with SB may experience grief and a sense of loss related to their child's disabilities (Grosse, Flores, Ouyang, Robbins, & Tilford, 2009; Rofail et al., 2013). A recent meta-analysis of studies investigating parental psychological adjustment to having a child with SB suggested that between 19% to 46% of mothers of children with SB, and 25% to 28% of fathers, meet criteria for at least one psychiatric diagnosis (most commonly depression, anxiety, and/or somatic disorders), with an overall effect size of .76 for both parents (Holmbeck & Devine, 2010; Vermaes, Janssens, Bosman, & Gerris, 2005). Caregivers of children with greater levels of disability and fewer financial resources are at increased risk for poor psychological adjustment (Vermaes et al., 2005). Furthermore, connections have been drawn between caregiver and child psychological functioning in SB, in that maternal depression creates increased risk for depression in children (Schellinger, et al., 2012).

1.2.6 Caregiver Health-Related Quality of Life

Relatively little research has specifically investigated HRQOL in parents or caregivers of children with SB. However, the extant literature indicates that parents of children with SB report significantly less sleep, social support, and leisure time as compared to parents of healthy children (Grosse et al., 2009), as well as role limitations in emotional, work, and parenting domains (Rofail et al., 2013).

1.2.7 Caregiver Burden

To my knowledge, no studies have utilized measures expressly designed to assess burden in caregivers of children with SB. However, it is notable that mothers of children with SB report that a substantial proportion of their time is spent on caregiving activities such that they feel required to be always on hand to provide assistance when needed (Loebig, 1990; Havermans & Eiser, 1991). In addition, parental caregivers report significant stress and economic burden related to having a child with SB (Rofail et al., 2013).

1.3 Pediatric SCI and Spina Bifida in the Developing World

The SCI and SB outcome literature suggests that individuals with limited financial resources are vulnerable to compromised physical and behavioral outcomes (Bellin et al., 2010; Holmbeck et al., 2003; Krause, DeVivo, & Jackson, 2004). To date, however, very little is known about the impact of SCI or SB in countries where the majority of citizens are disadvantaged, despite the fact that high rates of serious injury and birth defects are reported in these areas (Nantulya, 2002; WHO, 2003; WHO, 2008).

1.3.1 Epidemiology

No systematic investigation has reported the incidence of SCI among children who live in any developing country. However, there is concern that the burden of SCI may disproportionately fall on children in these areas, in that the conditions of poverty accumulate to create a dangerous environment where youth are vulnerable to injury (Carrillo, 2009; Evans, 2004; WHO, 2008). For example, poverty often means that housing is unsafe and parents are unable to stay home and care for their children during the day, increasing risk for falls and other potentially injurious events (Carrillo, 2009;

WHO, 2008). In addition, many of the developing areas where rates of SCI are unreported are plagued by violence. For example, Colombia is one of the most violent countries in the world; armed conflicts between the state, narco-terrorists, and paramilitary groups have resulted in highly unsafe living conditions for adults and children alike (Krug, Dahlberg, Mercy, Zwi, & Lozano, 2002; Krug, Mercy, Dahlberg, Zwi, 2002).

Regarding epidemiology of SB in developing areas, more data is available. Associations between socioeconomic status, maternal malnutrition, and risk for SB mean that the burden of neural tube defects is considerable in among people living in poverty (Yang, Carmichael, Canfield, Song, & Shaw, 2008). Indeed, much of Latin America, including Brazil, Venezuela, Bolivia, and Chile report high rates of SB, ranging from 4.73-15.25 per 10,000 live births, compared to roughly 3 per 10,000 births in the U.S. (WHO, 2003). Notably, the most recent data for Colombia estimates an SB incidence of 1.69 per 10,000 births, but data for this region is fragmented and unreliable, such that the upper limit of a 95% confidence interval for Colombian SB births is 7.26 per 10,000 (WHO, 2003). A more recent analysis of Colombian SB surveillance literature was unable to obtain an overall incidence estimate due to a paucity of systematically collected data (Rosenthal et al., 2013).

1.3.2 Psychological and Psychosocial Challenges

Although no investigations have explored mental health among children with SCI or SB in any developing country, a variety of factors suggest Colombian pediatric SCI and SB patients may be particularly vulnerable to post-injury emotional dysfunction. First, disabled children in Colombia are likely to experience barriers to normal psychosocial functioning and peer group reintegration to a greater degree than their first-world peers. As recently as 2004, it has been reported that only 20% of schools in Colombia are handicap-accessible, with most of these accommodations occurring in large cities; as a result, children who cannot travel without a wheelchair may be unable to return to school (International Disability Rights Monitor [IDRM], 2012). Furthermore, lack of access to costly rehabilitative resources, such as lift chairs, customized toileting facilities, and motorized wheelchairs may negatively impact children's independence and opportunities for social contact. Furthermore, the scarcity of treatment resources in Colombia extends to factors influencing physical health and recovery. For example, lack of access to a motorized wheelchair may mean that children with SCI or SB in developing areas are largely home-bound, particularly in areas where roads are poor and no other transportation options are available.

Second, SCI and SB patients who develop mental health problems in Colombia are likely to experience obstacles to obtaining psychological care. There is a considerable treatment gap for psychological disorders in Latin America, where it is reported that over half of individuals with mood and anxiety disorders do not receive services (Kohn, Saxena, Levav, & Saraceno, 2004). Psychopharmacological resources can also be scarce in Colombia, such that it is difficult for persons experiencing mental health problems, and particularly those who are poor, to obtain appropriate medications (Machado, Lopera, Diaz-Rojas, Jaramillo, & Einarson, 2008). Overall, there is reason to suspect that children who develop such disorders are at risk for being untreated or inadequately treated. In the context of an established risk group such as the physically disabled, this is serious cause for concern.

1.3.3 Physical Challenges: Access to Care

In addition to scarcity of psychological services, there is evidence to suggest that children with SCI and SB in Colombia experience difficulty acquiring necessary medical care, which may in turn adversely impact HRQOL and psychological well-being. The most prominent barrier to care is a minimal safety net for the poor or disabled (Library of Congress, 2007). Colombians experience one of the highest income inequality ratios in the world and although health care standards have improved in recent years, the poor continue to experience significant health disparities and high rates of mortality (Library of Congress, 2007). Roughly 51% of Colombia's poor are uninsured (World Bank, 2007) and, as such, children with SCI, SB, and other severe disabilities are likely to have no health insurance, minimal access to rehabilitative resources, and limited medical care to address secondary complications or necessary surgical interventions. Although Colombians with disabilities are legally guaranteed access to assistive devices (e.g., wheelchairs), many do not receive them, and very few poor families can afford to make such a purchase outright (IDRM, 2012). Humanitarian organizations are working to provide rehabilitation services and treatment to Colombians with physical disabilities, but there continue to be significant struggles with provision of such resources (USAID, 2011).

To date, no studies have investigated the impact of barriers to health care on Colombian children with SCI or SB, and it is therefore difficult to assess the impact of lack of access to medical services on children in the region. However, two pieces of data may shed light on the quality and availability of medical care to injured Colombian children. First, one mid-sized Colombian city instituting an injury surveillance system recently reported the rate of injury-related mortality in children to be 170.8 per 100,000 youth (Espitia-Hardeman, 2011). By way of context, this is more than 11 times the rate of death secondary to injury among children in the United States (CDC, 2008). Second, adult SCI patients living in Colombia report significantly reduced HRQOL in the areas of pain, general health, and role limitations due to physical problems, indicating substantial interference from health-related symptoms on engagement in meaningful life activities (Arango-Lasprilla, Nicholls, Olivera, Perdomo, & Arango, 2010). Perhaps related, this sample also reported access to minimal rehabilitative resources, raising the possibility that Colombians with SCI or other spinal cord dysfunction receive insufficient treatment that negatively impacts their overall sense of well-being (Arango-Lasprilla et al., 2010).

1.3.4 Caregivers in the Developing World

Even in industrialized nations, there is evidence to suggest that psychological dysfunction in SCI caregivers may be exacerbated in the presence of financial instability (Savage & Bailey, 2004; Vermaes et al., 2005). Caregivers of children with SCI and SB in the developing world experience numerous challenges that may negatively impact psychological functioning. For example, children with SCI and SB often require significant support and when resources are scarce, the bulk of care must be provided by parents or other unpaid familial caregivers with little or no respite (Arango-Lasprilla et al., 2010). The cost of medical and/or nursing services may be overwhelming for the poor, such that untrained family members are left to address medical issues as they arise (Arango-Lasprilla et al., 2010).

The mental health treatment gap in Latin America means that SCI and SB caregivers experiencing psychological problems may also be unlikely to receive treatment, potentially resulting in worsening or chronic problems (Kohn et al., 2004). In fact, findings from the single study investigating mental health outcomes among SCI caregivers in Colombia indicates that a majority of caregivers report feeling overwhelmed by their caregiving responsibilities, and nearly half report low satisfaction with life (Arango-Lasprilla et al., 2010). Greater economic needs in this sample, including the need for psychological services, were associated with greater levels of depression and burden (Arango-Lasprilla et al., 2010). Overall, limited access to rehabilitative, medical, financial, and psychological resources make it reasonable to suspect that both pediatric SCI/SB patients and their caregivers living in the developing world face considerable adversity that could negatively affect psychological health and well-being. To my knowledge, the extant literature has not investigated the experiences of children with SCI, SB, or their caregivers, in any developing country.

CHAPTER 2. CURRENT STUDY

2.1 Rationale

Spinal cord dysfunction has a pervasive impact on the lives of children and their families. Pediatric SCI patients, children with SB, and their caregivers face significant long-term challenges related to children's physical limitations and need for ongoing care, which may be exacerbated in the presence of limited financial resources and/or low socioeconomic status (Cate et al., 2002; Holmbeck et al., 2003; Krause, Kemp, & Coker, 2000; Rofail et al., 2013; Savage & Bailey, 2004). As such, children with SCI, SB, and their caregivers living in the developing world may be particularly vulnerable to psychological dysfunction. However, no studies have investigated mental health or

HRQOL in children with pediatric SCI, SB, or their caregivers in poor countries, representing a serious gap in the literature. Thus, investigating these variables is important toward assessing the need for improved medical and rehabilitative services in Colombia, as well as potentially informing the work of rehabilitation professionals practicing with Latino/a populations within the United States and other developed nations.

A brief note regarding the inclusion of a combined sample of children with SCI or SB is warranted. Although the mechanisms of spinal cord lesions and several key secondary complications in SCI versus SB create contrasts between the populations, many of the challenges encountered by affected children and their caregivers are similar in terms of factors that could be expected to affect psychological functioning (e.g., dependence on others, lack of social engagement, isolation, and significant burden). Moreover, in the developing world, both groups are equally in need of, and equally unlikely to receive, appropriate long-term care. Although some of the neuropsychological dysfunction associated with SB could potentially confound results of a study investigating cognitive variables in children with SCI and SB as a single sample, the current study is aimed at exploring affective factors and the impact of physical disability on children’s and caregivers’ quality of life. Moreover, given the similarities between the two conditions as well as their relatively low base rates, combining SCI and SB patients into a single sample is not without precedent in the literature (e.g., Abresch et al., 2007; Xiao, 2006).

2.2 Aims and Hypotheses

2.2.1 Primary Aims

Aim 1: To compare psychological functioning and HRQOL of children with spinal cord lesions in Colombia to an age-matched comparison group.

Hypothesis 1: It was hypothesized that children with spinal cord lesions would report significantly higher levels of depressive and anxious symptomatology, but lower levels of HRQOL, as compared to an age-matched comparison group when controlling for potential covariates such as sociodemographic characteristics (age, gender, socioeconomic status).

Aim 2: To compare the psychological functioning, health related quality of life, and level of burden in caregivers of children with spinal cord lesions to that of caregivers of an age-matched comparison group.

Hypothesis 2: It was hypothesized that caregivers of children with spinal cord lesions would report significantly greater levels of moderate to severe depressive and anxious symptomatology, significantly higher levels of burden, as well as lower levels of HRQOL, than caregivers of children without spinal cord lesions when controlling for potential covariates such as sociodemographic characteristics (age, gender, socioeconomic status).

2.2.2 Secondary Aims

Aim 3: To determine the relationship between hopefulness and levels of anxiety, depression, and HRQOL in children with spinal cord lesions.

Hypothesis 3: It was hypothesized that hopefulness would have a significant negative relationship with depressive and anxious symptomatology, but a significantly positive relationship with HRQOL.

2.3 Power Analysis

Because no previous studies have investigated psychological functioning in children with spinal cord lesions or their caregivers in countries that are categorized as "developing", there is little basis for predicting an effect size for the planned analyses for this cohort. The single study assessing depression and anxiety in children with SCI in the United States (Anderson et al., 2009) did not report an effect size when comparing data from the pediatric SCI sample to normative data, and the overall effect size for children with SB in the American literature was estimated at .30 in a recent meta-analysis (Pinquart & Shen, 2011). As such, a medium effect size was predicted, resulting in a necessary sample size of 64 participants per group (Cohen, 1992). The recommended number of participants for each of these analyses exceeds the resources of the current study and therefore suggests an increased risk for Type II error. Because available resources are inflexible secondary to personnel and funding limitations, and elevated risk of a Type II error is generally considered a less serious methodological issue than inflated risk of Type I error, this was addressed in the limitations section of resulting manuscript(s). Observed power for each of these analyses were reported and in the event analyses are insufficiently powered, effect sizes were relied upon for interpretation. With respect to Aim 5, in a multiple regression, a general guideline is approximately 15 participants for each predictor variable. Aim 5 includes 3 predictor variables, such that a sample size of 30 individuals per group is less than optimal.

CHAPTER 3. METHODS

3.1 Participants

Participants with SCI and SB were recruited from the Hospital Universatario Hernando Moncaleano Perdomo in Neiva, Colombia. The sample was comprised of four groups: 30 children with SCI or SB; 30 parents/caregivers of these children; 30 comparison group children matched on age, gender, and socioeconomic status; and 30 parents/caregivers of comparison group children. Inclusion criteria stated that children must be between the ages of 8 and 17 at the time of data collection. In addition, participants with SCI were required to be at least 6 months post-injury. Parents/caregivers were defined as the parent or other individual primarily responsible for the child's care, and must have spent more than three months in this role by self-report. Exclusion criteria stated that children should not have been previously diagnosed with a serious developmental disorder (e.g., Autism, Mental Retardation), or serious psychological or neurological problems (e.g., psychotic disorders, traumatic brain injury), which was also evaluated by parent report. Furthermore, child participants were excluded if they had sustained a traumatic brain injury, which was confirmed by medical record review. Parent exclusion criteria stated that parents should not have a history of serious psychological or neurological problems (e.g., psychotic disorders, dementia) as evaluated by self-report.

A total of 30 children and adolescents with spinal cord lesions were recruited. Comparison group members were matched on age, gender, and socioeconomic status. Each group consisted of 20 males (66.7%) and 10 females (33.3%), and children's mean age was 13.8 years (SD = 3.0 years) for the spinal cord lesion group and 13.6 years (SD =

2.9 years) for controls. Ninety percent (n = 54) children reported socioeconomic status at Levels 1 and 2, the poorest recorded by the Colombian government (there are 6 levels total). Most children (63.3%) in the spinal cord lesion group were attending school, with 1 child (3.3%) receiving special educational services for learning delays. All children in the comparison group (96.7%) were attending school, with the exception of one participant who had already graduated. All children in the spinal cord lesion group had received some type of physical therapy. Full demographic characteristics for the sample are presented in Table 1.

Among children with spinal cord lesions, 22 (73.3%) children were diagnosed with SB and 8 (26.7%) were diagnosed with SCI. Within the SB group (n = 22), 77.7% of children (n = 17) had history of hydrocephalus and 31.8% (n = 7) had history of Chiari malformation. The majority of children in the spinal cord lesion group (96.7%, n = 29) were paraplegic, with one child (3.3%) reporting tetraplegia. Most children in the spinal cord lesion group (63.3%, n = 19) had an American Spinal Injury Association (ASIA) Impairment Scale score of C, followed by 16.7% (n = 5) children at level B, 16.7 (n = 5) at level D, and 3.3% (n = 1) at level A. Eight children (26.7%) had received some level of mental health services in the past. Full clinical characteristics for the spinal cord lesion group are presented in Table 2.

A total of 60 caregivers (30 spinal cord lesion, 30 comparison group) were also recruited to participate in the present study. Ninety percent of caregivers of children with spinal cord lesions (n = 27) were female, and 96.7% of caregivers of healthy controls (n = 29) were female. The caregivers' mean age was 41.3 (*SD* = 11.0) years within the spinal cord lesion group and 39.7 (*SD* = 8.5) years within the comparison group. The majority of caregivers in spinal cord lesion (66.7%) and comparison groups (86.7%) were the children's mothers. Three caregivers in the spinal cord lesion group (13.3%) and one caregiver in the comparison group (3.3%) were grandmothers, while 2 caregivers in the spinal cord injury group (6.7%) and one in the comparison group (3.3%) were fathers. Caregivers of children with spinal cord lesions reported spending approximately 75.7 (SD = 24.0) hours per week caring for their children, as compared to 59.1 (SD =13.7) hours spent caring among the comparison group. None reported history of receiving mental health services. Full demographic characteristics for the caregiver sample are available in Table 3.

3.2 Measures

3.2.1 Demographic and Clinical Characteristics

Medical chart review and semistructured interviews with children and caregiver were used to obtain demographic and clinical characteristics. Child characteristics included age, gender, educational history, socioeconomic status, level and type of injury, time since injury, presence of secondary complications, history of previous psychological or psychiatric disorders, type and quantity of services received, and several indicators of injury severity (e.g., breathing problems, bladder/bowel issues, and means of mobility). Caregiver characteristics included age, gender, marital status, relationship to child, educational and occupational history, socioeconomic status, time spent caregiving, and history of previous psychological or psychiatric disorders.

3.2.2 Children's Depression Inventory (CDI)

The Children's Depression Inventory (Kovacs, 1980/1981) is a 27-item self-report depression scale designed to assess depression symptomatology in children ages 7 to 17 years. On each item, children are asked to endorse one of three statements that best describes their symptoms. Responses are scored on a 0 - 2 scale for each item, with 2 representing more severe symptoms and 0 representing the absence of a particular symptom, such that scores range from 0 (no symptoms) to 54 (severe symptoms). Scores above 20 are considered representative of clinically significant depressive symptomatology. The CDI has been utilized in a wide body of studies involving a variety of populations, including children with SCI and SB (Anderson et al., 2009; Garma et al., 2011; Oddson et al., 2006) and the Spanish version of the instrument (Davanzo et al., 2004) used in the current study has evidenced adequate reliability and validity (Cronbach's alpha = .72-.88).

3.2.3 Revised Children's Manifest Anxiety Scale – 2 (RCMAS-2)

The RCMAS-2 (Reynolds & Richmond, 2008) represents an updated version of the earlier RCMAS, one of the most widely used instruments for assessing anxiety in children in clinical and research samples in a variety of cultures and languages (Reynolds, Wilson, Austin, & Hooper, 2012). The RCMAS-2 is a self-report instrument consisting of 49 items designed to measure psychological anxiety, worry, social anxiety, and defensiveness among children ages 6 to 19. Each test item is answered "yes" or "no," and the instrument yields a Total Anxiety score, and three anxiety-related subscale scores (Physiological Anxiety, Social Anxiety, Worry). T-scores of 71 or higher are considered extremely problematic, scores from 61 to 70 are clinically concerning, and scores 60 and below are normal or non-problematic. The RCMAS-2 is available in Spanish and has been translated and back-translated by psychologists at Western Psychological Services, and has previously been used to assess anxiety in children with

SCI (Anderson et al., 2009; Garma et al., 2011; Zurmohle et al., 1998). Cronbach's alpha estimates for the individual subscales range from .75 to .92 (Reynolds & Richmond, 2008).

3.2.4 Pediatric Quality of Life Inventory (PedsQL) – Child Self-Report.

The PedsQL (Varni, Seid, & Rode, 1999) is a modular instrument that assesses HRQOL in children ages 2 to 18 years who have been diagnosed with various diseases and/or chronic conditions. The child self-report measure, which consists of separate forms for children ages 8 to 12 and 13 to 18 years, results in measures of children's general quality of life in terms of physical, emotional, social, and school functioning. The instrument consists of 23 items with problem statements that are rated on a 5-point Likert-type scale with 0 representing that the statement is "never a problem" and 4 indicating that it is "almost always a problem." Scores for each item contribute to either a Psychosocial Health Summary Score or a Physical Health Summary Score. Items are reverse-scored and linearly transformed into a 0-100 scale, such that scores closer to 100 represent better HRQOL. Numerous studies have reported interpretive score range suggestions for the instrument, and a recent review encompassing results from 25,000 children with chronic health issues recommended that scores below 70 on the version used in the current study be considered clinically significant (Varni, Burwinkle, & Seid, 2005). The PedsQL has been used to assess HRQOL in children with SCI and SB (Garma et al., 2011; Parekh et al., 2006) and translated into Spanish with adequate reliability and consistency in this language (Cronbach's alpha = .68-.88; Varni, Seid, & Kurtin, 2001).

3.2.5 Children's Hope Scale (CHS)

The CHS (Snyder et al., 1997) is a six-item self-report questionnaire assessing children's dispositional hope, conceptualized as a child's ability to engage in goal-directed thinking, identify pathways to a given goal, and his or her sense of self-efficacy (or agency) in attaining these goals. The instrument was designed for use with children ages 8 to 19 years. Each item reflects a belief consistent with the construct of hopefulness (e.g., "I can think of many ways to get the things in life that are most important to me") and is scored on a 6-point Likert-type scale (0 = none of the time to 6 = all of the time). Scores range from 0 to 36, with higher scores representing greater levels of hopefulness. Two subscales can be derived to describe children's self-perception of problem-solving abilities ("Pathways") as well as their sense of self-efficacy in overcoming obstacles ("Agency"). The instrument has been translated into Spanish, with moderate reliability (Cronbach's alpha = .64-.69; Frehe-Torres, 2010). Although the CHS has not been used with children with SCI or SB, this instrument has been utilized in research studies with other pediatric patients with chronic illness, such as sickle cell disease (Lewis & Kliewer, 1996) and juvenile rheumatoid arthritis (Barlow, Shaw, & Wright, 2001).

3.2.6 Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 (Spitzer, Kroenke, & Williams, 1999), a nine-item module of the Patient Health Questionnaire, was used to assess caregiver depressive symptomatology. On the PHQ-9, respondents are asked to indicate how often they have been bothered by each item using a 4-point Likert-type scale (0 = not at all to 3 = nearly every day). Response scores are totaled, and the total score ranges from 0 to 27, with higher scores reflecting higher levels of depression (Kroenke, Spitzer, & Williams, 2001). Regarding interpretation of the instrument, a score of 0 to 4 indicates no depressive symptoms, 5 to 9 suggests mild symptoms, 10 to 14 reflects moderate symptoms, 15 to 19 indicates moderately severe symptoms, and 20 to 27 indicates severe symptoms. The Spanish version utilized in this study (Wulsin, Somoza, & Heck, 2002), has been shown to be reliable and valid in assessing depression in Spanish speakers (Diez-Quevado, Rangil, Sanchez-Planell, Kroenke, & Spitzer, 2001; Donlan & Lee, 2010).

3.2.7 Beck Anxiety Inventory (BAI)

The BAI (Beck & Steer, 1990), a 21-item self-administered inventory designed to assess anxious symptomatology in adults, was used to measure anxious symptoms in caregivers. Each item presents an anxiety symptom, which patients are asked to rate on a 4-point Likert-type scale with 0 indicating absence of the symptom and 3 indicating severe symptoms. Total scores range from 0 (no anxiety) to 63 (severe anxiety), with scores from 0 to 9 being considered in the normal range, 10 to 18 representative of mild to moderate anxiety, 19 to 29 moderate to severe anxiety, and 30 to 69 severe anxiety. The BAI has been translated into many languages, including Spanish (Sanz & Navarro, 2003), and has demonstrated excellent reliability and validity (Cronbach's alpha = .93; Magán, Sanz, & García-Vera, 2008).

3.2.8 Medical Outcomes Study Short-Form Health Survey (SF-36)

The SF-36 (Ware & Sherbourne, 1992) was used to assess HRQOL in caregivers. The SF-36 is a self-report health questionnaire and one of the most widely used instruments to assess HRQOL in research and clinical settings. The instrument consists of 36 items that focus on eight different health dimensions, including: physical functioning, role-physical (role limitations due to physical problems), bodily pain, general health, vitality, social functioning, mental health, and role-emotional (role limitations due to emotional problems). Responses are scored on a 0-100 scale, with higher scores representing higher HRQOL. The SF-36 has been translated into many languages, including Spanish, and has acceptable reliability (Cronbach's alpha = .71-.84; Alonso, Prieto, & Antó, 1995) and validity in this language (Ayuso-Mateos et al., 1999).

3.2.9 Zarit Burden Interview (ZBI)

The ZBI (Zarit, Reever, Bach-Peterson, 1980) was used to measure caregiver burden. The ZBI is a 22-item self-report questionnaire that evaluates health, psychological well-being, finances, and social life in the context of the caregiver-patient relationship. Responses are scored on a 4-point scale ranging from "never" (0) to "nearly always" (4). Item scores are summed to obtain a total score, which can range from 0 to 88, with higher scores indicating greater levels of caregiver burden. In terms of interpretation, scores from 0 to 20 indicate little or no burden, 21 to 40 are suggestive of mild to moderate burden, 41 to 60 indicate moderate to severe burden, and 60 to 88 are classified as severe burden (Karlikaya, Yukse, Varlibas, & Tireli, 2005). The Spanish version of the ZBI (Martin et al., 1996) that utilized in this study has also been used to assess burden in caregivers of Spanish-speaking individuals with various chronic, severe conditions, including kidney failure (Alvarez-Ude, Valdes, Estebanez, & Rebollo, 2004) and multiple sclerosis (Rivera-Navarro, et al., 2009). The ZBI has demonstrated good internal reliability in Spanish (Cronbach's alpha = .92; Martin et al., 1996).

3.3 Procedures

Research staff reviewed emergency department records in locked storage at the Hospital Universatario Hernando Moncaleano Perdomo, the University of Neiva's hospital, in order to identify SCI or SB patients ages 17 years or younger who meet all inclusion criteria. Potential participants and their parents were called at home and given information about the study. For families agreeing to participate, the research team scheduled an appointment at their home. At the appointment, participants were asked to provide informed consent and assent and then interviewed by a psychologist under the supervision of a University of Neiva professor. The psychologist collected sociodemographic information as well as history of medical or psychological problems, and administered a series of questionnaires. Comparison group members were recruited through flyers at neighborhood churches, stores, and restaurants as well as by general word of mouth. Control group participants were given the choice to hold appointments at their homes or at the University of Neiva. Interviewers were instructed to administer questionnaires orally to children, while parents completed questionnaires independently.

3.4 Analyses

Aim 1: Analyses of covariance (ANCOVAs) compared scores from children with spinal cord lesions and an age-matched comparison group on measures of depressive and anxious symptomatology as well as HRQOL. Because children with spinal cord lesions and comparison group children were age- and gender-matched and because previous studies used for comparison (Anderson et al., 2009; Holmbeck et al., 2003; Kelly et al., 2012; Kelly & Vogel, 2013) reported raw scores on the CDI and RCMAS-2, raw scores were used in analyses.

Aim 2: Analyses of covariance (ANOVAs) compared scores from parental caregivers of children with spinal cord lesions and parents of comparison group children on measures of depressive and anxious symptomatology, burden, and HRQOL.

Aim 3: A general linear model was used to investigate whether a significant relationship existed between the Children's Hope Scale (CHS) and other child outcome variables (CDI, RCMAS-2, and Peds-QL scores).

CHAPTER 4. RESULTS

4.1. Comparisons between children with SCI and their caregivers versus children with SB and their caregivers

4.1.1 Child demographics, depression, anxiety, and HRQOL

Because children with SCI and SB were combined into a single spinal cord lesion group for main analyses, preliminary analyses were conducted to explore potential differences in demographic or clinical characteristics between children with SCI as compared to children with SB. Examination of the demographic variables revealed that children with SCI were older (*M* age SCI sample = 16.6 years, *SD* = 1.2 years; *M* age SB sample = 12.7 years, *SD* = 2.8 years; $t(28) = 3.76$, $p <.01$) and had greater functional impairment as assessed by American Spinal Injury Association (ASIA) scores ($\chi^2 = 9.76$, $p < .05$) as compared to children with SB. No other demographic variables were significantly discrepant between the SCI and SB groups. Preliminary analyses also compared levels of depression, anxiety, and HRQOL between children with SCI and SB. Analyses of covariance (ANCOVAS) controlling for age and ASIA scores did not reveal significant differences between SB and SCI groups on measures of depression (CDI; *F*(1, 28) = 0.10, $\eta^2 p$ = 0.00, *p* = 0.76), anxiety (RCMAS-2; *F*(1, 28) = 0.08, $\eta^2 p$ = 0.00, *p* = 0.78), or HRQOL (PedsQL; *F*(1, 28) = 0.06, $\eta^2 p$ = 0.00, *p* = 0.81) (see Table 4).

4.1.2 Caregiver demographics, depression, anxiety, burden, and HRQOL

Caregivers of children with SCI were compared with caregivers of children with SB on demographic and clinical variables. Results revealed only one significant difference between SCI and SB groups in terms of demographic variables. Specifically, months spent caring for children was significantly higher for SB caregivers (*M* for SB sample = 142.0 months, *SD* = 51.0 months; *M* for SCI sample = 38.6 months, *SD* = 70.8 months; *t*(28) = 4.42, *p* <.001). In terms of clinical variables, ANCOVA results controlling for months spent caregiving did not reveal significant differences on measures of depression (PHQ-9; *F*(1, 28) = 1.11, $\eta^2 p$ = 0.04, *p* = 0.30), anxiety (BAI; *F*(1, 28) = 1.06, $\eta^2 p$ = 0.07, *p* = 0.36), burden (ZBI; *F*(1, 28) = 0.43, $\eta^2 p$ = 0.02, *p* = 0.52), or HRQOL (SF-36; see Table 5) between caregivers of children with SCI and SB. Results from all comparisons are presented in Table 5.

4.2. Descriptive data for children with spinal cord lesions

Children with spinal cord lesions obtained a mean total raw score of 12.0 (*SD* = 6.6) on the CDI. T-scores on this instrument are calculated based on age range (7 to 12 years vs. 13 to 17 years) and gender, with T-scores of 65 and above indicating clinically significant symptomatology (Kovacs, 1980/1981). Children with spinal cord lesions obtained a mean T score of 52.2 (*SD* = 9.5), a score falling in the average range for depressive symptomatology. Within the spinal cord lesion group overall, 13% of children with spinal cord lesions (*n* = 4) fell at or above the cutoff for demonstrating clinically significant symptoms.

On the RCMAS-2, children with spinal cord lesions obtained a mean raw score of 17.2 (*SD* = 7.3). T-scores for the RCMAS-2 are calculated based on age bands of 9 to 14 and 15 to 19 years, with scores above 60 falling in the clinically significant range. Children with spinal cord lesions obtained mean T scores of 53.5 (*SD* = 9.0), a score in the average range. Further examination of the RCMAS-2 scores revealed a range of raw scores between 6 and 37 within the spinal cord lesion sample, with 27% of children (*n* = 8) scoring at or above the cutoff for clinical significance.

On the PedsQL, the mean total raw score for children with spinal cord lesions was 58.9 (*SD* = 12.2), a score in the clinically significant range and consistent with poor HRQOL. These results are presented in Table 6.

4.3. Spinal cord lesion vs. healthy control comparisons

4.3.1 Child and caregiver demographic characteristics

Prior to conducting main analyses, demographic characteristics were compared between children with spinal cord lesions and comparison group children. Findings revealed significant differences between groups in terms of educational status (see Table 1). More specifically, 96.7% of comparison group children (*n* = 29; one had already graduated high school) were enrolled in school, in comparison to only 63.3% (*n* =19) of children with spinal cord lesions ($\chi^2 = 8.4$, $p < .01$). One child in the spinal cord lesion group was home-schooled. No other demographic characteristics were significantly different between groups. Given these results, main analyses comparing children with spinal cord lesions to comparison group children included educational status as a covariate.

Comparison of baseline demographic characteristics between caregivers of children with spinal cord lesions and comparison group children revealed that comparison group caregivers had spent more time caring for their children (SCI/SB caregiver M = 114.4 months, SD = 72.5 months; healthy control caregiver M = 162.5 months, SD = 33.8 months; t = 3.30, $p <.01$). On the other hand, caregivers of children with spinal cord lesions spent significantly more hours per week caring for their child as compared to caregivers of healthy control children (SCI/SB caregiver M = 75.7 hours, SD = 24.0 hours; healthy control caregiver M = 59.1 hours, SD = 13.7 hours; $t(58) = -3.29$, $p < .01$). Because these factors are central to the clinical constructs of interest in the present study, time spent caregiving was not controlled for in main analyses.

4.3.2 Child depression, anxiety, and HRQOL

Levels of self-reported depression, anxiety, and HRQOL were compared between children with spinal cord lesions and comparison group children. Regarding depression, children in the spinal cord lesion group obtained a mean CDI raw score of 12.0 (SD = 6.6), compared to a mean score of 8.9 (SD = 5.0) among comparison group children. Children with spinal cord lesions obtained a mean T score of 52.2 (SD = 9.5; average range), compared to a mean T score of 47.7 (SD = 6.5; average range) among comparison group children. Results of an ANCOVA controlling for educational status did not reveal significant between-group differences on the CDI total raw score (F (1, 58) = 1.98, η^2p = 0.03, p = 0.17), or the Negative Mood (F(1, 58) = 0.15, η^2p = 0.00, p = 0.70), Interpersonal Problems (F(1, 58) = 2.13, η^2p = 0.04, p = 0.15), Ineffectiveness (F(1, 58) =

0.92, $\eta^2p = 0.02$, $p = 0.34$), Anhedonia ($F(1, 58) = 1.18$, $\eta^2p = 0.02$, $p = 0.28$), or Negative Self-Esteem ($F(1, 58) = 0.86$, $\eta^2p = 0.02$, $p = 0.36$) subscales (see Table 6). In terms of clinical significance, although more children with spinal cord lesions fell above the CDI cutoff (T ≥ 65) for clinically significant depressive symptoms as compared to comparison group children (13% and 3%, respectively), Chi square analysis indicated the likelihood of falling above the cutoff did not differ significantly between groups ($\chi^2 = 2.7$, $p =0.09$).

In terms of anxiety, children with spinal cord lesions obtained a mean RCMAS-2 total raw score of 17.2 ($SD = 7.3$), compared to a total raw score of 16.6 ($SD = 6.7$) among comparison group children. Children with spinal cord lesions obtained a mean T score of 53.5 ($SD = 9.0$; average range), compared to a mean T score of 52.1 ($SD = 8.3$; average range) among comparison group children. Results of an ANCOVA controlling for educational status revealed no significant differences between groups on the RCMAS-2 total raw score ($F(1, 58) = 0.13$, $\eta^2p = 0.00$, $p = 0.73$), or the Worry ($F(1, 58) = 1.94$, $\eta^2p = 0.03$, $p = 0.17$), or Social Anxiety ($F(1, 58) = 0.60$, $\eta^2p = 0.01$, $p = 0.44$) subscales. Children with spinal cord lesions did score significantly higher on the Physiological Anxiety subscale of the RCMAS-2 as compared to comparison group children (spinal cord lesion $M = 5.4$, $SD = 2.4$; comparison group $M = 3.9$, $SD = 2.1$; $F(1, 58) = 5.67$, $\eta^2p = 0.09$, $p < .05$). However, results from the Chi square analysis revealed that rates of scoring at or above the cutoff for clinical concern on the overall score for the RCMAS-2 (T ≥ 60) did not differ between spinal cord lesion and comparison group children (27% vs. 20%, respectively; $\chi^2 = 1.0$, $p = 0.50$).

Children in the spinal cord lesion group obtained a mean total PedsQL score of 58.9 (*SD* = 12.2), compared to a mean score of 78.7 (*SD* = 11.4) among comparison group children. ANCOVAs controlling for educational status revealed differences between groups on the PedsQL total raw score ($F(1, 58) = 29.30$, $\eta^2 p = 0.34$, $p < .001$), Physical Functioning scale ($F(1, 58) = 49.16$, $\eta^2 p = 0.46$, $p < .001$), Social Functioning scale ($F(1, 58) = 8.78$, $\eta^2 p = 0.13$, $p < .01$), and the School Functioning scale ($F(1, 58) = 7.72$, $\eta^2 p = 0.12$, $p < .01$). On each of these indices, children with spinal cord lesions reported worse HRQOL than their healthy peers as well as scores falling below the cutoff for clinical significance in terms of poor HRQOL (<70; Varni et al., 2005). Although children in the spinal cord lesion group obtained a mean score on the Emotional Functioning subscale falling in the clinically significant range (*M* = 64.0, *SD* = 20.1), scores on this subscale did not differ significantly between groups ($F(1, 58) = 0.06$, $\eta^2 p = 0.00$, $p = 0.81$). Full results are presented in Table 6.

4.3.3 Caregiver depression, anxiety, burden, and HRQOL

ANOVAS were used to compare caregivers of children with spinal cord lesions to caregivers of comparison group children on measures of depression, anxiety, burden, and HRQOL. In terms of depression, caregivers of children with spinal cord lesions obtained a mean raw score of 6.3 (*SD* = 5.5; mild depressive symptom range) on the PHQ-9, compared to a mean raw score of 5.0 (*SD* = 5.8; average range) among caregivers of comparison group children, a difference that did not reach statistical significance ($F(1, 58)$ 0.86, $\eta^2 p = 0.02$, $p = 0.36$). Twenty-seven percent ($n = 7$) of caregivers of children with spinal cord lesions had scores that fell in the clinically significant range for depressive symptoms, compared to 20.0% ($n = 5$) of caregivers of comparison group children. Chi square analyses did not reveal significant differences between caregiver groups in terms of the likelihood of falling in the clinically significant range for depressive symptomatology ($\chi^2 = 0.40$, $p = 0.40$).

On the Beck Anxiety Inventory, caregivers in the spinal cord lesion group obtained a total raw score of 10.1 (*SD* = 9.5), compared to a total raw score of 7.0 (*SD* = 9.4) among comparison group caregivers, a difference that failed to reach statistical significance ($F(1, 58) = 1.52$, $\eta^2 p = 0.03$, $p = 0.22$). These scores fell in interpretive ranges indicative of mild to moderate anxiety and normative levels of anxiety, respectively. Twenty-three percent of caregivers of children with spinal cord lesions ($n = 7$) fell within the clinically significant range for anxious symptomatology (BAI total score ≥ 19), compared to 10% of caregivers of comparison group children. However, Chi square analysis did not reveal significant differences in terms of likelihood of falling within the clinically significant range on the BAI when examined by caregiver group ($\chi^2 = 1.92$, $p = 0.16$).

In terms of caregiver burden, caregivers of children with spinal cord lesions obtained a total score of 33.4 (*SD* = 16.9) on the ZBI as compared to a total score of 20.1 (*SD* = 9.4) within the comparison caregiver group, indicating significantly more burden among the spinal cord lesion caregivers ($F(1, 58) = 14.04$, $n^2_{\mathrm{p}} = 0.20$, $p < .001$). Furthermore, caregivers of children with spinal cord lesions were significantly more likely to report moderate to severe burden as compared to caregivers of comparison group children (26.7% vs. 6.7%; $\chi^2 = 4.32$, $p < .05$).

Finally, regarding HRQOL, caregivers of children with SCI or SB demonstrated significantly worse HRQOL as compared to comparison group caregivers on SF-36 subscales assessing Physical Functioning ($F(1, 58) = 12.05$, $n^2_p = 0.17$, $p <.001$), Bodily Pain ($F(1, 58) = 6.29$, $n^2_p = 0.10$, $p <.05$,), General Health ($F(1) = 5.49$, $n^2_p = 0.09$, $p <.05$), Social Functioning ($F(1, 58) = 13.17$, $n^2_p = 0.19$, $p <.001$), Mental Health ($F(1) = 5.10$, $n^2_p = 0.08$, $p <.05$), and Role Limitations-Emotional ($F(1, 58) = 5.14$, $n^2_p = 0.08$, $p <.05$). However, significant differences were not observed on the Role Limitations-Physical ($F(1, 58) = 3.00$, $n^2_p = 0.05$, $p = .09$) and Vitality ($F(1, 58) = 3.04$, $n^2_p = 0.05$, $p =.09$) subscales of the SF-36. Full results are presented in Table 7.

4.4. Spinal cord lesion group-only analyses

4.4.1 Hopefulness, depression, anxiety, and HRQOL

Results of a general linear model using the Child Hope Scale total score as the dependent variable and total scores from the RCMAS-2, CDI, and PedsQL as independent variables revealed that when controlling for anxiety and HRQOL, CDI total score held a significant relationship with CHS total scores ($F(1, 28) = 8.35$, $n^2_p = 0.24$, $p < .01$). However, neither RCMAS-2 total scores ($F(1, 28) = 2.97$, $n^2_p = .10$, $p = .10$) nor PedsQL total scores ($F(1, 28) = 1.25$, $n^2_p = .05$, $p = .27$) held a significant relationship with hopefulness after controlling for other respective variables. The relationship between these variables expressed as a linear equation is CHS = 13.84 – .44(CHS) + .22(RCMAS-2) + .09(PedsQL); $R^2 = .38$; $b_{CDI} = -.44$, $SE_{CDI} = .15$, $p_{CDI} < .01$; $b_{RCMAS} = .22$, $SE_{RCMAS} = .22$, $p_{RCMAS} = .10$; $b_{PedsQL} = .09$, $SE_{PedsQL} = .08$, $p_{PedsQL} = .27$.

CHAPTER 5. DISCUSSION

The primary goal of the present study was to examine levels of depression, anxiety, and HRQOL among children with spinal cord lesions as compared to an age-matched comparison group in a developing country, as well as to examine these factors, along with burden, in their primary caregivers. To our knowledge, this is the first study to investigate psychosocial functioning in a group of children with spinal cord lesions or their caregivers in Latin America. Contrary to hypotheses, significant between-group differences were not observed in terms of depressive and anxious symptoms in either children or their caregivers. However, significant differences in HRQOL were observed between children with spinal cord lesions and the comparison group. Finally, results revealed significant differences between caregiver groups on measures of HRQOL and burden.

Results from the secondary aim of this study, to determine the relationship between hopefulness and levels of anxiety, depression, and HRQOL in children with spinal cord lesions, revealed that while levels of depression as reported on the CDI were predictive of CHS scores, neither anxiety nor HRQOL were significantly predictive of hopefulness.

5.1 Child Results

5.1.1. Child depression and anxiety

When controlling for educational status, between-group differences in self-reported depressive symptomatology were non-significant on the CDI total score and the subscales. Furthermore, the proportion of children reporting clinically significant depressive symptoms did not differ significantly between groups (13% vs. 3%). Children with and without spinal cord lesions also reported comparable levels of anxiety on the RCMAS-2, with scores for both groups falling in the average range. When subscales of the RCMAS-2 were compared by group, children with spinal cord lesions did not report significantly higher levels of worry or social anxiety as compared to comparison group children, but did report higher levels of physiological anxiety. This finding is likely related to overlap between psychosomatic symptoms of anxiety on the RCMAS-2 with physiological symptoms of spinal cord lesions (e.g., shortness of breath, physical discomfort, fatigue). In terms of the prevalence of clinically significant anxious symptomatology by group, 27% percent of children with spinal cord lesions and 20% of children in the comparison group were indicative of clinical concern on the RCMAS-2.

Current results indicating non-significant between-group differences are generally consistent with previous research on children with SCI. For instance, several studies have estimated the prevalence of clinically significant depressive symptomatology at 5% to 9% among children with spinal cord lesions, values which are comparable to normative data (Ammerman et al., 1998; Anderson et al., 2009; Holmbeck et al., 2003; Kelly et al., 2012; Kelly & Vogel, 2013; Zurmohle et al. 1998). There is some contrasting data come from the SB literature, however, in which Appleton et al. (1997) identified elevated rates of depressive symptomatology among children with SB as compared to their healthy peers. However, a comparatively large proportion of participants in the Appleton et al. (1997) study were female, a risk factor for internalizing symptoms in children with chronic health conditions (Pinquart & Shen, 2011).

In terms of anxiety, previous research has also identified comparable levels of clinically significant symptoms (6% to 9%) between children with spinal cord lesions and normative data (Ammerman et al., 1998; Kelly et al., 2012). However, Kelly & Vogel (2013) identified differences in rates of anxiety among children with SCI by age range, wherein 6.5% of young children and 17.2% of older adolescents met clinical cutoffs for anxious symptomatology.

The lack of between-group differences in depression and anxiety was unexpected in light of the barriers to normative psychosocial development (e.g., limited opportunities for social interaction and school attendance) experienced by Colombian children with spinal cord lesions. One explanation for the present results is that spinal cord lesions do not elevate risk for depressive or anxious symptomatology among children. Notably, Masten (2001) suggests that children generally are resilient, even in the context of disadvantage and adversity. Thus, it is possible children with spinal cord lesions in the current study were resilient, irrespective of lack of available medical condition-specific resources, and experience similar levels of psychological dysfunction to their peers a result.

Second, cultural factors unique to the present sample may also have contributed to non-significant between group findings in terms of child depression and anxiety. One of the primary tenets of Latino culture is familism, generally defined as an emphasis on interdependence between family members (Blue-Banning, Turnbull, & Pereira, 2002). Notably, previous research indicates that supportive family relationships are associated with decreased risk of emotional distress in children with spinal cord lesions; the primacy of such relationships may serve as a protective factor against depression and anxiety among Latino children with disabilities (Appleton et al., 1997; Augutis et al., 2007). Similarly, Colombian children with spinal cord lesions may feel they fulfill important family roles in ways not impacted by physical disability. Cultural emphasis on familial interdependence would also suggest that children with spinal cord lesions in the current sample are unlikely to have negative cognitions about being dependent on others for care, and would not expect to move out of the family home in adolescence even if they did not have functional limitations (Blue-Banning et al., 2002). Cultural values of the current sample may therefore minimize the degree to which current participants with physical disabilities feel different from other children and mitigate disability-related factors that negatively impact self-esteem and psychological functioning (Appleton et al., 1997; Blue-Banning et al., 2002; Ridosh, Braun, Roux, Bellin, & Sawin, 2011).

5*.1.2 Child HRQOL*

Children with spinal cord lesions obtained lower overall PedsQL scores as compared to comparison group children, as well as poorer scores on the Physical Functioning, Social Functioning, and School Functioning subscales. On each of these indices of HRQOL, children with spinal cord also lesions fell in the clinically significant range for impairment. However, significant differences between groups were not observed on the PedsQL Emotional Functioning subscale, on which children in both groups reported scores in the clinically significant range for poor functioning.

The finding that the current sample evidenced reduced HRQOL in terms of physical functioning is consistent with the extant literature on childhood physical disabilities (Abresch et al., 2007; Danielsson et al., 2008; Oladeji et al., 2007). Children with spinal cord lesions experience a host of physical disabilities and functional impairments that can profoundly limit their ability to interact with the world (McDonald & Sadowsky, 2002). Similarly, poorer functioning in social and school domains among children with spinal cord lesions in the present sample is in accord with findings from several previous studies (Abresch et al., 2007; Garma et al., 2011; Kelly & Vogel, 2013;

Muller-Godeffroy et al., 2008). Many current participants with spinal cord lesions were not able to attend school, seriously limiting opportunities for social engagement and academic success, and only one child (3.3%) in the spinal cord lesion group received special educational services.

In contrast to the majority of studies assessing HRQOL in children with spinal cord lesions (Abresch et al., 2007; Danielsson et al., 2008; Garma et al., 2011; Kelly & Vogel, 2013; Muller-Godeffroy et al., 2008), the present study did not identify between-group differences in terms of emotional functioning. It is notable both child groups reported poor functioning in this area, a finding that is in accord with the current study results on the measures of depression and anxiety. One possible explanation for this finding may be the scarcity of both physical and mental health resources in Latin America, combined with the reported poverty of the current sample (Kohn et al., 2004; Machado et al., 2008). It may be that irrespective of disability status, children in the present sample are at risk for physical and emotional difficulties secondary to myriad stressors associated with low socioeconomic status and limited access to care (Bradley & Corwyn, 2002).

5.1.3. Hopefulness

The secondary aim of this study was to investigate the relationship between children's levels of hopefulness with their self-reported anxiety, depression, and HRQOL. Analysis of these variables revealed that when controlling for anxiety and HRQOL, depressive symptomatology held a significant relationship with hopefulness in children with spinal cord lesions. This finding is likely secondary to the prominence of hopelessness in depressive symptomatology; however, it is interesting that HRQOL and anxiety did not hold a significant relationship with hopefulness in children with spinal cord lesions. Previous research has suggested that negative life events giving rise to psychological dysfunction may not result in decrements in hopefulness once children have had time to adjust to changes (Valle, Huebner, & Suldo, 2004). It is possible that the preponderance of children born with physical disabilities in the current sample and the considerable time since injury of children with SCI (*M* = 4.6 years; *SD* = 5.6 years) means that children did not experience a reduced sense of self-efficacy or ability to accomplish goals. It is also possible that measures of anxiety, HRQOL, and hopefulness assessed unrelated constructs. Nevertheless, current results do not allow for meaningful interpretation of psychological factors affecting goal-directed thinking and self-efficacy among children with spinal cord lesions.

5.2 Caregiver Results

5.2.1 Caregiver Depression and Anxiety

Caregivers of children with spinal cord lesions did not report significantly different levels of depressive or anxious symptomatology as compared to caregivers of comparison group children. However, caregivers of children with disabilities did obtain mean PHQ-9 and BAI scores indicative of mild to moderate depression and anxiety, as compared to scores in the average range on both measures for comparison caregivers. Relatively high rates of clinically significant depressive (27% and 20%) and anxious

(23% and 10%) symptomatology were reported, and rates of clinically significant symptomatology did not differ significantly between groups.

The prevalence of clinically significant depressive and anxious symptomatology in this group of spinal cord lesion caregivers was generally comparable to previous research. For instance, Kelly et al. (2011, 2012) reported that 21% to 22% of caregivers of children with SCI report clinically significant depressive symptoms and 16% to 20% report clinically significant anxiety. Vermaes and colleagues (2005) identified overall rates of psychological distress between 19% to 46% in parents of children with SB. However, the findings of non-significant differences between caregivers of children with spinal cord lesions and healthy children are inconsistent with the extant literature. Although the above studies did not utilize a healthy control group for comparison, the authors noted that the prevalence of anxiety and depression in caregivers of children with spinal cord lesions was elevated compared to the general U. S. population (anxiety: 3.1%, depression: 6.7%; Kessler, Chiu, Demler, & Walters, 2005). Moreover, Vermaes and colleagues (2005) identified an overall effect size of 0.76 for psychological disorders in parents of children with spina bifida, although the majority of reviewed studies used variables assessing psychological distress that are difficult to compare directly with current data.

Several factors may account for the unexpected lack of between-group differences in depression and anxiety among caregivers. Previous research has demonstrated that social support mediates psychological and emotional problems among caregivers of children with disabilities (Cameron, Herridge, Tansey, McAndrews, & Cheung, 2006). As such, the lack of differences between caregiver groups may be related to cultural values in Latin America which provide strong social support systems (Blue-Banning et al., 2002). However, a more likely explanation for the lack of significant differences may be the high prevalence of symptoms of depression and anxiety irrespective of group, suggesting a vulnerability to psychological dysfunction in the caregiver sample as a whole. Although adults living in poverty in the U.S. are at increased risk for psychological dysfunction (Galea et al., 2007), those who live in developing countries are particularly likely to experience housing insecurity, poor physical health, risk of violence, hopelessness, and barriers to psychological care (Patel & Kleinman, 2003). Consistent with data suggesting a critical lack of access to mental health services in Latin America (Kohn et al., 2004; Machado et al., 2008), none of the adults in the current sample reported history of psychological or psychiatric care. Taken together, poverty-related stressors and barriers to care may potentially explain the prevalence of depression and anxiety among caregivers in the current study. Although the prevalence of depression and anxiety in Colombian adults are has not been systematically investigated such that symptomatology in the current sample may be similar to population-level base-rates, findings nevertheless underscore the difficulties inherent in raising children in conditions of poverty regardless of child disability.

5.2.2 Caregiver HRQOL

Caregivers in the spinal cord lesion group obtained scores indicative of worse HRQOL compared to caregivers of healthy children in six SF-36 domains: Physical Functioning, Bodily Pain, General Health, Social Functioning, Mental Health, and Role Limitations – Emotional. Poorer HRQOL among caregivers of children with spinal cord lesions was consistent with our hypotheses as well as previous studies indicating negative impacts of caregiving on physical functioning, mental health, and social functioning (Grosse et al., 2009; Rofail et al., 2013). The finding of poorer social functioning in caregivers of children with spinal cord lesions as compared to comparison caregivers was surprising in light of the cultural context of the current sample; it may be that caregivers of children with disabilities in the current sample receive sufficient social support to help them address psychological concerns, but they are overall less socially active as compared to their less burdened peers. However, the finding of poorer physical functioning among caregivers of children with spinal cord lesions is different than what has been reported in previous studies (Rofail et al., 2013).

Significant differences in SF-36 subscales assessing physical functioning, bodily pain, and general health between caregivers of healthy children versus those with spinal cord lesions likely reflect the physically taxing nature of caring for a child with a disability in the developing world. In the absence of day care or nursing assistance, the responsibilities for dressing, washing, and helping children move about the home and community falls solely on caregivers and may involve significant physical demands (Arango-Lasprilla et al., 2010). For example, caregivers in the present study reported physically carrying their teenaged children around the community when roads were inaccessible or too damaged for wheelchairs. Such exertions could reasonably be expected to result in poor physical health and bodily pain. Moreover, health issues among caregivers may be particularly problematic in the context of limited health insurance in Colombia, where people living in poverty may experience significant barriers to obtaining adequate treatment for health problems (World Bank, 2007).

Interestingly, analyses did not reveal significant between-group differences on SF-36 subscales assessing Role Limitations – Physical or Vitality. It may be that caregivers of children with spinal cord lesions in the present sample feel they are in poor health overall, but have no choice but to continue providing care.

Although findings indicating worse mental health-related HRQOL among caregivers of children with spinal cord lesions was consistent with some previous research (Grosse et al., 2009; Rofail et al., 2013), it was nevertheless surprising in light of the lack of significant differences in depressive and anxious symptoms observed in the present sample. As such, it is important to note that SF-36 questions assessing mental health are global in nature and do not assess specific symptoms of anxious or depressive disorders in particular (Ware & Sherbourne, 1992). It is thus possible that SF-36 scores in the present sample are reflective of more broad psychological problems in areas not captured by the PHQ-9 or BAI (e.g., stress). Indeed, substantial levels of non-disorder-specific global psychological distress have been reported among caregivers of children with spinal cord lesions (Rofail et al., 2013). In addition, caregivers of children with spinal cord lesions also reported worse functioning in terms of emotional role limitations and social activities. Previous research has indicated that caregivers of children with spinal cord lesions report reduced time to spend in relationships outside the caregiving relationship (Rofail et al., 2013), factors that may also negatively impact mental health.

5.2.3 Caregiver Burden

As predicted, caregivers of children with spinal cord lesions reported greater levels of burden on the ZBI as compared to caregivers of healthy children. In addition, caregivers of children with disabilities were significantly more likely to experience moderate to severe burden; 27% of caregivers of children with spinal cord lesions obtained scores in this range, as compared to only 7% of comparison group caregivers. Unfortunately, the lack of previous investigations using caregiving burden-specific instruments among caregivers of children with spinal cord lesions complicates direct comparisons with the existing literature.

A recent review of caregiving burden in parents of children with SB (Rofail et al., 2013) reported studies using a wide variety of instruments, including many more appropriately related to HRQOL. However, results generally indicated that even in developed nations where respite services are available, caregivers of children with spinal cord lesions spend substantial amounts of their time and energy providing care to their children, leaving little time for other activities and responsibilities (Grosse et al., 2009; Rofail et al., 2013).

Notably, the construct of burden represents psychological dysfunction combined with impairment in various life domains (e.g., work, relationships, physical health) specifically as a result of caregiving responsibilities (Baronet, 1999). As such, the finding of significant differences in burden between caregivers of children with and without spinal cord lesions is interesting in the context of non-significant differences in depression and anxiety. More specifically, the likely presence of strong social support networks among current participants would suggest that caregivers would have significant support from other adults in the community and perhaps be less responsible for care as compared to caregivers of children with disabilities in developed nations. As an explanation of these seemingly disparate findings, it is possible that caregivers of children with disabilities in the third world receive adequate psychosocial support, but little instrumental support from family and community members who are also living in poverty. In addition, caregivers of children with spinal cord lesions did report overall worse mental health-related HRQOL as compared to caregivers of healthy children; the more global nature of this domain may be better reflective of factors associated with burden. Results thus suggest that despite culture-bound protective factors that may moderate risk factors for poor mental health in caregivers, caring for a physically disabled child in the absence of financial, medical, and rehabilitative resources presents enormous burden.

5.3. Limitations

Although results of the present study are an important first step to understanding the experience of children living with spinal cord lesions and their caregivers living in developing countries like Colombia, results should be interpreted in light of several limitations. First, because there is not an established model of spinal cord lesion care in Latin America, the experience of individuals with SCI living in other more or less developed areas (and thus more or less access to resources) may be different from that of the present sample. In Colombia, as in much of the developing world, inequalities between the rich and the poor and urban versus rural residents are stark. The city of Neiva was selected for study because it is a mid-sized, mid-income city, and therefore represents a middle range of available resources. Second, the failure to find significant between-group differences in the present study may be due to power considerations imposed by the small sample size; however, given that small effect sizes were observed, it is reasonable to conclude that inadequate power did not prevent detection of between-group differences. Nevertheless, studies utilizing larger sample sizes would provide greater power to detect differences between children with and without physical disabilities, and their caregivers, in Latin America. In addition, larger sample sizes would allow more fine-grained analysis of demographic characteristics associated with risk for emotional distress among children with spinal cord lesions and their caregivers.

Third, this study was cross-sectional. It is likely that children's levels of depression, anxiety, and HRQOL could change over time given the changing needs and roles of adolescence and adulthood. Additionally, caregivers' psychosocial functioning may well change as they and their children grow older. For future research, the use of a longitudinal design would likely capture changing needs and challenges in children and their caregivers that impact mental health and HRQOL over time. Fourth, other factors that could affect acceptance of disability such as cultural issues (e.g., health and religious beliefs), family dynamics and emotional support, problem-solving orientation, and individual coping skills, were not measured in the current study. Therefore, future studies should examine relationships between Latino cultural attitudes about disability, religious beliefs, and values with mental health and HRQOL among children and caregivers with disabilities. It is possible that protective factors imposed by Latino culture would provide fruitful avenues for rehabilitation research and practice in Colombia and beyond. Fourth, although each instrument utilized in the current study had been investigated for reliability and validity in Spanish-speaking populations, it is important to note that clinical cutoffs and normative data for these instruments are largely based on U.S. samples. It is possible that the use of non-culture-specific norms could have biased rates of clinically significant anxiety, depression, burden, and poor HRQOL in the present study.

Finally, the inclusion of children with both SB and SCI in the spinal cord lesion sample may have prevented detection of differences in functioning between children with these disorders as well as the relative impact of each on children's mental health when compared to healthy controls. Although many of the same limitations are experienced by youth with SCI and SB, children with SB are likelier to experience intellectual limitations that could conceivably affect their emotional functioning and quality of life. For example, learning disorders are relatively common in children with SB (Holmbeck et al., 2010), and some research has associated these disorders for increased risk of depression and anxiety (Wilcutt & Pennington, 2000). Although no significant differences in depression, anxiety, or HRQOL were identified between children with SCI and SB in the current study, it is important to note that these comparisons may not have had adequate power to detect differences.

5.4 Implications

In terms of implications for practice, current results are encouraging in that, on the one hand, despite the myriad challenges imposed by living in poverty with a physical disability, this group of Colombian children with spinal cord lesions and their caregivers did not report greater levels of depression and anxiety as compared to peers not facing these challenges. One the other hand, both groups reported diminished HRQOL as compared to comparison-group participants, and caregivers of children with spinal cord lesions additionally experienced significantly greater burden as compared to peers caring for healthy children. Results therefore highlight the need for improved mental health service delivery in Colombia to children with spinal cord lesions and their caregivers. Access to improved medical, rehabilitative, and psychological care could profoundly impact quality of life in the spinal cord lesion child and caregiver population, particularly with regard to respite services and resources to improve children’s ability to attend school and participate in the community. In addition, parents of Colombian children with permanent physical disabilities may not expect their children to achieve normative levels of participation as compared to their healthy peers; psychoeducation would likely assist parents to understand that their children can live full lives despite their different abilities.

Finally, irrespective of group, children and caregivers reported higher levels of anxious symptomatology and poorer HRQOL as compared to children and adults in normative samples in the U. S. Children in both groups also reported low HRQOL in terms of emotional functioning, and caregivers reported elevated levels of depressive symptoms irrespective of group. Taken together, these results strongly suggest access to low-cost mental health care services are sorely needed among Colombia’s poor. Culturally appropriate psychological services should be developed and evaluated in order to determine whether such interventions could improve the physical and mental health of children and their caregivers living in Colombia and other developing countries.

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APPENDIX A. TABLES

Table 1. Child Demographic Characteristics

	SB (*n* = 22)	SCI (*n* = 8)	SCI/SB (*n* = 30)	Healthy Controls (*n* = 30)
Sex (% male)	15 (68.2%)	5 (62.5%)	20 (66.7%)	20 (66.7%)
Age (years)	12.7 (±2.8)**	16.6 (±1.2)**	13.8 (±3.0)	13.6 (±2.9)
Race/Ethnicity				
Hispanic/Latino	22 (100.0%)	8 (100.0%)	30 (100.0%)	30 (100.0%)
Socioeconomic status				
Level 1	6 (27.3%)	5 (62.5%)	11 (36.7%)	11 (36.7%)
Level 2	13 (59.1%)	3 (37.5%)	16 (53.3%)	16 (53.3%)
Level 3	2 (9.1%)	0 (0.0%)	2 (6.7%)	2 (6.7%)
Level 4	1 (4.5%)	0 (0.0%)	1 (3.3%)	1 (3.3%)
Level 5	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Level 6	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Grade	7.1 (±4.3)	11.1 (±2.8)	8.3 (±4.3)	8.2 (±2.8)
Educational setting				
Mainstreamed	16 (72.7%)	3 (37.5%)	19 (63.3%)**	29 (96.7%)**
Special education	1 (4.5%)	0 (0%)	1 (3.3%)	0 (0%)
Home school	1 (4.5%)	0 (0%)	1 (3.3%)	0 (0%)
Not attending school	4 (18.2%)	5 (62.5%)	9 (30.0%)**	1 (3.3%)**
Other	1 (4.5%)	0 (0%)	1 (3.3%)	0 (0%)

Table 2. Child Clinical Characteristics – Spinal Cord Lesion Sample

	SB	SCI	SCI/SB
	(*n* = 22)	(*n* = 8)	(*n* = 30)
Level of injury			
Paraplegic	22 (100.0%)	7 (87.5%)	29 (96.7%)
Tetraplegic	0 (0.0%)	1 (12.5%)	1 (3.3%)
Cause of Injury			
Motor vehicle accident	-	2 (25%)	-
Firearm injury	-	3 (37.5%)	-
Other (fall, etc.)	-	3 (37.5%)	-
ASIA Impairment Scale			
A	1 (4.5%)	0 (0.0%)	1 (3.3%)
B	1 (4.5%)*	4 (50.0%)*	5 (16.7%)
C	15 (68.2%)*	4 (50.0%)*	19 (63.3%)
D	5 (22.7%)	0 (0.0%)	5 (16.7%)
Time since injury (years)	-	4.6 (±5.6)	-
History of hydrocephalus	17 (77.3%)	-	-
History of Chiari malformation	7 (31.8%)	-	-
Principal means of ambulation			
Walks independently	1 (4.5%)	0 (0.0%)	1 (3.3%)
Walks with assistive device	3 (13.6%)	2 (25.0%)	5 (16.7%)
Manual wheelchair	16 (72.7%)	4 (50.0%)	20 (66.7%)
Motorized wheelchair	0 (0.0%)	1 (12.5%)	1 (3.3%)
None	2 (9.1%)	1 (12.5%)	3 (10%)
Uses assistive devices in home	16 (72.7%)	5 (62.5%)	21 (70.0%)
Wears diapers	18 (81.8%)	5 (62.5%)	23 (76.7%)
Medical complications in past year			
Pressure ulcer	3 (13.6%)	1 (12.5%)	4 (13.3%)
Urinary tract infection/kidney stones	14 (63.6%)	4 (50.0%)	18 (60.0%)
Pneumonia/respiratory complications	0 (0.0%)	1 (12.5%)	1 (3.3%)
Other	0 (0.0%)	4 (18.2%)	4 (13.3%)
Health insurance status			
Private	10 (45.5%)	3 (37.5%)	13 (43.3%)
Subsidized	10 (45.5%)	5 (33.3%)	15 (50.0%)
None	2 (9.1%)	0 (0.0%)	2 (6.7%)
Non-psychiatric medications	9 (40.9%)	3 (37.5%)	12 (40%)
Medical services received			
Mental health	4 (18.2%)	4 (50.0%)	8 (26.7%)
Psychiatric medications	0 (0%)	0 (0%)	0 (0%)
Occupational therapy	18 (81.8%)	5 (62.5%)	23 (76.7%)
Other	0 (0.0%)	0 (0.0%)	0 (0.0%)
Pain management	0 (0.0%)	0 (0.0%)	0 (0.0%)
Physical therapy	22 (100.0%)	8 (100.0%)	30 (100.0%)
Recreational therapy	0 (0.0%)	0 (0.0%)	0 (0.0%)
Surgery	4 (18.2%)	0 (0.0%)	4 (13.3%)

$*p<.05$; $**p<.01$; $***p<.001$

Table 3. Caregiver Demographic Characteristics

	SB	SCI	SCI/SB	Healthy Control
	(*n* = 22)	(*n* = 8)	(*n* = 30)	(*n* = 30)
Sex (% female)	21 (95.5%)	6 (75.0%)	27 (90.0%)	29 (96.7%)
Age (years)	42.2 (±10.1)	38.9 (±13.5)	41.3 (±11.0)	39.7 (±8.5)
Race/Ethnicity				
Hispanic/Latino	22 (100.0%)	8 (100.0%)	30 (100.0%)	30 (100.0%)
Education (years)	10.36 (±3.8)	7.13 (±2.9)	9.5 (±3.8)	10.1 (±3.2)
Socioeconomic status				
Level 1	6 (27.3%)	5 (62.5%)	11 (36.7%)	11 (36.7%)
Level 2	13 (59.1%)	3 (37.5%)	16 (53.3%)	16 (53.3%)
Level 3	2 (9.1%)	0 (0.0%)	2 (6.7%)	2 (6.7%)
Level 4	1 (4.5%)	0 (0.0%)	1 (3.3%)	1 (3.3%)
Level 5	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Level 6	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Marital status				
Single	2 (9.1%)	0 (0.0%)	2 (6.7%)	4 (13.3%)
Married	11 (50.0%)	3 (37.5%)	14 (46.7%)	11 (36.7%)
Divorced/Separated	3 (13.6%)	1 (12.5%)	4 (13.3%)	6 (20.0%)
Widowed	2 (9.1%)	1 (12.5%)	3 (10.0%)	0 (0.0%)
Other	4 (18.2%)	3 (37.5%)	7 (23.3%)	9 (30.0%)
Relationship to child				
Mother	16 (72.7%)	4 (50.0%)	20 (66.7%)	26 (86.7%)
Father	1 (4.5%)	1 (12.5%)	2 (6.7%)	1 (3.3%)
Stepmother	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.3%)
Aunt	1 (4.5%)	0 (0.0%)	1 (3.3%)	0 (0.0%)
Uncle	0 (0.0%)	1 (12.5%)	1 (3.3%)	0 (0.0%)
Grandmother	4 (18.2%)	0 (0.0%)	4 (13.3%)	1 (3.3%)
Other	0 (0.0%)	2 (25.0%)	2 (6.7%)	1 (3.3%)
Number of people in household	4.6 (±1.6)	5.1 (±1.2)	4.7 (±1.5)	4.8 (± 1.2)
Months spent caring for child	142.0 (±51.0)***	38.6 (±70.8)***	114.4 (±72.5)**	162.5 (±33.8)**
Hours per week spent caring for	73.9 (±20.0)	80.6 (±34.0)	75.7 (±24.0)**	59.1 (±13.7)**
Employed outside of caregiving	5 (22.7%)	3 (37.5%)	8 (26.7%)	15 (50%)
Public assistance	9 (36.4%)	1 (12.5%)	9 (30.0%)	5 (16.7%)
Psychiatric services - history	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Psychiatric services - current	0 (0%)	0 (0%)	0 (0%)	0 (0%)

**p<.05; **p<.01; ***p<.001*

Table 4. Comparison of SB and SCI Child Groups on Primary Outcome Measures, Controlling for Age and ASIA Score

	SB	SCI	*df*	*F*	η^2_p	*p*
	(*n* = 22)	(*n* = 8)				
Children's Depression Inventory -	11.7 (±6.3)	12.9 (±7.9)	1	0.10	0.00	0.76
CDI - Negative Mood	2.3 (±1.6)	2.5 (±1.8)	1	0.47	0.02	0.50
CDI - Interpersonal Problems	1.3 (±2.3)	1.5 (±1.8)	1	1.02	0.04	0.29
CDI - Ineffectiveness	2.5 (±1.6)	2.5 (±1.5)	1	0.35	0.01	0.70
CDI - Anhedonia	3.9 (±2.2)	4.9 (±3.7)	1	0.15	0.01	0.71
CDI - Negative Self-Esteem	1.6 (±1.4)	1.5 (±0.8)	1	1.70	0.10	0.17
RCMAS-2 - Total Score	16.7 (±6.6)	18.4 (±9.3)	1	0.08	0.00	0.78
RCMAS-2 - Physiological	5.4 (±1.8)	5.5 (±3.7)	1	0.09	0.00	0.76
RCMAS-2 - Worry	6.8 (±3.8)	7.9 (±3.8)	1	0.18	0.01	0.67
RCMAS-2 - Social Anxiety	4.6 (±2.7)	5.0 (±3.6)	1	0.01	0.00	0.92
PedsQL - Total Score	59.9 (±12.6)	56.3 (± 11.5)	1	0.06	0.00	0.81
PedsQL - Physical	51.6 (±20.2)	45.7 (±23.5)	1	0.03	0.00	0.86
PedsQL - Emotional	67.5 (±18.6)	54.4 (±22.1)	1	1.02	0.04	0.32
PedsQL - Social Functioning	69.5 (±14.2)	64.4 (±15.2)	1	0.03	0.00	0.87
PedsQL - School Functioning	56.1 (±16.1)	66.9 (±8.8)	1	2.97	0.10	0.10

$^*p<.05$; $^{**}p<.01$; $^{***}p<.001$

Table 5. Comparison of SB and SCI Caregiver Groups on Primary Outcome Measures, Controlling for Months Spent Caregiving

	SB	SCI	*df*	*F*	η^2_p	*p*
	(*n* = 22)	(*n* = 8)				
Patient Health Questionnaire-9 - Total Score	6.1 (±5.5)	7.0 (±5.9)	1	1.11	0.04	0.30
Beck Anxiety Inventory - Total Score	9.8 (±9.9)	10.4 (±8.3)	1	1.06	0.07	0.36
Zarit Burden Interview - Total Score	33.3 (±14.1)	34.5 (±23.5)	1	0.43	0.02	0.52
Short Form-36						
Physical Functioning	79.3 (±21.6)	81.88 (±16.0)	1	0.72	0.00	0.79
Role-Physical	57.1 (±43.4)	87.5 (±13.4)	1	0.66	0.03	0.43
Bodily Pain	60.8 (±28.1)	82.2 (±19.5)	1	0.76	0.03	0.39
General Health	56.2 (±21.0)	56.9 (±24.5)	1	0.07	0.00	0.79
Vitality	56.4 (±29.2)	61.9 (±31.6)	1	0.13	0.01	0.72
Social Functioning	65.5 (±25.6)	79.7 (±25.8)	1	0.24	0.01	0.63
Mental Health	63.4 (±21.1)	67.0 (±32.7)	1	0.03	0.00	0.88
Role-Emotional	63.5 (±40.7)	50.0 (±53.5)	1	1.36	0.05	0.25

*$p<.05$; **$p<.01$; ***$p<.001$

Table 6. Comparison of Children with Spinal Cord Lesions and Healthy Controls, Controlling for School Attendance

	SB/SCI	HC	*df*	*F*	η^2_p	*p*
	(n = 30)	(n = 30)				
Children's Depression Inventory -	12.0 (±6.6)	8.9 (5.0)	1	1.98	0.03	0.17
CDI - Negative Mood	2.4 (±1.6)	2.0 (±1.7)	1	0.15	0.00	0.70
CDI - Interpersonal Problems	1.4 (±2.2)	0.8 (±0.9)	1	2.13	0.04	0.15
CDI - Ineffectiveness	2.5 (±1.6)	1.8 (±1.3)	1	0.92	0.02	0.34
CDI - Anhedonia	4.1 (±2.6)	3.0 (±2.2)	1	1.18	0.02	0.28
CDI - Negative Self-Esteem	1.6 (±1.2)	1.2 (±1.3)	1	0.86	0.02	0.36
RCMAS-2 - Total Score	17.2 (±7.3)	16.6 (±6.7)	1	0.13	0.00	0.73
RCMAS-2 - Physiological	5.4 (±2.4)	3.9 (±2.1)	1	5.67	0.09	0.02*
RCMAS-2 - Worry	7.1 (±3.8)	8.67 (±3.6)	1	1.94	0.03	0.17
RCMAS-2 - Social Anxiety	4.7 (±2.9)	4.0 (±2.9)	1	0.60	0.01	0.44
PedsQL - Total Score	58.9 (±12.2)	78.7 (±11.4)	1	29.30	0.34	<.001***
PedsQL - Physical	50.0 (±20.9)	86.5 (±14.4)	1	49.16	0.46	<.001***
PedsQL - Emotional	64.0 (±20.1)	67.2 (±15.5)	1	0.06	0.00	0.81
PedsQL - Social Functioning	68.2 (±14.4)	82.0 (±14.8)	1	8.78	0.13	<.01**
PedsQL - School Functioning	59.0 (±15.2)	74.3 (±16.5)	1	7.72	0.12	<.01**

$*p<.05$; $**p<.01$; $***p<.001$

Table 7. Comparison of Caregivers of Children with and without Spinal Cord Lesions

	SB (*n* = 22)	HC (*n* = 8)	*df*	*F*	η^2_p	*p*
Patient Health Questionnaire-9 - Total Score	6.3 (±5.6)	5.0 (±5.8)	1	0.86	0.02	0.36
Beck Anxiety Inventory - Total Score	10.1 (±9.5)	7.0 (±9.4)	1	1.52	0.03	0.22
Zarit Burden Interview - Total Score	33.4 (±16.9)	20.1 (±9.4)	1	14.04	0.20	<.001***
Short Form-36						
Physical Functioning	80.0 (±20.0)	94.5 (±10.9)	1	12.05	0.17	<.001***
Role-Physical	65.5 (±39.8)	81.7 (±32.1)	1	3.00	0.05	0.09
Bodily Pain	66.7 (±27.5)	83.3 (±23.3)	1	6.29	0.10	0.02*
General Health	56.4 (±21.6)	67.5 (±14.2)	1	5.49	0.09	0.02*
Vitality	57.9 (±29.4)	69.8 (±22.6)	1	3.04	0.05	0.09
Social Functioning	69.4 (±26.0)	90.4 (±17.9)	1	13.17	0.19	<.001***
Mental Health	64.4 (±24.3)	78.3 (±22.9)	1	5.10	0.08	0.03*
Role-Emotional	59.8 (±44.0)	82.2 (±59.8)	1	5.14	0.08	0.03*

**p<.05; **p<.01; ***p<.001*

APPENDIX B. INSTRUMENTS

Demographic Interview

Interviewer instructions: If possible, please conduct the following interview with the child and caregiver together. Especially if the caregiver is not the child's parent and/or has not been providing care for a significant period of time, children may be able to provide additional information that the caregiver cannot.

Who is completing this form?
_____ Caregiver
_____ Caregiver and patient together

I. Child Information

1. What is the child's race?
   _____ Caucasian
   _____ Black
2. How old is the child? _______
3. How was the child injured?
   ____ During birth
   ____ Motor vehicle accident (passenger)
   ____ Hit by a car (pedestrian)
   ____ Playing sports
   ____ Recreational activity (diving)
   ____ Fall
   ____ Firearm injury
   ____ Struck by something
   ____ Struck by someone
   ____ Shaken
   ____ Other (please describe):____
4. Was the child injured intentionally by someone else?
   ____ No, my child was injured accidentally (non-violence)
   ____ Yes, my child was intentionally injured by someone else (violence)
   ____ Yes, my child intentionally injured himself or herself (violence)
   ____ I don't know
5. What was the child's educational setting just prior to injury?
   _____ Regular program in regular school
   _____ Special program in regular school
   _____ Special school
   _____ Home schooling
   _____ Not attending school (Reason?):____________________________________
   _____ Other (Please list):____
6. Did the child receive special education services before being injured?
   _____ No
   _____ Yes
   _____ n/a – child was not in school
7. If yes, for what reason? (Please check all that apply)
   _____ Attention Deficit Hyperactivity Disorder
   _____ Difficulty with behavior
   _____ Learning Delays/Disability
   _____ Physical or other health impairment
   _____ Other (Please list): ________________________________

_____ Not applicable

8. In what grade was the child when he/she suffered the injury? (If injury occurred during summer or between school terms, mark the last grade he/she completed before injury)? ________

9. At any point prior to the child's injury, was the child ever held back in school?
_____ No
_____ Yes (Reason?): _________________________

10. At any point prior to the child's injury, did he/she child ever receive counseling or psychiatric services?
_____ No
_____ Yes (Reason?):____

11. At any point prior to the child's injury, was he/she ever prescribed medications for emotional, psychological, or behavioral reasons?
_____ No
_____ Yes (Reason?): __________________

12. Is the child paraplegic or tetraplegic (quadriplegic)?
____ Paraplegic
____ Tetraplegic (quadriplegic)

13. In the past year, has the child had any medical complications (e.g., pressure sores)?
_____ No
_____ Yes

14. If yes, select all that apply:
_____ Surgery
_____ Pressure sore
_____ Urine infection/stones
_____ Skin infection
_____ Fracture
_____ Pneumonia/respiratory complications
_____ Other (Please list): ____
_____ Not applicable

15. Does the child wear diapers?
____ No
____ Yes

16. If yes, how often?
____ 24 hours/day
____ Overnight only
____ Other: __________________________
____ Not applicable

17. Does the child require assistance to breathe?
____ No
____ Yes

18. When the child was injured, approximately how many days did he/she spend in the hospital?
____

19. Since the child was released after the initial injury, has he/she been admitted to the hospital?
____ No
____ Yes (1 time)
____ Yes (multiple times)

20. If yes, approximately how many days has he/she spent in the hospital after being discharged following the initial injury? __________ Not applicable _____

21. If yes, for what condition(s) has he/she been hospitalized?
_____ Surgery

_____ Pressure sore
_____ Urine infection/stones
_____ Skin infection
_____ Fracture
_____ Pneumonia/respiratory complications
_____ Other (Please list): _______________________________
_____ Not applicable

22. What is the child's current educational setting?
    _____ Regular program in regular school
    _____ Special program in regular school
    _____ Special school
    _____ Home schooling
    _____ Not attending school (Reason?):_____________________
    _____ Other (Please list):______________________________________
23. Does the child currently receive special education services?
    _____ n/a – child not in school
    _____ No
    _____ Yes
24. If yes, for what reason? (Please check all that apply)
    _____ Attention Deficit Hyperactivity Disorder
    _____ Difficulty with behavior
    _____ Learning Delays/Disability
    _____ Physical or other health impairment
    _____ Other (Please list): ______________________________________
    _____ Not applicable
25. What is the child's current grade level in school? __________
26. How does the child's current school performance compare to his/her pre-injury school performance?
    _____ He/She is doing better now in school
    _____ He/She is doing about the same now in school
    _____ He/She is doing worse now in school
27. Since the child's injury, has he/she been held back in school?
    _____ No
    _____ Yes (Reason?): __________________________________
28. Does the child currently work in an employment setting outside of school?
    _____ No
    _____ Yes
29. If yes: About how many hours per week? ____Not applicable _____
30. What is the child's primary means of mobility? (i.e., What do they use 75% of the time?)
    _____ Walks independently without braces, crutches, or walker
    _____ Walks with assistance
    _____ Braces
    _____ Braces with assistive device (e.g., crutches or walker)
    _____ Crutches
    _____ Walker
    _____ Uses manual wheelchair
    _____ Uses motorized wheelchair
    _____ Stroller
    _____ Other (Please list): ______________________________________
31. If the child uses a manual wheelchair, is he/she able to use it independently (that is, without being pushed by you or someone else)?

_____ Yes
_____ No
_____ Not applicable

32. At any point since the child’s injury, has he/she received mental health services (i.e., counseling)?
    _____ No
    _____ Yes (Reason?): ____________________________
33. If yes, is the child currently receiving mental health services?
    _____ No
    _____ Yes (Reason?): _____________________________
    _____ Not applicable
34. Since the child’s injury, has he/she been prescribed psychiatric medications for emotional, psychological, or behavioral reasons?
    _____ No
    _____ Yes (Reason?): ____________________________
35. If yes, is the child currently taking medications?
    _____ No
    _____ Yes (For what reason?): ____________________________
    _____ Not applicable
36. Has the child received any of the below services?
    _____ Physical therapy
    _____ Occupational therapy
    _____ Recreational therapy
    _____ Pain management
37. If one or more of these services was not received by the child, why not?
    _____ He/she doesn’t need them
    _____ They aren’t available
    _____ Other (please write reason: __________________________________)
    _____ Not applicable
38. Does the child use assistive devices in the home (for example: chair lift, handicap-accessible toilet or shower)?
    _____ Yes
    _____ No
39. If the child does not use these devices, why not?
    _____ He/she doesn’t need assistive devices
    _____ They aren’t available
    _____ Other (please write reason:__________________________________)
    _____ Not applicable
40. Does the child have health insurance?
    _____ Yes
    _____ No
41. Is the child currently taking other medications besides non-psychological or psychiatric medications regularly?
    _____ Yes (Please list: ____)
    _____ No
42. Who supports the child financially?
    _____ Parent(s) (may or may not include caregiver being interviewed)
    _____ Other family members (may or may not include caregiver being interviewed)
    _____ Public assistance
    _____ Child is self-employed
    _____ Other (describe: ____)

43. What is the child’s current socioeconomic status?
    ____ Level 1
    ____ Level 2
    ____ Level 3
    ____ Level 4
    ____ Level 5
    ____ Level 6
    ____ Don’t know

II. Caregiver Information

44. What is your race?
    _____ Caucasian
    _____ Black
45. What is your relationship to the child?
    _____Mother ____Father
    _____Stepmother ____Stepfather
    _____Foster mother ____Foster father
    _____Aunt ____Uncle
    _____Grandmother ____Grandfather
    _____Other (Please list): ________________________________
46. What is your gender?
    _____ Male
    _____ Female
47. What is your age? _____
48. Do you live with the child?
    _____ Yes
    _____ No
49. Which statement best represents your relationship status?
    _____ Never married
    _____ Married/Civil union
    _____ Separated
    _____ Divorced
    _____ Widowed
    _____ Other (Please list):
50. At any point prior to the child’s injury, did you ever receive counseling or psychiatric services?
    _____ No
    _____ Yes (Reason?): ____

51. At any point prior to the child’s injury, were you ever prescribed psychiatric medications for your own emotional, psychological, or behavioral reasons?
    _____ No
    _____ Yes (Reason?): ____

52. Approximately how long, in months, have you been the child’s primary caregiver?__________
53. Approximately how many hours per week do you spend caring for the child? ______________
54. Including you, how many other people are currently living in your household? ____________

55. How many years of education do you have? ______________
56. Are you currently employed outside the home?
    _____ No
    _____Yes
57. If yes, what is your occupation? _________________________________ Not applicable ____
58. If yes, what is your employment status?
    _____ Part-time
    _____ Full-time
    _____ Not applicable
59. If no, do you receive public assistance?
    _____ No
    _____ Yes
    _____ Not applicable
60. Is there another financial contributor to your household (e.g., spouse, parent, other family member)?
    _____ No
    _____ Yes
61. What is your current socioeconomic status?
    ____ Level 1
    ____ Level 2
    ____ Level 3
    ____ Level 4
    ____ Level 5
    ____ Level 6
    ____ Don't know
62. Do you have reliable transportation?
    _____ No
    _____ Yes
63. Since your child's injury, have you received counseling or psychiatric services?
    _____ No
    _____ Yes (Reason?): ____

64. If yes, are you currently receiving services?
    _____ No
    _____ Yes (Reason?): ____
    _____ Not applicable
65. Since your child's injury, have you been prescribed psychiatric medications for emotional, psychological, or behavioral reasons?
    _____ No
    _____ Yes (Reason?): ____

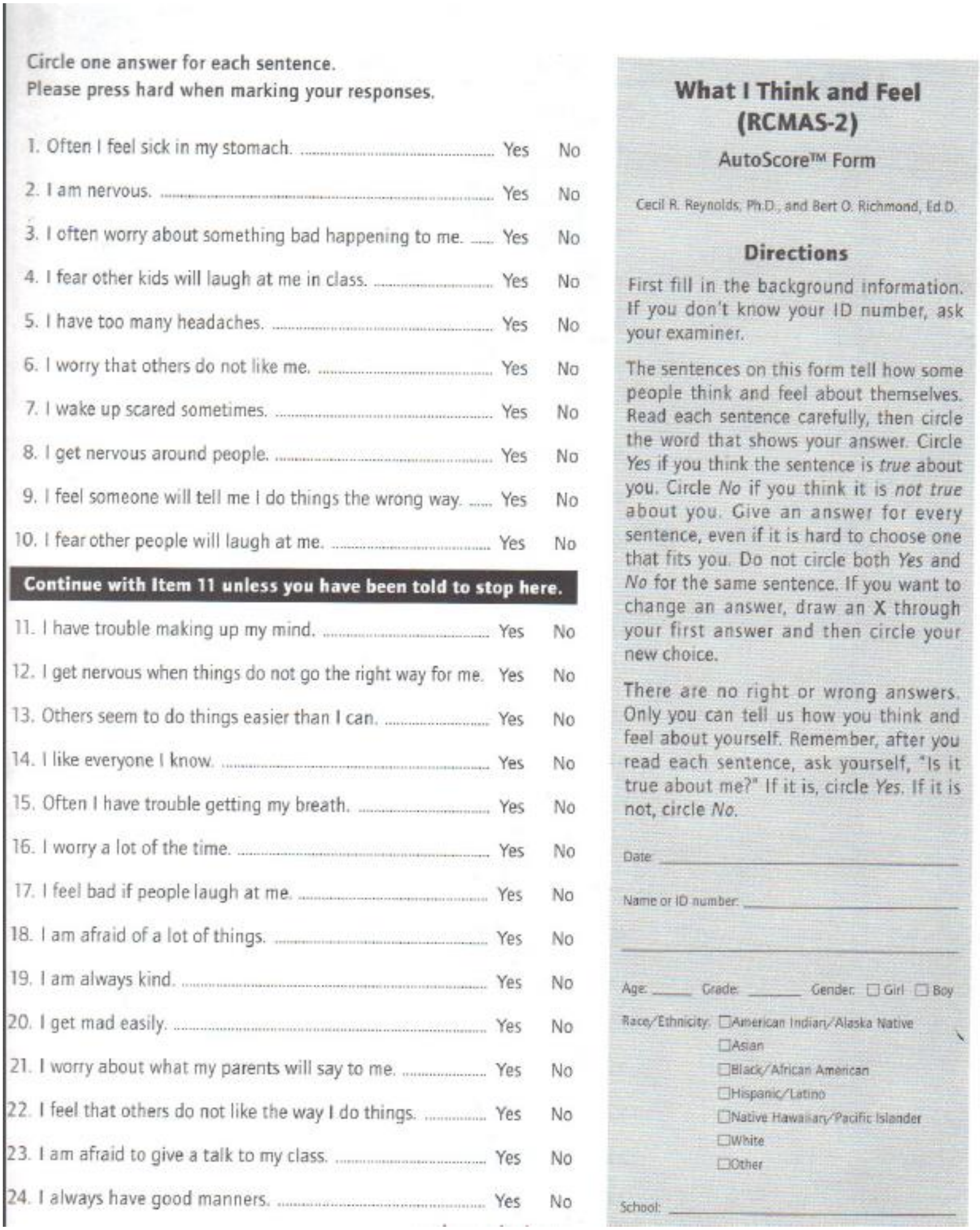
66. If yes, are you currently taking medications?
    _____ No
    _____ Yes (Reason?): ____
    _____ Not applicable

Children’s Depression Inventory.

1. I am sad once in awhile.
   I am sad many times.
   I am sad all the time.
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.
3. I do most things O.K.
   I do many things wrong.
   I do everything wrong.
4. I have fun in many things.
   I have fun in some things.
   Nothing is fun at all.
5. I am bad all the time.
   I am bad many times.
   I am bad once in a while.
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.
7. I hate myself.
   I do not like myself.
   I like myself.
8. All bad things are my fault.
   Many bad things are my fault.
   Bad things are not usually my fault.
9. I do not think about killing myself.
   I think about killing myself but I would not do it.
   I want to kill myself.
10. I feel like crying every day.
    I feel like crying many days.
    I feel like crying once in a while.
11. Things bother me all the time.
    Things bother me many times.
    Things bother me once in a while.
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.
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.
14. I look O.K.
    There are some bad things about my looks.
    I look ugly.
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.
16. I have trouble sleeping every night.
    I have trouble sleeping many nights.
    I sleep pretty well.
17. I am tired once in a while.
    I am tired many days.
    I am tired all the time.
18. Most days I do not feel like eating.
    Many days I do not feel like eating.
    I eat pretty well.
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.
20. I do not feel alone.
    I feel alone many times.
    I feel alone all the time.
21. I never have fun at school.
    I have fun at school only once in a while.
    I have fun at school many times.
22. I have plenty of friends.
    I have some friends but I wish I had more.
    I do not have any friends.
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.
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.
25. Nobody really loves me.
I am not sure if anybody loves me.
I am sure that somebody loves me.
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.
27. I get along with people.
I get into fights many times.
I get into fights all the time.

Revised Children's Manifest Anxiety Scale – 2



Circle one answer for each sentence.
Please press hard when marking your responses.

1. Often I feel sick in my stomach. .... Yes No
2. I am nervous. .... Yes No
3. I often worry about something bad happening to me. .... Yes No
4. I fear other kids will laugh at me in class. .... Yes No
5. I have too many headaches. .... Yes No
6. I worry that others do not like me. .... Yes No
7. I wake up scared sometimes. .... Yes No
8. I get nervous around people. .... Yes No
9. I feel someone will tell me I do things the wrong way. .... Yes No
10. I fear other people will laugh at me. .... Yes No

Continue with Item 11 unless you have been told to stop here.

11. I have trouble making up my mind. .... Yes No
12. I get nervous when things do not go the right way for me. Yes No
13. Others seem to do things easier than I can. .... Yes No
14. I like everyone I know. .... Yes No
15. Often I have trouble getting my breath. .... Yes No
16. I worry a lot of the time. .... Yes No
17. I feel bad if people laugh at me. .... Yes No
18. I am afraid of a lot of things. .... Yes No
19. I am always kind. .... Yes No
20. I get mad easily. .... Yes No
21. I worry about what my parents will say to me. .... Yes No
22. I feel that others do not like the way I do things. .... Yes No
23. I am afraid to give a talk to my class. .... Yes No
24. I always have good manners. .... Yes No

What I Think and Feel (RCMAS-2)

AutoScore™ Form

Cecil R. Reynolds, Ph.D., and Bert O. Richmond, Ed.D.

Directions

First fill in the background information. If you don't know your ID number, ask your examiner.

The sentences on this form tell how some people think and feel about themselves. Read each sentence carefully, then circle the word that shows your answer. Circle *Yes* if you think the sentence is *true* about you. Circle *No* if you think it is *not true* about you. Give an answer for every sentence, even if it is hard to choose one that fits you. Do not circle both *Yes* and *No* for the same sentence. If you want to change an answer, draw an **X** through your first answer and then circle your new choice.

There are no right or wrong answers. Only you can tell us how you think and feel about yourself. Remember, after you read each sentence, ask yourself, "Is it true about me?" If it is, circle *Yes*. If it is not, circle *No*.

Date: ____________________

Name or ID number: ____________________

____

Age: ____ Grade: ____ Gender: ☐ Girl ☐ Boy

Race/Ethnicity: ☐ American Indian/Alaska Native
☐ Asian
☐ Black/African American
☐ Hispanic/Latino
☐ Native Hawaiian/Pacific Islander
☐ White
☐ Other

School: ____________________

25. It is hard for me to get to sleep at night. .... Yes No
26. I worry about what other people think about me. .... Yes No
27. I feel alone even when there are people with me. .... Yes No
28. I get teased at school. .... Yes No
29. I am always good. .... Yes No
30. My feelings get hurt easily. .... Yes No
31. My hands feel sweaty. .... Yes No
32. I worry about making mistakes in front of people. .... Yes No
33. I am always nice to everyone. .... Yes No
34. I am tired a lot. .... Yes No
35. I worry about what is going to happen. .... Yes No
36. Other people are happier than I am. .... Yes No
37. I am afraid to speak up in a group. .... Yes No
38. I tell the truth every single time. .... Yes No
39. I have bad dreams. .... Yes No
40. I get angry sometimes. .... Yes No
41. I worry about being called on in class. .... Yes No
42. I worry when I go to bed at night. .... Yes No
43. It is hard for me to keep my mind on my schoolwork. .... Yes No
44. I sometimes say things I should not say. .... Yes No
45. I worry about someone beating me up. .... Yes No
46. I wiggle in my seat a lot. .... Yes No
47. A lot of people are against me. .... Yes No
48. I have told a lie. .... Yes No
49. I worry about saying something dumb. .... Yes No

PedsQL

In the past ***ONE month****, how much of a* ***problem*** *has this been for you …*

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

In the past ***ONE month****, how much of a* ***problem*** *has this been for you …*

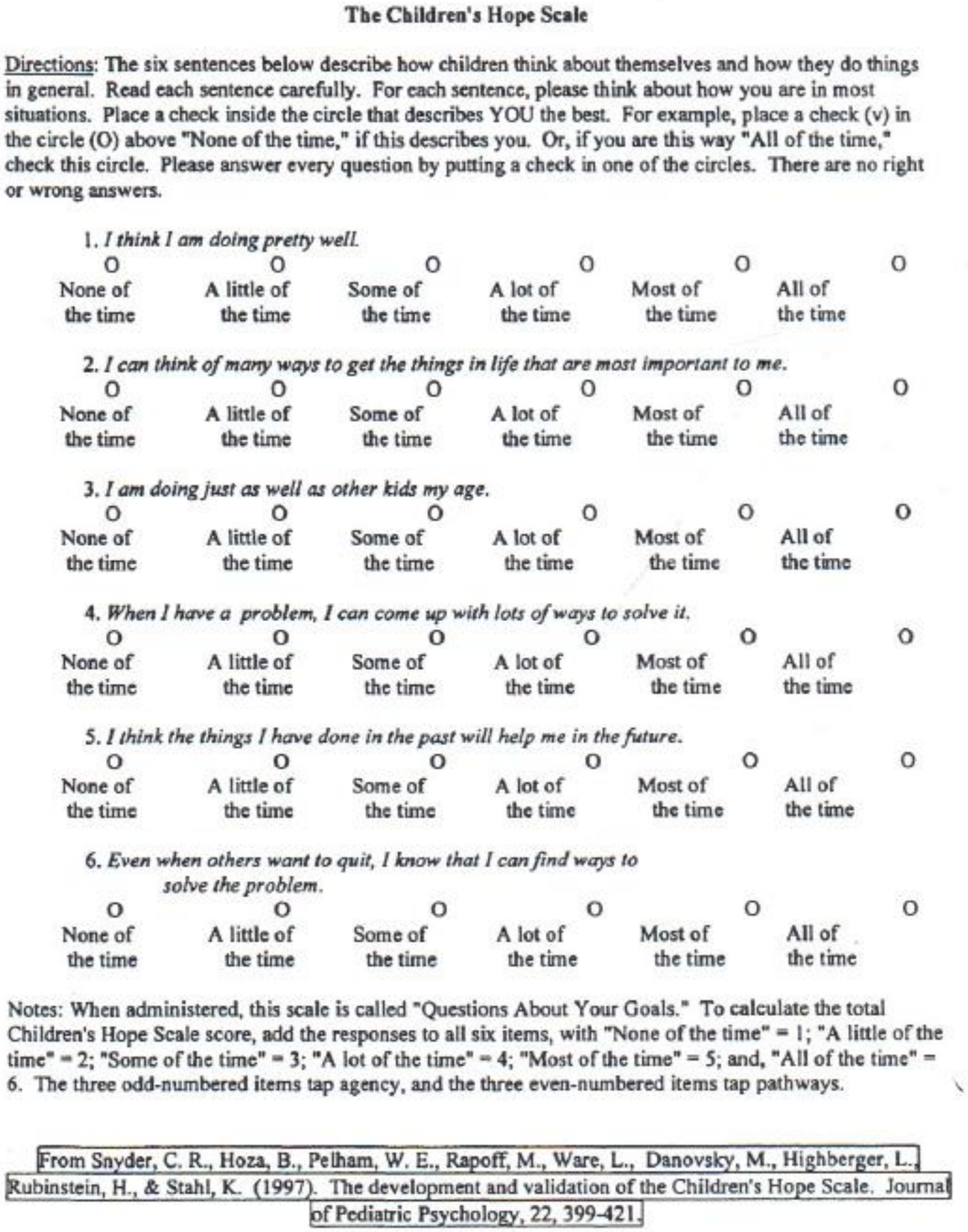
ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT SCHOOL *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

Children's Hope Scale



The Children's Hope Scale

Directions: The six sentences below describe how children think about themselves and how they do things in general. Read each sentence carefully. For each sentence, please think about how you are in most situations. Place a check inside the circle that describes YOU the best. For example, place a check (v) in the circle (O) above "None of the time," if this describes you. Or, if you are this way "All of the time," check this circle. Please answer every question by putting a check in one of the circles. There are no right or wrong answers.

1. *I think I am doing pretty well.*

O	O	O	O	O	O	O
None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time	

2. *I can think of many ways to get the things in life that are most important to me.*

O	O	O	O	O	O	O
None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time	

3. *I am doing just as well as other kids my age.*

O	O	O	O	O	O	O
None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time	

4. *When I have a problem, I can come up with lots of ways to solve it.*

O	O	O	O	O	O	O
None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time	

5. *I think the things I have done in the past will help me in the future.*

O	O	O	O	O	O	O
None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time	

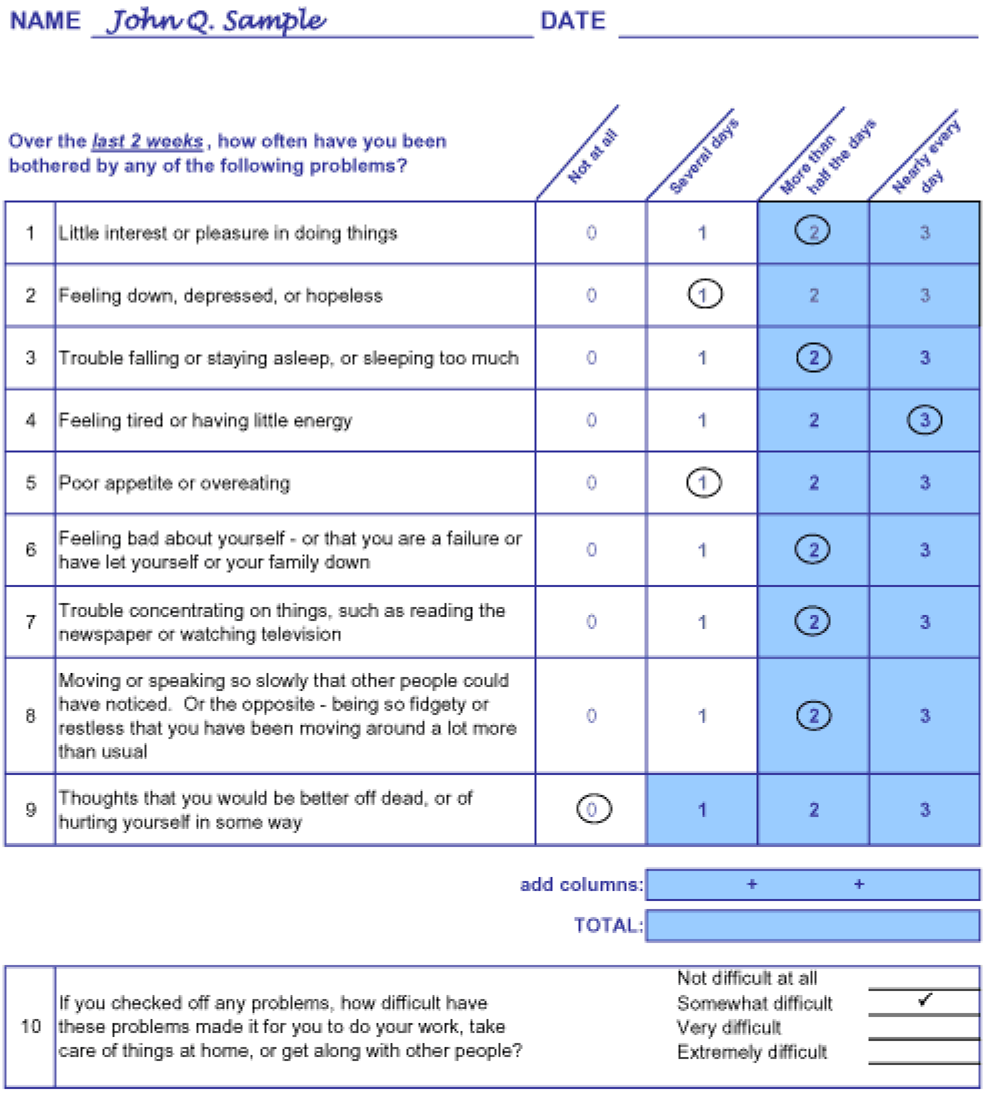
6. *Even when others want to quit, I know that I can find ways to solve the problem.*

O	O	O	O	O	O	O
None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time	

Notes: When administered, this scale is called "Questions About Your Goals." To calculate the total Children's Hope Scale score, add the responses to all six items, with "None of the time" = 1; "A little of the time" = 2; "Some of the time" = 3; "A lot of the time" = 4; "Most of the time" = 5; and, "All of the time" = 6. The three odd-numbered items tap agency, and the three even-numbered items tap pathways.

From Snyder, C. R., Hoza, B., Pelham, W. E., Rapoff, M., Ware, L., Danovsky, M., Highberger, L., Rubinstein, H., & Stahl, K. (1997). The development and validation of the Children's Hope Scale. Journal of Pediatric Psychology, 22, 399-421.

Patient Health Questionnaire-9



NAME John Q. Sample DATE

Over the *last 2 weeks*, how often have you been bothered by any of the following problems?

		Not at all	Several days	More than half the days	Nearly every day
1	Little interest or pleasure in doing things	0	1	[✓ 2]	3
2	Feeling down, depressed, or hopeless	0	[✓ 1]	2	3
3	Trouble falling or staying asleep, or sleeping too much	0	1	[✓ 2]	3
4	Feeling tired or having little energy	0	1	2	[✓ 3]
5	Poor appetite or overeating	0	[✓ 1]	2	3
6	Feeling bad about yourself - or that you are a failure or have let yourself or your family down	0	1	[✓ 2]	3
7	Trouble concentrating on things, such as reading the newspaper or watching television	0	1	[✓ 2]	3
8	Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	0	1	[✓ 2]	3
9	Thoughts that you would be better off dead, or of hurting yourself in some way	[✓ 0]	1	2	3
		add columns:		+	+
		TOTAL:			

10	If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	
		Somewhat difficult	✓
		Very difficult	
		Extremely difficult	

Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

	Not At All	Mildly but it didn't bother me much.	Moderately - it wasn't pleasant at times	Severely – it bothered me a lot
Numbness or tingling	0	1	2	3
Feeling hot	0	1	2	3
Wobbliness in legs	0	1	2	3
Unable to relax	0	1	2	3
Fear of worst happening	0	1	2	3
Dizzy or lightheaded	0	1	2	3
Heart pounding/racing	0	1	2	3
Unsteady	0	1	2	3
Terrified or afraid	0	1	2	3
Nervous	0	1	2	3
Feeling of choking	0	1	2	3
Hands trembling	0	1	2	3
Shaky / unsteady	0	1	2	3
Fear of losing control	0	1	2	3
Difficulty in breathing	0	1	2	3
Fear of dying	0	1	2	3
Scared	0	1	2	3
Indigestion	0	1	2	3
Faint / lightheaded	0	1	2	3
Face flushed	0	1	2	3
Hot/cold sweats	0	1	2	3
Column Sum				

Scoring - Sum each column. Then sum the column totals to achieve a grand score. Write that score here ____________ .

SF-36

Medical Outcomes Study: 36-Item Short Form Survey Instrument
RAND 36-Item Health Survey 1.0 Questionnaire Items

1. In general, would you say your health is:	
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. **Compared to one year ago**, how would your rate your health in general **now**?	
Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

(Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	[1]	[2]	[3]
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
5. Lifting or carrying groceries	[1]	[2]	[3]
6. Climbing **several** flights of stairs	[1]	[2]	[3]
7. Climbing **one** flight of stairs	[1]	[2]	[3]
8. Bending, kneeling, or stooping	[1]	[2]	[3]
9. Walking **more than a mile**	[1]	[2]	[3]
10. Walking **several blocks**	[1]	[2]	[3]
11. Walking **one block**	[1]	[2]	[3]

12. Bathing or dressing yourself	[1]	[2]	[3]

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?
(Circle One Number on Each Line)

	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. **Accomplished less** than you would like	1	2
15. Were limited in the **kind** of work or other activities	1	2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks,** have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?
(Circle One Number on Each Line)

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	1	2
18. **Accomplished less** than you would like	1	2
19. Didn't do work or other activities as **carefully** as usual	1	2

20. During the **past 4 weeks,** to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
(Circle One Number)
Not at all 1 Slightly 2 Moderately 3 Quite a bit 4 Extremely 5

21. How much **bodily** pain have you had during the **past 4 weeks**?
(Circle One Number)
None 1 Very mild 2 Mild 3 Moderate 4 Severe 5 Very severe 6

22. During the **past 4 weeks,** how much did **pain** interfere with your normal work (including both work outside the home and housework)?
(Circle One Number)
Not at all 1 A little bit 2 Moderately 3 Quite a bit 4 Extremely 5

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6

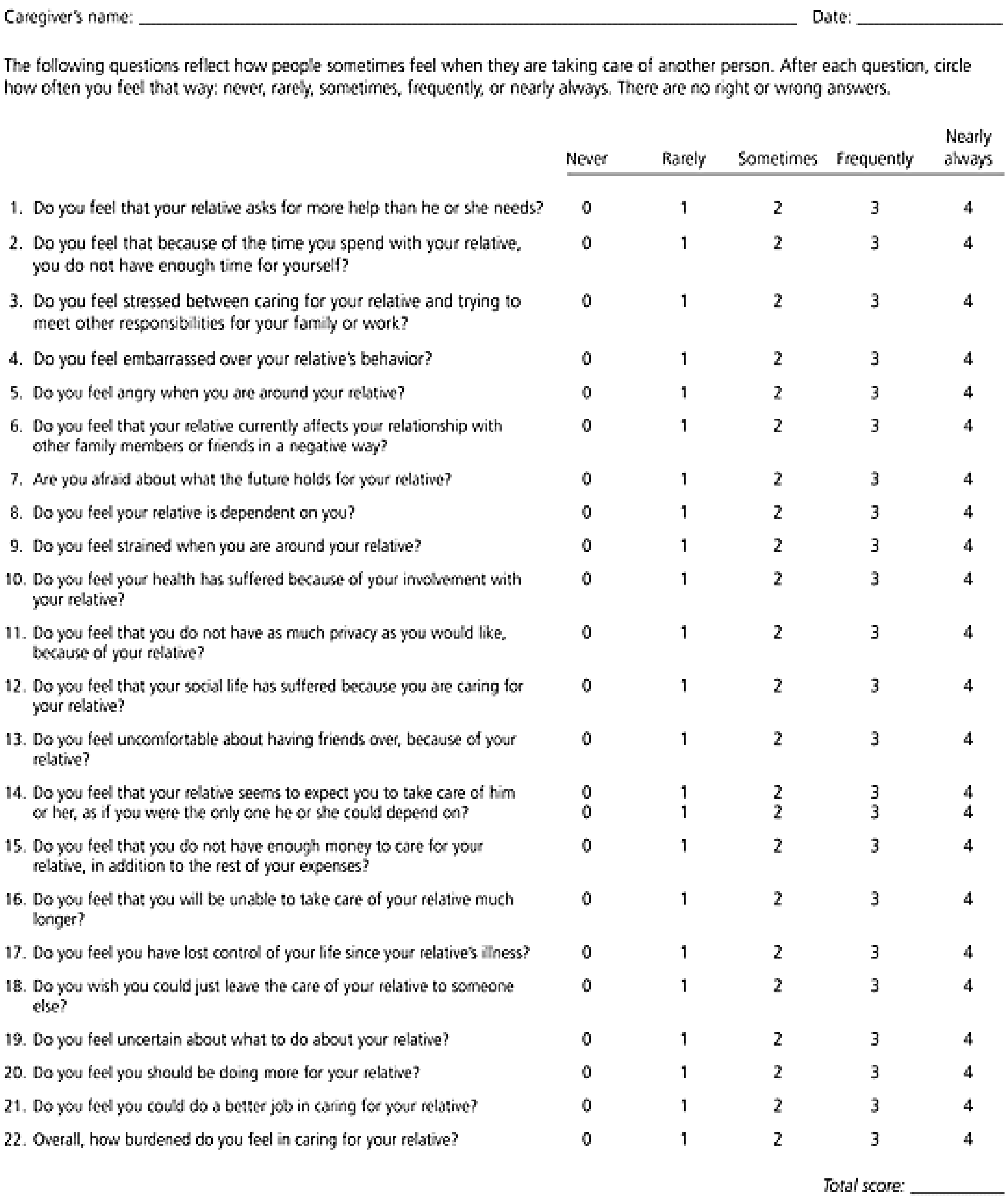
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the **past 4 weeks,** how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?
(Circle One Number)
All of the time 1 Most of the time 2 Some of the time 3 A little of the time 4 None of the time 5

How TRUE or FALSE is <u>each</u> of the following statements for you.
(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

Zarit Burden Interview



Caregiver's name: ______________________________ Date: ______________

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0 0	1 1	2 2	3 3	4 4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score: __________