May 2015

Predicting Parent Health-related Quality of Life in a Community Sample: a Cumulative Risk Model

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PREDICTING PARENT HEALTH-RELATED QUALITY OF LIFE IN A COMMUNITY SAMPLE: A CUMULATIVE RISK MODEL

by

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A Thesis Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Master of Science

in Psychology

at

The University of Wisconsin-Milwaukee

May 2015

ABSTRACT
PREDICTING PARENT HEALTH-RELATED QUALITY OF LIFE IN A COMMUNITY SAMPLE:
A CUMULATIVE RISK MODEL

by

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The University of Wisconsin-Milwaukee, 2015
Under the Supervision of Professor W. Hobart Davies

National surveys estimate that nearly 30% of children have at least one chronic medical condition and the prevalence is likely to continue to increase. This trend has drawn attention to improving child and parent quality of life in families affected by pediatric chronic conditions. Health-related quality of life (HRQoL) of parental caregivers has been tied to poorer child functioning as well as parent mental health concerns across pediatric conditions. Several predictors of poor Parental HRQoL consistently emerge: single parent status; low socioeconomic status; poor general family functioning; lower child HRQoL; and a lack of social support. The current study evaluated the combined effect of multiple risk factors for poor parental HRQoL using a cumulative risk index (CRI). Such a model for parental functioning may provide a more systemic understanding of HRQoL in the context of pediatric chronic illness broadly. The current study compared linear and quadratic cumulative risk models in predicting parent HRQoL. A linear CRI model was found to account for variance in parent HRQoL beyond that accounted for by individual risk factors. The quadratic model of risk was not supported. Results indicate standard pediatric practice should involve a comprehensive evaluation of the relative risks in the parent's environment because of the close relationship with child functioning.

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Predicting Parent Health-Related Quality of Life in a Community Sample: A Cumulative Risk Model

The National Longitudinal Survey of Youth-Child Cohort indicates that the prevalence of pediatric chronic conditions has increased from 12.8% in 1988 to 26.6% in 2006 (Van Cleave, Gortmaker, & Perrin, 2010). Based on this estimate, approximately 9.5 million families in the United States have a child with a chronic illness. Additionally, it is well understood that pediatric chronic illnesses cause a significant amount of immediate distress for both the child and their family members relative to families of healthy children (e.g. Cousino & Hazen, 2013; Herzer et al., 2010; Palermo, 2000; Palermo & Eccleston, 2009). The distress associated with parenting a child with a chronic illness is well captured by the concept of health-related quality of life (HRQoL) due to the wide variety of life domains affected for these parents. Across chronic conditions, parents report impaired HRQoL and prior research has identified numerous individual risk factors for poorer parental outcomes (Broger & Zeni, 2011; Cohen, Vowles, & Eccleston, 2010; Dardas & Ahmad, 2014; Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; Gavin & Wysocki, 2006; Gray, Graef, Schuman, Janicke, & Hommel, 2013; Halterman et al., 2004; Huang, Chang, Chi, & Lai, 2014; Janicke, Mitchel, & Stark, 2005; Mullins et al., 2011; Wallander & Varni, 1998). At present, no attempt has been made to evaluate the combined effect of multiple risk factors for poor parental HRQoL across chronic conditions. It is the aim of this study to develop and evaluate a comprehensive cumulative risk model predicting parental HRQoL that can be applied across pediatric chronic conditions.

First, the current literature on parental health-related quality of life in the context of pediatric chronic illness will be reviewed. Secondly, the Disability-Stress Coping Model (Wallander & Varni, 1992) will be considered as a theoretical framework for the current proposal. Subsequently, the previously identified risk factors for poorer parental HRQoL across chronic conditions will be examined. Next, the existing cumulative risk models in the pediatric psychology literature will be evaluated, with a specific emphasis upon how these models can be broadened to predict HRQoL in parents of children with a variety of chronic illnesses. Finally, the specific cumulative risk model currently proposed will be defined, and the methods planned to complete the study will be outlined.

Parental Health-Related Quality of Life and Pediatric Chronic Illness

Before examining the impact of HRQoL impairments associated with parenting a chronically ill child, the concept of a chronic illness must first be defined. The definition of a chronic condition has changed substantially over time, becoming increasingly broad (Halfon & Newacheck, 2010; Newacheck & Taylor, 1992; Van Cleave, Gortmaker, & Perrin, 2010). A variety of definitions of chronic conditions are in use at present, which may explain the range of prevalence estimates currently available. Specifically, prevalence rates of chronic conditions vary from 10-30% (Halfon & Newacheck, 2010; Hunfeld et al., 2001). For the purposes of the current proposal, a chronic condition will be defined as any medical condition lasting longer than six months. This definition is similar to the inclusion criteria used in most psychological research (e.g. Herzer et al., 2010) and will include conditions such as asthma, inflammatory bowel disease (IBD), food allergies, Type 1 Diabetes (T1D), and chronic pain.

Health-related quality of life (HRQoL) is a multidimensional concept representing how individuals subjectively perceive the impact of health on their physical and psychosocial functioning in a number of life domains (Matza, Swensen, Flood, Secnik, & Leidy, 2004). Lower HRQoL is often associated with poor psychosocial functioning in numerous areas, such as cognitive, social, physical, and family functioning as well as increased anxiety and depression (Hatzmann, Heymans, Ferrer-I-Carbonell, van Praag, & Grootenhuis, 2008; Haverman et al., 2014; Hunfeld et al., 2001; Kunz, Greenley, & Howard 2011; Medrano, Berlin, & Davies, 2011). For example, Hatzmann and colleagues (2008) compared the self-reported health-related quality of life of parents of chronically ill children with that of parents of healthy children. In addition to reporting impaired quality of life, many parents in the study conducted by Hatzmann and colleagues reported increased negative mood and depressive symptoms. A parent was defined as at risk for a HRQoL impairment when their self-reported score fell below the 25^{th} percentile of the healthy-control sample. In this sample, parents of chronically ill children reported significantly worse HRQoL than parents of healthy children, with nearly 45% of parents being at risk for health-related quality of life impairments.

Parental health-related quality of life impairments are concerning because of the close relationship between parent functioning, child functioning, treatment adherence, and child physical health. Specifically, in a review of research regarding parents of children with chronic pain, Palermo and Eccleston (2009) state that parents generally report significant distress and an awareness that they are no longer parenting their ill-child optimally, but report an inability to behave more adaptively. Palermo and Eccleston also highlight the connection between maternal distress and increased child-reported

physical pain. According to this review, parental functioning is important in the sense that parents in this situation are highly distressed individuals who warrant attention and because parental distress is so closely tied to child health functioning and outcomes. Logan and Scharff (2005) drew similar conclusions to Palermo and Eccleston (2009), clearly linking parent behavior with child functional disability related to recurrent pain syndromes. Reciprocally, increased functional disability and disease activity in children is associated with significantly worse HRQoL in parents (Gray et al., 2013; Piazza-Waggoner, Adams, Muchant, Wilson, & Hogan, 2008). Palermo, Valrie, and Karlson (2014) summarize the bidirectional relationship between pediatric pain and parent functioning in a developmentally-oriented review of the subject. Notably, this review is specific to pediatric chronic pain, but may apply more broadly to pediatric chronic conditions generally due to the great degree of similarity in parental functioning and impairment across conditions (Broger & Zeni, 2011; Cousino & Hazen, 2013; Gavin & Wysocki, 2006; Herzer et al., 2010; Knafl & Zoeller, 2000; Medrano et al., 2011; Moreira et al., 2013; Pelchat, Lefebvre, & Bourgeois-Guerin, 2009).

Similar patterns of impairment have also been identified in a community sample of parents of children with chronic conditions (Medrano et al., 2011). For example, Medrano and colleagues evaluated the use of the PedsQL™ Family Impact Module (FIM; Varni et al., 2004), in a community sample of parents of children with or without a chronic condition. Notably, the FIM is a frequently used HRQoL measure and has been used in several studies of disease specific samples (Hainsworth, Davies, Khan, & Weisman, 2007; Mano, Khan, Ladwig, & Weisman, 2009). In the community-based study conducted by Medrano et al. (2011), parents of children with any chronic condition

reported significantly lower HRQoL and worse family functioning than parents of children without a chronic condition. The relationship between the presence of any chronic condition and reduced HRQoL is notable because it suggests that the medical details of the child's chronic condition may not be as large a predictor of parent functioning as disease-specific models have assumed (Medrano et al., 2011; Stein & Jessop, 1982).

In a similar study conducted in the Netherlands with a disease-specific sample, Haverman and colleagues (2014) reported findings consistent with those of Medrano and colleagues (2011). Namely, parents of children with active arthritis reported worse HRQoL compared to parents of healthy controls in a number of domains related to daily functioning (Haverman et al., 2014). In this sample, parents of children with arthritis reported worse cognitive functioning and increased depressed emotions compared to parents of children not currently experiencing symptoms of arthritis. Taken together, the findings of Haverman and colleagues (2014) and Medrano and colleagues (2011) suggest that the patterns of parental functioning in a disease-specific sample and the general community are similar enough that a non-disease specific model predicting HRQoL may be appropriate (Stein & Jessop, 1982).

Disability-Stress-Coping Model

Wallander and Varni (1992) proposed a non-disease specific model based on the idea that psychological adjustment in children with chronic conditions is largely independent of the nature of the illness itself. The Disability-Stress-Coping Model incorporates several broad categories of risk and resilience factors (Wallander & Varni, 1992). Risk factors include disease factors, degree of functional independence, and

psychosocial stressors. For example, **disease specific factors** would incorporate diagnosis, severity, complications, and cognitive functioning associated with the condition. Disease specific factors have been identified as risk factors for poor child and parent functioning by a number of research groups, each finding a strong statistical relationship between disease severity and treatment intensity and psychosocial functioning (Gray et al., 2013; Haverman et al., 2014; Kunz et al., 2011; Matza et al., 2006; Stein et al., 1987; Wallander et al., 1989a).

An additional risk factor for poor psychological adjustment in chronically ill children, **functional independence**, can also be conceptualized as the opposite of functional disability, which is an impairment in day-to-day functioning of the child (Palermo, 2000). The degree of child-impairment is also consistently related to poorer psychological outcomes in both the chronically ill child and their parents (Hainsworth et al., 2007; Logan & Scharff, 2005; Wallander & Varni, 1998). **Psychosocial stressors**, another risk factor for poor functioning included in Wallander and Varni's model (1992), include concepts such as pre-existing psychopathology and the occurrence of additional stressful life events. Independent research groups have also identified stress, child psychosocial functioning, and psychopathology symptoms to be related to overall psychosocial functioning in parents of children with chronic conditions (Cohen et al., 2010; Cousino & Hazen, 2013; Eccleston et al., 2004; Gray et al., 2013; Hatzman et al., 2008; Huang et al., 2014; Mano et al., 2009; Medrano et al., 2013; Pelchat et al., 2009; Wallander et al., 1989c). According to Wallander and Varni (1992), disease variable, functional independence, and psychosocial stressors should be considered together to establish a complete understanding of a child's risk for poor psychosocial outcomes.

The Disability-Stress-Coping Model also considers resilience factors such as positive intrapersonal functioning, socio-ecological, and stress-processing variables (Wallander & Varni, 1992). **Intrapersonal variables** would include baseline temperament, problem-solving competency, and motivation. While these variables have not been addressed as thoroughly in pediatric psychology, one of the primary interventions used to improve parent functioning and HRQoL is problem solving skills training (PSST; Askins et al., 2009; Eccleston, Palermo, Fisher, & Law, 2012; Law, Fisher, Fales, Noel, & Eccleston, 2014; Sahler et al., 2013; Seid, Varni, Gidwani, Gelhard, & Slymen, 2010). **Socio-ecological variables** include availability of social support, adaptation of other family members, socioeconomic status, and general functioning of the family system. These variables have been studied extensively in parents of children with chronic conditions, all studies finding relationships between the functioning of multiple family members, family resources, social support, and family functioning in general (Brown et al., 2008; Chambers, 2003; Cohen et al., 2010; Demirtepe-Sayguli & Bozo, 2011; Gavin & Wysocki, 2006; Gray et al., 2013; Herzer et al., 2010; Ievers & Drotar, 1996; Janicke, Mitchell, & Stark, 2005; Josie et al., 2007; Lewandowski et al., 2010; Mano et al., 2009; Moriera et al., 2013; Mullins et al., 2011; Palermo et al., 2000; Palermo & Chambers 2005; Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004; Wallander & Varni, 1989a; Wallander et al., 1989b; Wallander et al., 1989c). Finally, **stress-processing** variables focus on the individual's cognitive approach to stressors and utilization of effective coping strategies. Coping skills in particular have been shown to be related to parent psychosocial outcomes in parents of chronically ill children (Brand & Coetzer, 1994; Broger & Zeni, 2011; Knafl & Zoeller, 2000; Palermo

& Chambers, 2005; Pelchat, Lefebvre, & Perreault, 2003; Piazza-Waggoner et al., 2008; Wallander & Varni 1989a).

Because of the wide variety of factors considered in Wallander and Varni's (1992) conceptualization of risk and resilience, individuals may present with vastly different patterns of strengths and weaknesses. One must consider the full range of disease-related factors, individual functioning, and contextual factors to fully understand an individual's full pattern of risk and resilience (Wallander & Varni, 1998). Wallander and Varni (1992) developed this theoretical framework to conceptualize a child's chronic illness as an ongoing, persistent stressor for the child as well as family members. Although this model is primarily used to describe the adjustment of a child to his/her own chronic condition, it can be applied more broadly to account for the psychosocial functioning of family members of a child with a chronic condition given the large amount of empirical evidence of these factors similarly influencing parent and family functioning (for reviews see Chambers 2003; Cousin & Hazen, 2013; Lewandowski et al., 2010; Palermo, 2000; Pelchat et al., 2007; Wallander & Varni, 1998).

Predictors of Parental Health-Related Quality of Life

While the presence of a pediatric chronic condition increases parental risk for lower HRQoL (Medrano et al., 2011), numerous additional specific risk factors for poor parental HRQoL have been considered. Many of these variables have been studied independently of one another, despite the wide acceptance of the Disability-Stress-Coping model and other models like it (Demirtepe-Sayguli & Bozo, 2011; Gavin & Wysocki, 2006; Gray et al., 2013; Haverman et al., 2014; Holmbeck, 1997; Moos & Schaefer, 1984; Piazza-Waggoner et al., 2008; Pless & Plinkerton, 1975; Stein & Jessop,

1982; Wallander & Varni, 1992). In their review of the literature on child adjustment to chronic illnesses, Wallander and Varni's (1998) call for researchers to consider defining risk factors in non-disease specific ways to encourage evaluation of psychological adjustment beyond the confines of a single chronic illness.

Stein and Jessop (1982) similarly argued that children with varying chronic conditions are more alike than they are different. Specifically, children with chronic conditions have similar experiences of social isolation, physical limitations, and increased family burden. Stein and Jessop make a case to attend to the "whole child (p.354)" rather than treating the "diseased organ or system (p. 354)" in isolation. Their concept of a whole child includes the context in which the child lives as well as the risk and resilience factors associated with children him/herself. Contrary to the argument of Stein and Jessop (1982) and Wallander & Varni (1992), however, most research has examined relationships between risk factors and poor HRQoL in samples of parents of children with one specific chronic condition (e.g., Brand & Coetzer, 1994; Cohen, Vowles, & Eccleston, 2010; Dardas & Ahmad, 2014; Demirtepe-Sayguli & Bozo, 2011; Eccleston et al., 2004; Gray et al., 2013; Greenly & Cunningham, 2009; Halterman et al., 2004; Haverman et al., 2014; Huang et al., 2014; Hunfeld et al., 2001; Ievers & Drotar, 1996; Janicke et al., 2005; Kunz et al., 2011; Logan & Scharff, 2005; Mackner, Crandall, & Szigethy, 2006; Mano et al., 2009; Moriera et al., 2013; Piazza-Waggoner et al., 2008). Primarily, this research has been conducted with parents of children with IBD or chronic pain, though the same variables are identified as risk factors across conditions. For example, parental HRQoL has been studied frequently in samples of parents of children with pediatric IBD and chronic pain, with increasing disease severity identified as a

consistent predictor of greater impairments in parental HRQoL in both populations (Gray et al., 2013; Greenley & Cunningham, 2009; Hunfeld et al., 2001; Kunz et al., 2011).

One such study regarding the HRQoL of parents of children with a chronic condition limited the sample to mothers of children with chronic pain (Hunfeld et al., 2001). In this study, children kept diaries for three weeks reporting the frequency, duration, and intensity of their pain as a measurement of disease activity. Mothers completed the Impact on Family Scale (IFS; Stein & Jessop, 1985), which measures HRQoL in several areas including financial burden, social impact, personal strain, and coping strategy. To evaluate the hypothesis that increased disease activity would inversely affect parental HRQoL, linear regression analyses were run including only child gender and pain characteristics as predictors. A clear relationship was established such that higher intensity and frequency of pain was associated with poorer parental HRQoL. Though Hunfeld and colleagues demonstrated that disease activity and parental HRQoL are related, they do not address the potential confounds of access to social support, general family functioning, economic resources, or child adjustment.

Kunz et al. (2011) conducted a similar study to Hunfeld and colleagues (2001), examining the same variables, but recruiting exclusively parents of adolescents with Crohn's disease. In this study, disease activity was measured using the physician global assessment rating scale. Disease activity was then categorized qualitatively as either minimal or significant disease activity. Parental HRQoL was measured using the PedsQL™ Family Impact Module (FIM; Varni et al., 2004), which breaks parental HRQoL into similar subscales as used by the IFS (Stein & Jessop, 1985). Like the study by Hunfeld et al. (2001), Kunz and colleagues (2011) used linear regression modeling to

predict HRQoL, this time including both disease activity and child adjustment as predictors. Kunz et al. demonstrated that both of these predictors accounted for unique variance in parental HRQoL, but still failed to examine a comprehensive risk profile of parents.

As seen in the work by Hunfeld et al. (2001) and Kunz and colleagues (2011), most predictors are evaluated in a congruent fashion across chronic conditions and show the same relationships regardless of which chronic condition is represented in the sample or how the risk variables are measured. The consistently identified risk factors for poor HRQoL in parents of children with different chronic conditions include: perceived social support; child disease severity; general family functioning; child functioning; and single-parent status and socioeconomic status (SES) (See Brown et al., 2008, Cousino & Hazen, 2013, Herzer et al., 2010, and Pelchat, Lefebvre, & Levert, 2007 for reviews). As there is now some consensus regarding particular risk factors for poor parental HRQoL in disease-specific samples, it is important to consider how these isolated factors interact to create an overall level of risk.

Cumulative Risk Models

One method for considering the combined influence of multiple factors on a single outcome variable is to develop a cumulative risk model. Several such cumulative risk models have been developed to predict parental HRQoL in pediatric psychology, though all of these have been tested in disease specific samples (Everhart, Fiese, & Smyth, 2008; Gumidyala & Greenley, 2014; Josie, Greenley, & Drotar, 2007). A cumulative risk model assumes that it is the total number of risk factors, not the qualitative nature of each, which is related to poor adjustment (Jones, Forehand, Brody,

& Armistead, 2002). Alternative models exist to consider the influence of several variables on an outcome, namely an additive model and an indirect risk model. An additive model of risk identifies the distinct, qualitative nature of each risk factor and considers the specific influence of individual variables on adjustment. An indirect risk model postulates that more remote contextual sources of risk (e.g., SES) may influence a second tier of risk factors (e.g., parenting), though these more distal risk sources do not directly influence psychological adjustment.

Jones and colleagues (2002) compared the value of each of these three models in predicting psychosocial adjustment of African American children in single-mother families. The risk variables included in this study were community level risks such as violent deaths and crime, income below the poverty line, maternal depressive symptoms, and inadequate parenting (i.e. parent-child relationship quality and monitoring). For the cumulative risk model, high risk families, those in the bottom 30% of the sample on all measures, were assigned a score of one on each factor and all others were given a score of zero. These scores were then summed and the overall risk score was entered into a regression model controlling for maternal age and education level. For the additive model, each individual score was entered into a hierarchical regression analysis. With the indirect model, a path analysis was used with distal factors (community level risks and income) predicting proximal factors (parenting and maternal depression), which subsequently predicted outcome. In a comparison of these three models, Jones and colleagues (2002) found a clear advantage of the cumulative risk model in parsimoniously predicting psychological adjustment in at-risk children. Specifically, the

cumulative risk model accounted for significantly more variance in outcome than the other two models and used fewer predictors in a simpler model.

Similar cumulative risk models have been proposed to predict parental HRQoL in several pediatric populations (Everhart et al., 2008; Gumidyala & Greenley, 2014). Gumidyala and Greenley (2014) used a cumulative risk index (CRI) to predict parental HRQoL in parents of children with IBD. This model included disease type and activity, child psychological functioning, general family functioning, disease-specific family functioning, and socioeconomic status as risk factors. Gumidyala and Greenley's CRI calculated total risk scores as the sum of presence/absence codes for each of the individual risk factors. For example, if an individual reported an annual income below the state mean, that person would receive an additional one point toward their overall CRI score. While this approach simplified the calculation of the CRI, it minimized the naturally occurring variability in risk factors. Gumidyala and Greenley's model of cumulative risk significantly predicted parent HRQoL; however, this study may have been limited further by assuming a linear relationship between cumulative risk and parent HRQoL.

The limitation of assuming a linear relationship was evaluated previous by Everhart et al. (2008). In this study, Everhart and colleagues developed a model predicting parental HRQoL in parents of children with asthma and specifically evaluated whether a linear or quadratic cumulative risk model better predicted parent HRQoL. Their model included measures of socioeconomic status, number of parents in the household, disease severity, child quality of life, family burden, and family stress. To calculate their CRI, Everhart and colleagues computed z-scores for each individual's

score on a specific risk factor and added the z-scores. The benefit of such an approach is that it allows for consideration of protective factors, such as higher family functioning, in the computation of the CRI. Further, using z-scores maintains the degree of variability present in the sample. As a linear model, Everhart and colleagues' model negatively predicted parent HRQoL, but the quadratic model demonstrated significantly improved model fit. The work of Everhart et al. supports the commonly held idea that risk factors tend to amplify one another, leading to a quadratic decrease in HRQoL, rather than additive linear decrease (Jones et al., 2002).

The Current Proposal

The goal of the present study is to assess whether a more comprehensive CRI predicting parental HRQoL can be developed for a non-disease specific sample. Prior models have included measures of disease severity, family functioning, number of parents in the household, and stress (Everhart et al., 2008; Gumidyala & Greenley, 2014). The present model will also include child functional disability, perceived social support, and SES, all of which have been previously shown to be related to parental HRQoL (Demirtepe-Sayguli & Bozo, 2011; Hainsworth et al., 2007; Moreira et al., 2013; Mullins et al., 2011). First, the present study will evaluate the value of such a comprehensive measure of risk in predicting parental HRQoL by comparing the predictive power of the CRI with other, known predictors of parent HRQoL. Based on the findings of Everhart et al. (2008), it is proposed that this model will demonstrate a quadratic relationship with parental HRQoL; specifically that, as the CRI value doubles, the impairment in HRQoL will tend to quadruple rather than increasing according to a linear function.

Methods

Participants

Participants included 244 mothers and 69 fathers of children between the ages of 6- and 12-years-old with one or more medical condition lasting more than six months. Full demographic information for the current sample is presented in Table 1. Generally, participants were married (69%), white (84%), had a mean age of 36.1 years (*SD*=7.2), and had some college education (*M*=16.1 years, *SD*=2.27). Parents reported on primarily approximately equal numbers of male (54%) and female (46%) children. The mean age of children was 8.7 years (*SD*=2.05). The target children in the current study presented with various chronic conditions, with the most common being asthma (28%), other chronic illness (e.g. Von Willebrands, neurofibromatosis, optic gliomas, sensory processing disorder, cyclic vomiting syndrome, bilateral sensorineural hearing loss; 28%), ADHD (22%), and food allergies (21%). All participants were recruited from the community through a combined undergraduate and graduate psychology course at the University of Wisconsin-Milwaukee. Non-English speaking parents and parents of children with only significant, chronic behavioral disorders (e.g. conduct disorder, oppositional defiant disorder) were excluded from the sample.

Procedure

Participants were recruited to participate in an online survey available at surveymonkey.com by students currently enrolled in a combined undergraduate and graduate psychology course to fulfill a course requirement. Credit was given for recruiting effort and students were not be penalized for failing to recruit the required number of participants. Once participants provide informed consent, they were prompted

to provide basic demographic information and complete a series of questionnaires. Prior to being asked whether their child had a chronic conditions, parents were asked to choose the focus child. Because of this, the current study would be expected to reflect the prevalence of chronic conditions in the population, but underestimate the prevalence of parents dealing with a child with a chronic condition. Similarly parents were prohibited from automatically responding about their child with the most severe condition due to the age restriction of the study and the requirement that they choose their oldest child in the age range. The study was approved by the University of Wisconsin-Milwaukee Institutional Review Board.

Measures

The data for this study are part of a larger online survey. Only measures pertaining to the present study are included.

Background Information. Participants were asked to answer a variety of demographic questions pertaining both to themselves and to their child with a chronic condition. Such items include gender, age, marital status, and education level. Parents were also asked to indicate whether there were any other adult caregivers in the household.

Disease Activity. Respondents were asked a number of questions related to disease activity such as: what chronic condition their child has; whether they have other children with a chronic condition; and how many symptom-free days their child had in the last two weeks. Additionally, participants were asked: how many days of school their child missed in the last two months; how many emergency department visits and inpatient hospital admissions the child required in the last 6 months; and how many other

medical appointments the child had in the last 6 months. The non-disease specific disease activity questions developed for the current study were based on the work of Stein and colleagues (1987), who provided examples of non-disease specific aspects of disease severity. For inclusion in the CRI, responses to the question pertaining to symptom-free days were reverse scored such that all higher scores indicated greater risk.

Social Support. A single-item measure of perceived social support was used to assess the degree to which the participants feel that they have trustworthy individuals in their lives to rely on in times of need (Blake & McKay, 1986). Response options included "zero," "one," "two to five," "six to nine," and "10 or more individuals." Blake and McKay developed their questionnaire for use in a large scale epidemiological study and demonstrated strong predictive value of this one item in predicting disease related morbidity and mortality. Responses on this measure were reverse scored based upon the authors' original finding that having one or more supportive people in one's life was associated with decreased morbidity. As such, responses of "zero" were scored as 1, indicating greater risk and all other responses were scored as -1.

Parent HRQoL and Family Functioning. The Family Impact Module (FIM; Varni et al., 2004) is a 36-item self-report questionnaire that was used to measure both parent self-reported HRQoL and family functioning in the context of the child's chronic condition. Validation studies with parents of children with complex chronic conditions demonstrated high internal consistency reliability (HRQoL summary $\alpha = 0.96$). The FIM includes four subscales: Physical Functioning (n=6) and Psychosocial functioning (n=14), Daily Activities (n=3), and Family Relationships (n=5). Responses are given on a five-item Likert scale with zero being "never a problem" and four being "always a

problem." The total score is computed by averaging the scores for all 36 items. A Parent HRQoL Summary score is computed by summing the responses to the first 20 items and then dividing by the number of responses completed. A Family Functioning Summary score is computed by summing the 8 items comprising the Daily Activities and Family Relationships scales and then dividing by the number of responses completed. All items on the FIM are linearly transformed to a 0 to 100 point scale, meaning that higher FIM scores indicate higher HRQoL or less negative impact on the family. For use in the cumulative risk index, Family Functioning scores were reverse scored so that higher scores indicated increased risk.

Child Functional Disability. The Child Activity Limitations Questionnaire (CALQ; Hainsworth et al., 2007) is a 21 item self- and parent-report measure which yields a total functional disability score by summing the difficulty ratings for individual daily activities. Activities included in this scale are standard day-to-day activities such as completing chores or housework, attending school, or spending time with friends. Parental difficulty ratings are given on a six-item Likert scale with zero being "Not at all difficult" and five being "Extremely difficult." Higher CALQ scores indicate increased functional disability. Hainsworth and colleagues demonstrated that the CALQ has very strong internal consistency ($\alpha = 0.91$) and construct and discriminant validity as a self- and parent-report written questionnaire for children with chronic pain ages 8-18 years (Hainsworth et al., 2007).

Child Health-Related Quality of Life. Parents completed the PedsQL™ 4.0 (Varni, Seid, & Kurtin, 2001), which is a 23-item child- and parent-proxy report questionnaire of child HRQoL that yields a total score as well as four sub scores

(physical, emotional, social, and school; Varni et al., 2001). Only parent-proxy reports of child HRQoL will be obtained in the present study. All items on the PedsQL^{TM} are reverse scored and linearly transformed to a 0 to 100 point scale such that higher scores indicate better HRQoL. Initial validation studies in both community and pediatric settings demonstrated high internal consistency reliability for children ages 8-18 years (total score parent-report $\alpha = 0.90$). For inclusion in the cumulative risk index, the child HRQoL scores were reverse scored so that higher scores consistently indicated greater risk.

Data Analyses

Demographic and risk variables were summarized with descriptive statistics. The range, mean, and standard deviation of scores was computed for each measure, as well as the internal consistency in the current sample. Normality of the sample distribution is not an assumption of regression modeling, and as such was not considered unless the residuals of the regression models demonstrated significant non-normality, as indicated by skewness and kurtosis. Cumulative risk scores were calculated based on the cumulative risk indices (CRI) outlined by Everhart and colleagues (2008). Reports of social support, symptom free days, SES, family functioning, and child functioning were reverse scored so that higher scores consistently indicate greater risk. Pearson's and Spearman's correlations were run to identify individual factors associated with HRQoL scores. Variables that demonstrate a significant correlation were then coded to be included in the CRI. Individual responses and scores on each variable were coded as z-scores based on the sample mean. For categorical variables, such as presence of other adult caregivers and social support, low risk responses will be scored as -1 and high risk

responses will be scored as 1 to mimic the valence of the z-scores. Z-scores and categorical variable scores will then be summed to yield the overall CRI.

Hypothesis 1 stated that the CRI would be a better predictor than other, known predictors of parent HRQoL. Specifically, as the amount of parental risk increased, parent HRQoL would decrease. To test this hypothesis, the predictive utility of the linear CRI was compared to other individual risk factors that demonstrated strong correlations in the initial set of hierarchical regression analyses. The most strongly related individual risk factor was entered in the first step of the model, with the linear CRI added in the second step. Model fit for regression analyses was assessed using the R^2 for the model, the standardized Beta for each predictor, and the significance of the F-change statistic for each step in a hierarchical regression model. A post-hoc power analysis was completed with an estimated sample size of 120 based on pilot data. With an alpha of 0.05, two predictors, and a medium effect size (0.30), the power to detect significant relationships was estimated to be 0.996.

Hypothesis 2 proposed that a quadratic risk index would be a stronger predictor of parent HRQoL than a linear risk index. To test this, the linear CRI was transformed such that all variables were positive and then squared. The relationship between the linear and quadratic CRIs and overall parent HRQoL was assessed using hierarchical regression modeling. The linear CRI was entered in step one with the quadratic CRI being added in the second step. Model fit was assessed using the same indices as were used to evaluate hypothesis 1 (i.e., the R^2 for the model, the standardized Beta for each predictor, and the significance of the F-change statistic for each step in a hierarchical regression model). A post-hoc power analysis was completed with an estimated sample size of 120 based on

pilot data. With an alpha of 0.05, two predictors, and a medium effect size (0.30), the power to detect significant relationships was estimated to be 0.996.

Results

Descriptive Statistics

Disease Severity

The majority of parents (60%) reported that their child had missed no school-days in the past two weeks. Decreasing numbers of parents reported that their child missed one or two days, three to five days, six to eight days, and nine to eleven days (See Table 3). With regard to the number of symptom-free days their child experienced in the last two weeks, parent responses appeared to fall into a bimodal distribution (See Table 3). Specifically, 22% of parents reported no symptom free days at all and 30% reported 13-14 symptom free days in the past two weeks; however, all response options were endorsed in the current sample (See Table 3).

Similarly to the reports of school absences, the majority of parents reported no ED visits (60%) or inpatient treatment (91%) in the last six months. A small percentage of parents reported one visit to the emergency department or inpatient treatment instances (See Table 3). Fewer than 10% of parents endorsed two or more ED visits or instances of inpatient treatment in the last six months (See Table 3). No parents reported more than five ED visits in the last six months. Additionally, no parents in the current sample reported that their child had received inpatient treatment more than four times in the last six months. See table three for a full presentation of the frequency of these responses in the current sample.

The number of other medical appointment pertaining to their child's chronic condition in the last six months was more widely distributed than were other measures of disease severity. The majority (54%) of parents reported one or two non-emergent or non-inpatient medical appointments in the last six months. Twenty percent of parents reported no such appointments, 14% reported three to five, 8% reported six to eight, and 4% reported nine or more such appointments in the last six months (See Table 3).

Social Support

Because they were analyzed with the consideration of risk of disease specific mortality and morbidity, and given the findings of the initial validation study that the presence of at least one supportive person significantly decreased the risk of disease related morbidity and mortality, (Blake & McKay, 1987) the responses to the social support item were categorized as "no people near me whom I can count on in stressful times" or at least one such person. The overwhelming majority of participants reported having at least one supportive person in their lives (96%; Table 1).

Family Impact Module

The current sample reported a mean HRQoL of 65.5 out of a possible score of 100 (min=6.25, *SD*=16.0; Table 2). The 20 items comprising the HRQoL scale of the FIM demonstrated very strong internal consistency in the current sample (α=0.94). Within the HRQoL scale (20 items), the Physical (6 items) and Psychosocial (14 items) subscales were also computed. Parents reported a mean Physical HRQoL score of 61.7 (*SD*=18.8; Table 2) and a mean Psychosocial HRQoL score of 67.6 (*SD*=167.7; Table 2). Both scales demonstrated high internal consistency in the current community sample ($\alpha_{physical}$=0.87; $\alpha_{psychosocial}$=0.93).

The mean Family Functioning score in the sample was 62.7 (*SD*=19.6) with scores spanning the full possible range of scores (min=0.00, max=100). Full descriptive data for all parent HRQoL and family functioning subscales is presented in Table 2. Overall Family Functioning scores demonstrated satisfactory internal consistency in the current sample, with α=0.91. As with HRQoL, Family Functioning (8 items) was comprised of two subscales, the Family Day-to-Day Activities (3 items) and Family Relationships (5 items) subscales. Both subscales demonstrated strong internal consistency: for the Day-to-Day Functioning items α=0.84; for the Family Relationship scale α=0.94.

Child Functional Disability

The functional disability scores were highly variable in the current sample, with a mean of 20.9 and a standard deviation of 20.5 (See Table 2). The 21 items used to calculate functional disability had an internal consistency of α=0.95.

Child HRQoL

Parent-reported child HRQoL scores had a mean of 80.5 (*SD*=16.2) with scores falling within the full possible range (min=0, max=100). The PedsQL™ (Varni et al., 2001) HRQoL score is calculated using all 23 items, which demonstrated an internal consistency of α=0.94 in the current sample.

Development of the Cumulative Risk Index

Pearson's r or Spearman's rho correlations were used to identify risk factors associated with poorer parental HRQoL. Table 4 presents all correlations between risk variables and parent health-related quality of life and the corresponding significance level. Only those variables that demonstrated a significant relationship with parent

HRQoL were included in the calculation of the cumulative risk index. Note that variables in the correlation analyses were not reverse scored; however, those variable demonstrating a positive correlation were reverse scored for inclusion in the CRI to make lower scores consistent with lower risk. Only variables demonstrating significant correlations are discussed below (See Table 4).

The presence or absence of social support was negatively correlated with parent HRQoL, such that having one or more supportive people in one's life (coded as -1 to indicate lower risk) was associated with higher health-related quality of life (See Table 4). Child functional disability was also negatively associate with parent health-related quality of life (i.e., as functional disability increased, HRQoL decreased). Family functioning and child HRQoL were both positively correlated with parent HRQoL, such that both variables tended to increase together. Because higher scores indicated lower risk in this instance, both family functioning and child HRQoL scores were reverse scored for use in the CRI. Additionally, having at least one other child in the household (coded as 1 to indicate increased risk) with a chronic condition was negatively correlated with parent HRQoL.

One of the five disease severity items were correlated with parent health-related quality of life, indicating that, overall, as children had fewer symptom-free days, parent HRQoL worsened (See Table 4). The number of symptom-free days in the past two weeks was positively correlated with parent HRQoL, such that as the parent reported the child being well for more days, their self-reported health-related quality of life increased. Because of this positive relationship, the number of symptom free days reported was

reverse coded for inclusion in the CRI. Other disease severity items demonstrated no significant relationship with parent HRQoL and as such were not included in the CRI.

For quantitative measures (e.g., family functioning), z scores based on the sample mean were calculated and reverse coded as necessary for the CRI. Presence/absence codes (i.e. social support, other chronically ill children) were coded as negative or positive one to mimic the valence of possible z scores. Once variables were coded or transformed to z-scores, they were then summed. Overall, the linear cumulative risk index scores had a mean of -1.4 (*SD*=3.84), which indicates that, on average, parents in the current sample had more protective than risk factors and tended to be a low risk group. The linear CRI demonstrated a negative relationship with HRQoL, such that as risk increased, parent health-related quality of life decreased (See Table 5).

The quadratic CRI was calculated by linearly transforming the linear CRI scores to ensure that they were all positive and then squaring the transformed values. The quadratic CRI had a mean of 88.2 (*SD*=98.2) and was highly variable, with scores ranging from 4.9 to 855.5. The quadratic CRI also demonstrated a significant negative correlation with parent HRQoL (See Table 5).

Regression Modeling

Hypothesis 1. The first set of regression analyses evaluated whether the linear CRI was a stronger predictor of parent HRQoL than other individual risk factors. The three risk factors that demonstrated the strongest relationship with parent HRQoL were family functioning, child functional disability, and child HRQoL. Child functional disability and child HRQoL were used in subsequent regression analyses. Family functioning was not used as an individual predictor because family functioning and

parent HRQoL were measured using the same scale and were thus designed to be highly correlated. Because of this, the predictive relationship between these two scores may slightly overestimate the actual relationship between parent health-related quality of life and family functioning and thus limit the generalizability of the regression analyses to other measures of parent HRQoL. To test the assumption of regression models, which requires that the residuals, rather than the data themselves, be normally distributed, the skewness and kurtosis of the residuals was evaluated for each model.

In each of the two regression analyses comparing the linear CRI to other variables, the individual risk factor was entered in the first step of the model with the CRI added in the second step. Child functional disability demonstrated a significant negative predictive relationship with parent HRQoL in step one, but this relationship was non-significant when the CRI was added in step 2 (See Table 6). The linear CRI significantly, negatively predicted parent HRQoL (β=-0.775; p=0.001). Overall, the model was a satisfactory model, as demonstrated by the F Change statistic for each step (F_1=27.5; F_2=12.386), both of which were significant. This indicates that including the linear CRI in addition to the CALQ scores significant improved the predictive ability of the regression model (See Table 6). The residuals of the regression model were not significantly skewed (skewness=-0.181 SEskewness=0.357) or kurtotic (kurtosis=0.629; SEkurtosis=0.702), indicating that the previous regression analysis did not violate the assumptions of regression modeling.

The linear CRI was then compared to child HRQoL in a parallel set of regression analyses (See Table 7). Again, child HRQoL was entered in the first step of the regression analysis with the linear CRI added in the second step. As with functional

disability, child HRQoL significantly predicted parent HRQoL in the first step, but this relationship was non-significant when the linear CRI was included in the second step. The linear CRI again demonstrated a significant, negative predictive relationship with parent HRQoL when child HRQoL was included in the model (β=-0.441, p<0.001). Overall, the model was a satisfactory model, as demonstrated by the F Change statistic for each step (F_1=63.51; F_2=26.98), both of which were significant. Such findings indicate that the regression model including the linear CRI accounted for significantly more variability in parent HRQoL than the model using only child HRQoL. The residuals of the regression model were not significantly skewed (skewness=-0.079 SEskewness=0.152) or kurtotic (kurtosis=0.296; SEkurtosis=0.303), indicating that the previous regression analysis did not violate the assumptions of regression modeling.

In summary, hypothesis 1 was supported in that the linear CRI predicted variance in parent HRQoL beyond that accounted for by two of the largest individual risk factors. This conclusion is based upon the predictive value of the individual predictors as well as the significance of the increase in the amount of variance in parent HRQoL accounted for by the overall model. See Tables six and seven for full results of the comparison of the linear CRI with child functional disability and child health-related quality of life respectively.

Hypothesis 2. The second set of regression analyses evaluated the predictive utility of the linear CRI compared to the quadratic CRI in order to evaluate whether risk demonstrates a linear or quadratic relationship with parent HRQoL. Because of concerns about colinearity in these analyses, a variety of indicators were considered, namely the significance of the individual standardized betas, the significance of the change in each

step of the model, and the overall R^2 of the model at each step. To test the assumption of regression models, which requires that the residuals, rather than the data themselves, be normally distributed, the skewness and kurtosis of the residual scores was evaluated for each model. The linear CRI was included in the first step of the regression model and the quadratic CRI was added in the second step (See Table 8). Initially, the linear CRI significantly, negatively predicted parent HRQoL (β=-0.521, p<0.001); however, adding the quadratic CRI did not significantly improve the fit of the model (See Table 8). Specifically, the R^2 of the model did not change at all when the quadratic CRI was included ($R^2change_1$= 0.272; $R^2change_2$<0.001; $Fchange_1$=96.221; $Fchange_2$=0.160). The residuals of the regression model were not significantly skewed (skewness=-0.056 SEskewness=0.151) or kurtotic (kurtosis=0.298; SEkurtosis=0.301), indicating that the previous regression analysis did not violate the assumptions of regression modeling. Based on all of the above indicators, the linear CRI demonstrated a much stronger predictive relationship with parent HRQoL than did the quadratic CRI.

In summary, hypothesis two was not supported in that the linear CRI predicted significantly more variance in parent HRQoL than the quadratic CRI. This conclusion is based upon the predictive value of the two cumulative risk indices as well as the significance of the increase in the amount of variance in parent HRQoL accounted for by the overall model. See table eight for full results of the comparison of the linear and quadratic CRI.

Discussion

Overall, the current project showed mixed support for the two primary hypotheses. First, hypothesis 1, which stated that the cumulative risk index would

account for variance in parent HRQoL beyond that accounted for by the strongest individual risk factors, was supported. Specifically, the linear CRI added to the predictive utility of a regression model predicting parent health-related quality of life when either child functional disability of child health-related quality of life was entered into the model first. The second hypothesis, which stated that the quadratic cumulative risk index would account for more variance in parent HRQoL than the linear CRI, was not supported. The findings of the regression modeling testing hypothesis one are considered initially, followed by an examination of the regression models testing hypothesis 2. Subsequently, the relationship between the findings of the current study and the existing literature is reviewed, with recommendations for future research. Finally, the limitations of the current study are examined followed by overall conclusions.

Results of Hypothesis 1

The results supported this hypothesis. Hypothesis 1 stated that the CRI account for additional variance in parental HRQoL beyond that explained by other, known predictors of parent HRQoL. Child functional disability and child HRQoL were both identified as significantly related to parent health-related quality of life using correlational analyses. In two separate hierarchical regression models, the linear cumulative risk index significantly improved the prediction of parental HRQoL over either of these predictors individually. These results are consistent with prior cumulative risk models developed in pediatric psychology (Everhart et al., 2008; Gumidyala & Greenley, 2014; Josie et al., 2007). Considering that past cumulative risk models were developed in disease-specific samples, the current findings demonstrate that a non-disease specific risk model significantly predicts parent HRQoL across pediatric chronic

conditions. Additionally, these findings indicate that the relative degree of risk associated with numerous factors improves prediction of parent health-related quality of life beyond the influence of highly significant individual risk factors.

In developing the cumulative risk indices, numerous specific risk factors were shown to be associated with parent HRQoL in a non-disease specific sample (See Table 3). Specifically, social support, child functional disability, child HRQoL, having another chronically ill child, and the number of symptom-free days the child had in the last two weeks demonstrated significant relationships with parent HRQoL. Such results support the findings of previous research (Brown et al., 2008; Cohen et al., 2010; Dardas & Ahmad, 2014; Demirtepe-Sayguli & Bozo, 2011; Eccleston et al., 2004; Gavin & Wysock, 2006; Gray et al., 2013; Greenley & Cunningham, 2009; Hainsworth et al., 2007; Halterman et al., 2004; Hatzmann et al., 2008; Haverman et al., 2014; Herzer et al., 2010; Hunfeld et al., 2001; Ievers & Drotar, 1996; Kunz et al., 2011; Mano et al., 2009; Medrano et al., 2013; Moreira et al., 2013; Piazza-Waggoner et al., 2008; Stein & Jessop, 1982; Stein et al., 1987; Wallander & Varni 1998; Wallander et al., 1989a; Wallander et al., 1989b; Wallander et al., 1989c).

Several potential risk factors did not show the expected significant relationships in the current sample. Four disease-severity indices were not related to parent HRQoL, specifically the number of emergency department, inpatient treatment instances, and other medical appointments in the last six months as well as the number days of school missed in the last two weeks. It is likely that, because this was a community sample, there was not enough variability in parent responses to identify any potential significant relationship. This explanation is supported by the frequency analysis conducted initially,

which indicated that the vast majority of participants reported very low numbers of such events. In a sample including parents of children with more severe illnesses, such as parents of children on active cancer treatment, or parents of children with chronic cardiac conditions, these items may demonstrate significant relationships with parent HRQoL due to increased variability in responding.

Additionally, no demographic information demonstrated significant relationships with parent HRQoL. In the case of gender, the finding trended toward significance, and it is possible that, with a sample including more fathers, gender may show a significant relationship with parent HRQoL. This relationship was trending toward mothers reporting lower HRQoL than fathers. Education, the current study's index of socioeconomic status also was not significantly related to parent HRQoL. This non-significant relationship is in contrast to several studies identifying a relationship between income level or SES broadly and parent HRQoL and other measures of parent psychosocial adjustment to a child's chronic illness (Brown et al., 2008; Josie et al., 2007; Mullins et al., 2011). It is likely that the current sample was not sufficiently variable with regard to education level to capture any significant relationships between SES and parent HRQoL. Further, Mullins and colleagues (2011) identified income specifically as a significant mediator in the relationship between single-parent status and parent adjustment to a child's chronic illness. It may be that education is not an adequate indicator of SES in this circumstance and that a more explicit measure of income level would be more appropriate.

The fact that a large number of risk factors were associated with parent health-related quality of life supports Wallander & Varni's Disability-Stress-Coping Model

(1992). According to this model, contextual, disease-specific, personal, familial, and social variables should be related to one another as well as psychosocial outcomes in a highly complicated web of relationships. Contrary to Wallander and Varni's proposed model, this intricate web of mediated and moderated relationships may be less closely associated with parent health-related quality of life than the overall number of risk factors in a parent's life. The findings of the current study support the extension of Wallander and Varni's model from child psychosocial outcomes to parent psychosocial outcomes, but may weaken the argument for the clinical relevance of the specific interrelationships between risk factors proposed in the model.

Results of Hypothesis 2

The results of the current project did not support this hypothesis. Hypothesis 2 stated that a quadratic risk index would be a stronger predictor of parent HRQoL than a linear risk index. In a hierarchical regression model with the linear CRI entered first, the quadratic CRI did not change the overall variance accounted for by the model. This finding directly contrasts the findings of Everhart and colleagues (2008). Everhart et al. argued that the quadratic risk index was a stronger predictor of parent HRQoL in a sample of parents of children with asthma. In the current study, which had adequate statistical power to identify even a small, but significant, relationship between the quadratic CRI and parent HRQoL, only the linear CRI was associated with parent outcome. While it is still possible that, in a large enough sample, the quadratic CRI could marginally improve model fit over the linear CRI, the clinical utility of such an infinitesimal improvement must be considered. Given these findings, it is more statistically parsimonious to assume the simpler linear relationship between risk and

parent HRQoL. According to this model, a one unit increase in risk would lead to a corresponding one unit decrease in parent HRQoL.

Relation to Previous Literature

The results of this project supported the findings of past research examining cumulative risk models in pediatric psychology, in addition to extending the literature toward a non-disease specific understanding of how numerous risk factors combine to influence parent health-related quality of life. Similarly to other research, a cumulative risk model incorporating previously identified risk factors for poor parental functioning was significantly related to worsening parent HRQoL (Everhart et al., 2008; Gumidyala & Greenley, 2014; Josie et al., 2007). All models, including the current study, identified significant, negative relationships between a linear model of risk and parent HRQoL.

The primary difference between this project and prior work was the inclusion of parents of children with various chronic conditions, which necessitated a non-disease specific approach to quantifying disease activity. Prior work used disease specific measures (Everhart et al., 2008; Josie et al., 2007) or qualitative coding of disease characteristics from patient medical records (Gumidyala & Greenley; 2014) to quantify this concept. The current project identified several non-disease specific indicators of disease severity and treatment intensity based upon the concepts outlined by Stein and colleagues (1987) to evaluate disease activity in the current sample. The difference in quantification of disease severity is noteworthy as a significant extension of the current literature, which relies largely upon disease-specific questionnaires (e.g. Everhart et al., 2008; Kunz et al., 2011; Piazza-Waggoner et al., 2008). Further research should examine

the generalizability of the measures of disease severity used in the present study to other samples.

Contrary to prior research, the proposed quadratic risk index did not account for more variance in parental HRQoL than the linear CRI (c.f. Everhart et al., 2008). The use of a larger, non-disease specific sample in the current study suggests that previous findings may be idiosyncratic of either the disease considered (i.e. asthma), or the sample used. Additional research should be conducted in an additional disease specific sample, as it is possible that risk is related to parent HRQoL in a quadratic manner in certain disease samples or more high risk populations. It is also possible that the relationship between risk and parent HRQoL was influenced in the present study by the fact that the sample was relatively low risk, being a community sample.

The present study is an important first step toward understanding the combined impact of multiple risk factors on parental health-related quality of life. This is the first study known to the author to consider this breadth of risk factors in any sample and the use of a cumulative risk index in a non-disease specific sample. Consistent with prior work, the CRI demonstrated a strong predictive relationship with parent HRQoL above and beyond strong individual risk factors (Everhart et al., 2008; Gumidyala & Greenley, 2014; Josie et al., 2007). It is important to consider this index in a non-disease specific sample because, as argued by Stein and Jessop (1982), chronically ill children and their families face numerous adversities in their lives, but these difficulties are more alike across diseases than they are different. Moving toward a non-disease specific understanding of risk factors for poor parental psychosocial functioning would allow for increased translation of existing research across diseases and may help to improve the

identification of parents at risk for poor functioning in pediatric psychology as a field. The current study was a significant step in the direction of this non-disease specific approach.

Future Directions

The present study was the first attempt to develop a non-disease specific comprehensive risk index and as such there are many potential directions for future research. Initially, it would be beneficial to conduct an examination of the risk factors tested in the present study in a sample of parents with a wider variety of chronic conditions to ensure that it truly is non-disease specific. Examining this risk index in such a sample would allow for additional examination of the disease activity items and would allow for a second consideration of the quadratic risk index. Another evaluation of the predictive utility of the quadratic risk index would be highly beneficial in that the two studies that have tested this model have come to directly contradictory conclusions (c.f. Everhart et al., 2008). Because of the variability of conclusions about whether the relationship between risk and adjustment is linear or quadratic, this model should be tested again in a sample of parents of children with a wider variety of chronic conditions.

Future research should also consider the possibility that HRQoL in mothers than fathers are associated with different risk factors. No previous study of cumulative risk has had a sample of fathers large enough to consider such a pattern. Given that paternal HRQoL shows slightly different relationships with individual risk factors than does maternal HRQoL (Broger & Zeni, 2011; Dardas & Ahmad, 2014; Kunz et al., 2011; Mano et al., 2009; Pelchat et al., 2009; Pelchat et al., 2007; Pelchat et al., 2003), it is possible that the CRI should be calculated differently based on gender.

Finally, future research should aim to increase the clinical utility and applicability of the current CRI by examining which individual items are most closely related to parent functioning. The length of the measures used in the current study prohibits the direct translation of the model to clinical practice; however, a concise item set would be much more easily integrated into clinical practice to allow clinicians to quickly identify which parents are most at risk for poor HRQoL. If certain, highly predictive items could be identified to predict HRQoL in a community sample, this brief set of items could be validated and its predictive utility in identifying at risk parents could be considered.

Limitations

There are several limitations of the current project. As discussed previously, the sample was quite homogenous with regard to disease-severity. Because of this lack of variability, several disease-severity items that are likely associated with parent HRQoL did not demonstrate significant relationships (i.e. emergency department visits and inpatient treatment). Future research should examine the use of a cumulative risk index in a more heterogeneous sample including parents of children with less severe diseases in a community sample (e.g. food allergies) as well as parents of children with more typically severe illnesses (e.g., cancer, cystic fibrosis, sickle cell disease). Use of such a sample may support the utility of the non-disease specific indicators of disease activity used in the current study and allow for testing of the use of a CRI in a more variable sample.

The sample included in the current study was also homogenous with respect to a number of key demographic variables, namely gender and socioeconomic status (i.e. education level), which have previously been associated with parent HRQoL (Broger & Zeni, 2011; Brown et al., 2008; Gavin & Wysocki, 2006; Huang et al., 2014; Josie et al.,

2007; Knafl & Zoeller, 2000; Kunz et al., 2011; Mullins et al., 2011; Pelchat et al., 2009; Pelchat et al., 2007; Pelchat et al., 2003). Future research should strive to include a more diverse sample with regard to gender and SES to evaluate the potential for different relationships in a less homogenous sample.

The current study was also limited with regard to the quantification of the degree of risk associated with some of the variables, specifically social support, having other children with chronic conditions, and the presence of other adult caregivers in the home. The dichotomous coding of these variables may have minimized the amount of risk present relative to the sample. For example, having no one to count on in stressful times may be an anomalous response based on the sample, making it farther from the center of the response distribution, and thus an indicator of greater risk. However, because of the use of presence/absence codes, the sample responses were condensed into two groups and although z-scores would have changed the codes to reflect risk, the subsequent codes would be less theoretically based and somewhat arbitrary. In the future, open ended numerical responses should be allowed to permit more nuanced statistical analyses, which would more accurately represent the degree of risk associated with certain responses.

Clinical Implications

Clinicians working with chronically ill children in any setting should be aware of the relationship between parent HRQoL and child mental and physical health outcomes (Palermo & Chambers, 2005). Because of the cyclical relationship between parent and child functioning, identifying parents at risk for poor HRQoL should be included in standard treatment for pediatric chronic illnesses. This is particularly true of clinicians

working in integrated primary care settings, as the current study demonstrated that even in a lower risk, community based sample, a significant number of parents still report poor HRQoL. Additionally, because their children are higher functioning and require less acute medical care, these parents may be more likely to be overlooked by healthcare professionals. Based on the findings of the current study and the close relationship between parent and child functioning (see Palermo & Chambers, 2005 for a review), a comprehensive evaluation of parental risk for poor psychosocial functioning should be conducted as part of every chronically ill child's treatment.

At present, this kind of assessment is both cost and time prohibitive, not to mention the fact that many parents may find such an assessment overly intrusive. Utilizing a brief electronic questionnaire based on an Item Response Theory (IRT) (Reckase, 1972) model would allow for such an assessment to be conducted in the waiting room, prior to a child's appointment with their pediatrician or primary care doctor. This type of assessment may make parents more open to providing this information, as it would not detract from the already limited amount of time that the clinician spends with their child. Further, an IRT model questionnaire would allow for a comprehensive evaluation of risk factors as well as a more in depth analysis of the intensity of endorsed risk factors, all in a timely manner.

Conclusion

The current project demonstrated that a non-disease specific cumulative risk index can be used to predict parent HRQoL across pediatric chronic conditions. Conceptually, this study indicated that the overall amount of risk present in a parent's life is more relevant to his/her quality of life than the qualitative nature of the individual risk factors

present. Such an interpretation is in accordance with the conceptualization of a cumulative risk model as described by Jones and colleagues (2002). Further, the study used novel indicators of disease activity that were applicable across chronic conditions, which should also be the subject of further empirical scrutiny. In the future, it may be beneficial to evaluate this set of risk factors in a sample that is more diverse with regard to gender, SES and disease severity, as these variables were not consistently significantly associated with parent HRQoL in the current sample but may be in a more representative sample.

The present study also evaluated whether a linear or quadratic cumulative risk index was a stronger predictor of parent health-relate quality of life. Contrary to what was initially proposed, the relationship between risk and parent health-related quality of life was not best conceptualized by a quadratic model, but rather by a linear model. It may be beneficial to evaluate the model used in the present study in various disease-specific samples as well as other, more diverse non-disease specific samples to assess whether this pattern is consistent across samples. This is an important direction for future research, as understanding whether certain pediatric chronic illnesses are associated with a particular pattern of risk has implications for how clinicians identify at risk families. It is also important to consider whether this relationship between overall risk and parent health-related quality of life is stable across conditions and samples. Such findings would add significant support to a non-disease specific approach to understanding the psychosocial impact of pediatric chronic illnesses.

This study extends the literature regarding the relationship between cumulative parental risk and health-related quality of life to a non-disease specific community

sample and demonstrates that the relationship between risk and HRQoL is likely linear. Future research should examine whether this relationship holds across samples that are more diverse with respect to parent gender, socioeconomic status, and pediatric chronic conditions. These findings are an important step toward a non-disease specific conceptualization of parent psychosocial functioning in the context of pediatric chronic conditions. Parent health-related quality of life is a complicated phenomenon related to numerous aspects of individual, family, and social variables. The current study contributes to the understanding that it is the overall amount of risk in a parent's life, rather than the qualitative nature of his/her risk factors, that most impacts parental health-related quality of life.

Table 1. Frequency of demographic and risk variables.

Variable	N	Valid Percentage
Parent Gender		
Female	244	78
Male	69	22
Marital Status		
Married	215	69
Single, never married	49	16
Divorced	34	11
Separated	8	3
Widowed	5	2
Race/Ethnicity		
White	261	84
African American	18	6
Asian	9	3
Latino/a	9	3
Mixed Race	5	2
Other	7	2
Native American	3	1
Child Gender		
Male	166	54
Female	143	46
Chronic Condition		
Asthma	81	28
Other	81	28
ADHD	66	22
Food Allergies	64	21
Sleep Problems	51	18
Encopresis	48	17
Enuresis	41	14
Recurrent Ear Infections	33	11
Non-Migraine Headaches	22	8
Recurrent Abdominal Pain	21	7
Depression	20	7
Migraine Headaches	14	5
Diabetes	4	1
Other children with a chronic condition	36	12
Social Support		
Zero people	13	4
At least one person	299	6

Table 2. Descriptive statistics for demographic, family functioning, and risk variables

Variable	Minimum	Maximum	Mean	Standard Deviation
Education	6	20	16.1	2.3
Parent Age	19	56	36.1	7.2
Child Age	6	12	8.7	2.1
Parent HRQoL	6.25	100	65.5	16.0
Physical HRQoL	4.17	100	61.7	18.8
Psychosocial HRQoL	5.36	100	67.6	16.7
Family Functioning	0	100	62.7	19.6
Family Day-to-Day Activities	0	100	58.9	23.5
Family Relationships	0	100	64.7	21.6
CALQ	0	83	20.9	20.5
Linear Cumulative Risk Index	-7.8	19.3	-1.4	3.8
Quadratic Cumulative Risk Index	4.9	855.5	88.2	98.2

Table 3. Frequency of endorsement of disease severity measures

Disease Severity Category	Percentage
School absences in the last two weeks	
None	60
One or two	28
Three to five	9
Six to eight	3
Nine to eleven	1
Symptom-free days in the last two weeks	
None	22
One to three	10
Four to six	11
Seven to nine	9
Ten to twelve	18
Thirteen to fourteen	30
Emergency department visits in the last six months	
None	60
One	29
Two	9
Three	2
Four	1
Five	0
Inpatient treatment in the last six months	
None	91
One	6
Two	1
Three	1
Four	0
Five	0
Other medical appointments in the last six months	
None	54
One or two	54
Three to five	14
Six to eight	8
Nine to eleven	1
Twelve to fourteen	1
Fourteen to eighteen	0
Eighteen to twenty	1
More than twenty	1

Table 4. Correlations between risk variables and parent health-related quality of life

Variable	Pearson's *r*	Significance (*p*)
Parent Age	-0.029	0.642
Child Age	-0.018	0.779
Education	0.051	0.412
CALQ	-0.629	<0.001
Family functioning	0.683	<0.001
Child HRQoL	0.447	<0.001
Variable	**Spearman's rho**	**Significance (*p*)**
Having another chronically ill child	-0.266	<0.001
Social Support	-0.197	0.001
Other Adult Caregiver	0.048	0.444
Marital Status	0.034	0.582
Parent Gender	0.098	0.117
Child Gender	0.039	0.533
Symptom-Free Days	0.135	0.033
School Missed	-0.086	0.171
Emergency Department Visits	-0.025	0.687
Inpatient Treatment	-0.027	0.670
Other Medical Appointments	-0.102	0.103

Table 5. Correlations between risk indices and parent health-related quality of life

Variable	Pearson's *r*	Significance (*p*)
Linear Cumulative Risk Index	-0.497	<0.001
Quadratic Cumulative Risk Index	-0.488	<0.001

Table 6. Hierarchical regression comparing the predictive value of child functional disability (Step 1) to the linear CRI (Step 2) with parent HRQoL as the outcome variable.

Step	R Squared	R Squared Change	F Change	Sig. of F Change	β	Sig. of β
1	.396	0.396	27.505	<0.001	-0.629	<0.001
2	.536	0.140	12.386	0.001	0.050	0.823
					-0.775	0.001

Table 7. Hierarchical regression comparing the predictive value of child HRQoL (Step 1) to the linear CRI (Step 2) with parent HRQoL as the outcome variable.

Step	R Squared	R Squared Change	F Change	Sig. of F Change	β	Sig. of β
1	0.199	0.199	63.51	<0.001	0.447	<0.001
2	0.276	0.077	26.98	<0.001	0.103	0.225
					-0.441	<0.001

Table 8. Hierarchical regression comparing the predictive value of the linear CRI (Step 1) to the quadratic CRI (Step 2) with parent HRQoL as the outcome variable.

Step	R Squared	R Squared Change	F Change	Sig. of F Change	β	Sig. of β
1	0.272	0.272	96.221	<0.001	-0.521	<0.001
2	0.272	0.000	0.160	0.689	-0.586	0.001
					0.068	0.689

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