

Couples Coping with a Child's Chronic Illness:
Effects of Dyadic Coping on Stress and Well-Being

by

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A Thesis Presented in Partial Fulfillment
of the Requirements for the Degree
Master of Counseling

Approved April 2016 by the
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May 2016

ABSTRACT

The prevalence of chronic illness among children in the United States is on the rise (CDC, 2014). Having a child with a chronic illness can be a substantial source of stress for a couple, including physical, emotional, and financial demands of caregiving as well as difficult decision-making regarding the child's health (Mayo Clinic, 2015). Coping with such stressors can have a negative effect on the couple's well-being, and, if not managed within the relationship, can lead to increased negative outcomes for both partners. Partners can, however, learn to cope with stress by engaging in the coping process together with dyadic coping (DC). Couples can engage in positive (i.e., supportive emotion-focused, supportive problem-focused, and delegated) or negative forms of DC. DC has been shown to mitigate stress for couples, while increasing reports of individual well-being (IWB) and relational well-being (RWB), but it has not been examined in the context of couples with a child with a chronic illness.

To bridge this gap, the present study examined how couples cope with general stress as well as stress associated with their child's diagnosis of a chronic illness (CI-related stress) and whether *positive DC* and *negative DC* moderate association between stress (general stress and CI-related stress) and well-being (IWB and RWB). Consistent with hypotheses, there were significant main effects of both types of stress (general and CI-related stress) on both types of well-being (IWB and RWB). Contrary to the hypotheses that DC (positive DC and negative DC) would moderate the associations between both types of stress and both types of well-being, only one significant interaction was found between CI-related stress and *negative DC* on IWB. Implications of these findings are discussed.

TABLE OF CONTENTS

	Page
LIST OF TABLES.....	iv
LIST OF FIGURES	v
CHAPTER	
1 INTRODUCTION.....	1
Stress Associated with a Child’s Chronic Illness	4
Theoretical Framework: Systemic-Transactional Model of DC	6
Dyadic Coping (DC).....	6
Effects of Dyadic Coping on Stress	8
Effects of Dyadic Coping on Well-Being.....	9
The Present Study	10
2 METHODS	14
Recruitment	14
Participants.....	14
Procedure	16
Measures	17
Data Analytic Plan.....	22
3 RESULTS..	24
Descriptives.....	24
RQ and H1: Association between Stress and Well-Being	24
RQ and H2: Moderating Effects of Positive	25
RQ and H3: Moderating Effects of Negative.....	26
4 DISCUSSION	28

CHAPTER	Page
Effects of Stress on Well-being	28
Moderating Effects of Positive Dyadic Coping	29
Moderating Effects of Negative Dyadic Coping.....	31
Limitations	33
Future Directions	36
REFERENCES	39
APPENDIX	
A TABLES.....	44
Descriptive Statistics for Demographic Study Variables	45
Frequencies for Child’s Chronic Illness by Couple	46
Correlations among Study Variables.....	47
Descriptive Statistics for All Study Variables by Gender	48
General Stress and Well-Being Model Results	49
CI-Related Stress and Well-Being Model Results.....	50
General Stress and Positive DC on Well-Being Model Results	51
CI-Related Stress and Positive DC on Well-Being Model Results.....	52
General Stress and Negative DC on Well-Being Model Results.....	53
CI-Related Stress and Negative DC on Well-Being Model Results.....	54
B RECRUITMENT SITES.....	56
C SCREENING QUESTIONNAIRE.....	60
D RESEARCH SURVEY	62
E IRB APPROVAL.....	73

APPENDIX	Page
F IRB MODIFICATION	76
G INFORMED CONSENT	79
H RECRUITMENT FLYER	83

LIST OF FIGURES

Figure	Page
1. Interaction between CI-Related Stress and Negative DC on IWB	55

CHAPTER 1

INTRODUCTION

According to the United States (US) Centers for Disease Control (CDC, 2014), chronic illness among children is not only the leading cause of disability in the US, it is also the leading cause of death, accounting for nearly 70% of all childhood deaths in the US. A chronic illness is a long-lasting, incurable but treatable condition that gradually worsens overtime, affecting the everyday life of the afflicted (CDC, 2014). Chronic illnesses may vary in severity, but they are typically degenerative and present continual issues with the progression of the disease. Many chronic illnesses progress despite efforts to treat and contain the disease activity, causing compromised quality of life and lifelong disability and often lead to death (CDC, 2014; Center for Managing Chronic Disease, 2014). According to the Mayo Clinic's (2015) list of diseases, chronic illnesses in children can take many forms, including the following: metastatic and non-metastatic forms of cancer; blood cancer (e.g., leukemia); auto-immune disorders (e.g., juvenile rheumatoid arthritis, lupus); HIV/AIDS; cystic fibrosis; cerebral palsy, neurological disease (e.g., multiple sclerosis, juvenile fibromyalgia, Spina Bifida); and severe digestive disorders (e.g., gastroparesis, Hepatitis-C).

The prevalence of chronic illness among children in the US is significant and on the rise (CDC, 2014). According to the above definition of chronic illness, nearly 18% of children suffered from a chronic illness in 2011, and in 2014, this number increased to over 25%. Based on annual reports, this is a significant increase. Chronic illness is the second leading cause of death in children, ages 1-14 years old, and specifically, cancer is the second leading cause of death in children ages 5-14 years old. From 2012 to 2013,

there were significant increases in over half of the top ten most prevalent childhood chronic illnesses, resulting in an overall increase of chronic illness in children in 2014 (CDC, 2014). This indicates that an increasing number of couples face the challenges of coping with the implications of their child's chronic illness. For example, cancer is one of the many chronic illnesses that affect the lives of children and their parents (couples), with an estimated 16.5 million children ages 14 and under and 1.4 million ages 15 to 19 being formally diagnosed with some form of cancer in 2011 (CDC, 2014). In 2011, with 1,922,000 fatalities from childhood cancer, nearly two million couples, (approximately three to four million parents) lost a child (aged 19 years or younger) to cancer alone (US Cancer Statistics Working Group, 2014). This is only one example of the many chronic illnesses that affect the lives of children and couples. Statistical outcomes of other chronic illnesses are more complicated to report, given the variation in inclusion and exclusion of certain chronic illnesses among data collecting agencies. For example, the classification of chronic illness reported by the CDC, Mayo Clinic, and Center for Managing Chronic Disease differ. However, numbers continuously reflect the staggering number of parents (couples) who are tasked with coping with their child's chronic illness each year.

Having a child with a chronic illness can be a substantial source of stress for parents (i.e., couples; Hamlett, 1992; Kazak, 1989). These sources of stress include: physical and emotional strains and demands on the parents (the couple; Boss, Caron, Horbal, & Mortimer, 1999), stress and pressure to become educated about the child's chronic illness and treatment options (Mayo Clinic, 2015), attending to practical duties of the child's illness (Mayo Clinic, 2015), and psychological distress and anxiety about

unpredictable future outcomes (Boss et al., 1999). These sources of stress related to the child's chronic illness can be detrimental to social and occupational functioning, (Chentsova-Dutton, Shucter, Hutchin, & Strause, 2002).

According to the National Alliance for Caregiving's (NAC) 2009 report, 78% of parents of children with chronic illnesses reported making significant changes to their employment situation due to caregiving responsibilities, such as cutting hours, taking a leave of absence, switching to a less demanding job, giving up work entirely, and losing benefits. Among parents who reported being employed before the child's diagnosis, just over half were still employed at some time while they were caring for their child. Additionally, an overwhelming majority of parents report that caregiving has affected their social and financial well-being, such as limiting the amount of time they spend with friends and family and their restricting ability to participate in other recreational activities. Over 85% of parent caregivers reported feeling that they need more help or information on various topics related to caregiving as well as information related to their own well-being, specifically how to communicate and manage stress effectively (NAC, 2009).

The (additional) demands on parents' (couples') physical, emotional, and financial resources can certainly lead to the experience of increased stress, and these stressors can be particularly challenging to manage. Undoubtedly, coping with stressors can have a negative effect on the couple's well-being, and, if not managed within the relationship, can lead to increased negative outcomes for both partners (e.g., Bodenmann, Ledermann, & Bradbury, 2007). Parents of children with chronic illnesses are twice as likely as the general adult population to report they are in fair/poor health, with nearly

70% experiencing physical strain from caregiving and over half with high ratings for emotional stress (i.e., four or five a 5-point scale; NAC, 2009). Although not directly examined by the NAC, the experience of these stressors can negatively impact partner's well-being (Bodenmann et al., 2007). Partners can, however, cope with stress' deleterious effects by engaging in the coping process together (Bodenmann, 2005).

Dyadic coping is a process in which couples cope with a stressor together to manage and cope with stress in the context of their relationship (Bodenmann, 2005). Dyadic coping has been shown to have positive effects on individual well-being (Bodenmann, Meuwly, & Kayser, 2011) and relational well-being (Bodenmann, 2005) for coping with various stressors (Falconier, Jackson, Hilpert, Bodenmann, 2015). Dyadic coping has been examined in the context of health-related stress with couples where one partner suffers from a chronic illness and has shown to have beneficial effects on the couple as well as on individual partners (Acitelli & Badr, 2005). Specifically, dyadic coping has demonstrated positive effects for the individual partners and the couple among couples dealing with a partner's breast cancer diagnosis (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Kayser, Watson, & Andrade, 2007) and prostate cancer diagnosis (Regan et al., 2014). Given that there are multiple stressors faced by couples who have a child with a chronic illness (as noted above), as well as research indicating that dyadic coping is helpful for coping with health-related concerns, it may be important to examine how dyadic coping can help partners cope with stress as it relates to their child's chronic illness; however, there is a dearth of research on this topic.

Stress Associated with a Child's Chronic Illness (CI-related stress)

A child's diagnosis of a chronic illness can present a couple with a number of

stressors (e.g., stress related to informing others of the child's illness, caregiving demands, decisions regarding treatment, etc.), as many chronic illnesses have the potential to alter significantly the child's and the couple's quality of life (Mayo Clinic, 2015). With CI-related stress, couples are tasked with managing finances to tend to medical expenses, determining caregiving roles, and coordinating schedules to accommodate medical needs, doctor's appointments, and other caregiving tasks. Couples are also confronted with decisions regarding their child's treatment, informing friends and family, and discussing the child's condition and the issues surrounding it with teachers and administrators at the child's school (Mayo Clinic, 2015). Many couples with chronically ill children experience depression, anxiety, and personal health problems that occur as a detriment to focusing on the child's health, as well impairments in psychosocial functioning (e.g., lack of time and resources to socialize, loss of employment, etc.; Chentsova-Dutton et al., 2002). These factors put couples at risk for reduced individual and relational well-being (Chentsova-Dutton et al., 2002).

CI-related stress may also consist of the stress or distress couples experience concerning their child's unclear future (e.g., the child's diagnosis and prognosis), and couples may be affected by stress relating to the actual or potential change in the child's health (Chentsova-Dutton et al., 2002). This stress may relate to a poor or terminal prognosis for the child or to other harsh realities such as the unrealized future potential and limited access to normal childhood experiences for the child. CI-related stress may also be associated with parents' (partners') inability to fulfill the protector role or difficulties navigating uncertainties that they cannot control (Chentsova-Dutton et al., 2002). The experience of the unknown can be a considerable source of distress for a

couple (Black, 1998), and all of these stressors can have negative effects on couples' individual and relational well-being (Betz & Thorngren, 2006). Given this, it is important that researchers and clinicians working with couples coping with their child's chronic illness are aware of the ways partners can cope together to help mitigate the negative effects that CI-related stress can have on IWB and RWB.

Theoretical Framework: Systemic-Transactional Model of Dyadic Coping

Bodenmann's systemic-transactional model (STM) of dyadic coping (1995, 1997, 2005) considers that within a romantic relationship, the stress communication and stress management process is shared between partners (Bodenmann, 1997). Because of couples' shared social context or interdependence (Kelley & Thibaut, 1978), stress and coping responses are stimulated by a vested interest in managing shared concerns and working toward mutual goals (Bodenmann, 1995, 2005). As the effort to stabilize the stress of one's partner also aims to reduce one's own stress, both partners have a vital interest in managing the stress (Bodenmann, 1997). As such, dyadic stress refers to any emotional or problem-centered stress that directly concerns a couple (Bodenmann, 1997; Randall & Bodenmann, 2009), such as the stress related to a child's health (Hamlett, 1992; Kazak, 1989). To manage such stressors, the STM postulates that couples can participate in the coping process together by engaging in dyadic coping (Bodenmann, 1997).

Dyadic coping (DC). DC refers to the way in which couples cope when one or both partners are experiencing stress (Bodenmann, 2005). Due to partner's shared interdependence, although the stress may initially only impact one partner, as in the example of work stress, stress is considered a dyadic construct because it can affect both partners' well-being by spilling over into the dyad. As the stressor concerns both

partners, the couple can engage in a joint effort to manage the stress, reducing the stress for each partner while enhancing the quality of the relationship (Bodenmann, 2005).

Couples can engage in both positive (i.e., supportive emotion-focused, supportive problem-focused, and delegated) or negative (i.e., ambivalent, hostile, and superficial) forms of DC (Bodenmann et al., 2011). *Positive DC* includes supportive DC where support is provided by one partner in an attempt to assist the other partner's coping efforts. Couples engaging in *supportive DC* either work on the problem directly (*problem-focused DC*) or cope with emotions associated with the problem (*emotion-focused DC*). *Positive DC* also includes delegated DC in which one partner asks the other partner to assume certain tasks, duties, and responsibilities in an effort to reduce one's own stress. *Negative DC* consist of disingenuous support (ambivalent DC), support with a negative connotation (hostile DC), and behaviors devoid of genuine support, such as denial (superficial DC). Ambivalent DC includes one partner supporting the other partner unwillingly or as if his or her support should not be needed. Hostile DC may present as support accompanied with sarcasm, disparagement, distancing, mocking, or minimizing the partner's stress. Superficial DC involves insincere support, such as asking how the partner is feeling and then not listening or failing to provide empathy (Bodenmann, 2005).

The STM (Bodenmann, 1997) of DC has been applied in health contexts to understand how partners may cope jointly in the presence of an illness. Research by Kayser and colleagues has examined how couples cope together with the stress associated with a breast cancer diagnosis (e.g., Kayser et al., 2007). Couples who cope with the stressor together are thought to view the illness and stressors as a “we-disease” and utilize an interdependent approach to manage and cope with the stress (Badr et al., 2010; Kayser et al., 2007). Couples taking a dyadic focus to deal with one partner's illness reported

greater stress efficacy and dyadic adjustment (Badr et al., 2010) and higher marital quality and individual well-being (Kayser et al., 2007). Although associations between DC and well-being have been examined in various health contexts, the possible beneficial (or detrimental) associations between stress related to CI-related stress on IWB and RWB have not yet been examined in the literature, which is the focus of the present study. Couples coping with the child's chronic illness may engage in *positive DC* by using collaborative stress management efforts, such as joint problem-solving, stress communication, sharing and listening to each other's feelings about the stress, and taking on responsibilities of the other partner. However, these couples may also engage in *negative DC*, which could take the form of denial, failing to take one's partner's concerns seriously, providing support with negative provisions (i.e., holding it against one's partner), or minimizing one's partner's feelings about the child's health.

Effects of dyadic coping on stress. Research has shown that DC can have positive effects on couples' ability to manage both general stress (e.g., Bodenmann, 2005) and health-related stress (e.g., Badr et al., 2010). When dealing with general stressors, couples who engage in *positive DC* report a reduced stress experience (Bodenmann et al., 2011; Schwarzer & Busch, 2005; Revenson, Kayser, & Bodenmann, 2005). In studies examining the effects DC in couples coping with a partner's chronic illness, results showed that engaging in *positive DC* reduced the impact of the shared stress (e.g., Acitelli & Badr, 2005; Badr et al., 2010; Kayser, 2005; Kayser et al., 2007; Meier et al., 2011; Revenson, 2003). Additionally, conceptualizing the stress as a dyadic stress supported couples' ability to engage effectively in *positive DC* (Acitelli & Badr, 2005).

Effects of dyadic coping on well-being. In the context of couples coping with general stressors, DC has been found to be a strong positive predictor of both IWB and RWB (Bodenmann et al., 2011). Research has shown that couples who engage in *positive DC* report higher marital quality (Bodenmann, 2005; Bodenmann et al., 2011; Wunderer & Schneewind, 2008) and greater IWB (Bodenmann, 2006; Bodenmann et al., 2011). A five year longitudinal study found that *positive DC*, specifically emotion-focused and problem-focused DC, is positively correlated with relationship quality and reduction of general stress which resulted in increased IWB (Bodenmann & Cina, 2006). Additionally, a two-year longitudinal study assessing the relationship between DC and marital quality among 90 couples revealed that more *positive DC* and less *negative DC* were significantly associated with marital quality over two years (Bodenmann, Pihet, & Kayser, 2006).

Researchers have examined the effects of DC on couples coping with various types of chronic illness in which one partner was ill (e.g., Acitelli & Badr, 2005; Badr et al., 2010; Kayser, 2005; Meier et al., 2011). Results showed that engaging in *positive DC* is associated with increased IWB (Meier, et al., 2011) and RWB (Acitelli & Badr, 2005; Bodenmann, 2005; Bodenmann et al., 2011). Specifically, Badr and colleagues (2010) have examined the effects of DC when coping with an advanced stage illness and also found that engaging in *positive DC* had positive effects on couples' IWB and RWB and engaging in *negative DC* had negative effects on IWB and RWB (Badr et al., 2010). Similarly, in a study with one partner diagnosed with COPD, more *positive DC* and less *negative DC* were associated with higher levels of IWB, and more *negative DC* and less

positive DC were associated with lower levels of IWB reported by both partners (Meier et al., 2011).

Taken together, DC has been shown to have beneficial effects on mitigating experiences of stress for couples (Badr et al., 2010), while increasing levels of both IWB (Bodenmann et al., 2006) and RWB (Meier et al., 2011). Research continues to support a positive association between couples engaging in positive forms of DC and partners' own well-being (Bodenmann, 2005) as well as relationship quality and satisfaction (Bodenmann, 2005; Bodenmann et al., 2011). However, there is a dearth of literature that examines DC in the context of couples dealing with health-related stressors, and there is currently no literature examining DC in the context of stress related to a child's chronic illness (CI-related stress). Given that couples with chronically ill children are challenged with substantial stress that may impact their IWB and RWB, this an important area for researchers and clinicians to gain a better understanding of the association between stress, well-being, and DC for these couples, as this may have implications for counseling prevention and intervention.

The Present Study

The goal of the present study was to examine how couples cope with general stress as well as stress associated with their child's diagnosis of a chronic or life-limiting illness (CI-related stress). For the purpose of this study, IWB was measured as symptoms of depression and anxiety, and RWB was measured by relationship satisfaction. Specifically the following research questions (RQ) were examined and hypotheses (H) were tested:

RQ 1: What is the association between stress (general stress and CI-related stress) and IWB and RWB?

H1a: General stress and IWB. Based on research suggesting that stress can have a negative effect on IWB (Johnson & Sarason, 1978), it was hypothesized that general stress would be negatively associated with IWB.

H1b: CI-related stress and IWB. Based on research suggesting that stress can have a negative effect on IWB (Badr et al., 2010), it was hypothesized that reported CI-related stress would be negatively associated with IWB.

H1c: General stress and RWB. Based on research suggesting that stress has a negative effect on RWB (see Randall & Bodenmann, 2009 for a review), it was hypothesized that general stress would be negatively associated with RWB.

H1d: CI-related stress and RWB. Based on research suggesting that stress has a negative effect on RWB (Badr et al., 2010), it was hypothesized that general stress would be negatively associated with RWB.

RQ 2: Does *positive dyadic coping* (DC) moderate the association between stress (general stress and CI-related stress) and well-being (IWB and RWB)?

H2a: General stress and *positive DC* on IWB: Based on prior research that has shown *positive DC* has a positive effect on IWB (Bodenmann et al., 2011), it was hypothesized that *positive DC* would moderate the

association between stress and IWB, such that couples with higher *positive DC* would report higher IWB.

H2b: CI-related stress and *positive DC* on IWB: Based on prior research that has shown *positive DC* has a positive effect on IWB (Bodenmann et al., 2011), it was hypothesized that *positive DC* would moderate the association between CI-related stress and IWB, such that couples with higher *positive DC* would report higher IWB.

H2c: General stress and *positive DC* on RWB: Based on prior research that has shown *positive DC* has a positive effect on RWB (Bodenmann, 2005; Bodenmann, et al., 2006; Bodenmann et al., 2007; Bodenmann et al., 2011), it was hypothesized that *positive DC* would moderate the association between general stress and RWB, such that couples with higher *positive DC* would report higher RWB.

H2d: CI-related stress and *positive DC* on RWB: Based on prior research that has shown *positive DC* has a positive effect on RWB (Bodenmann, 2005; Bodenmann, et al., 2006; Bodenmann et al., 2007; Bodenmann et al., 2011), it was hypothesized that *positive DC* would moderate the association between CI-related stress and RWB, such that couples with higher *positive DC* would report higher RWB.

RQ 3: Does *negative DC* moderate the relationship moderate the association between stress (general stress and CI-related stress) and well-being (IWB and RWB)?

H3a: General Stress and *negative DC* on IWB. Based on prior research that has shown *negative DC* has a negative effect on IWB (Meier, et al., 2011), it was hypothesized that *negative DC* would exacerbate the association between general stress and IWB, such that couples with higher *negative DC* would report lower IWB.

H3b: CI-related stress and *negative DC* on IWB. Based on prior research that has shown *negative DC* has a negative effect on IWB (Meier, et al., 2011), it was hypothesized that *negative DC* would exacerbate the association between CI-related stress and IWB, such that couples with higher *negative DC* would report lower IWB.

H3c: General stress and *negative DC* on RWB. Based on prior research that has shown *negative DC* has a negative effect on RWB (Bodenmann, et al., 2011), it was hypothesized that *negative DC* would exacerbate the association between general stress and RWB, such that couples with higher *negative DC* would report lower scores of RWB.

H3d: CI-related stress and *negative DC* on RWB. Based on prior research that has shown *negative DC* has a negative effect on RWB (Bodenmann, et al., 2011), it was hypothesized that *negative DC* would exacerbate the association between CI-related stress and RWB, such that couples with higher *negative DC* would report lower scores RWB.

CHAPTER 2

METHODS

Recruitment

Participants were recruited by posting flyers on: (1) community organizations' Listserves for parents on national health-related websites; (2) Listserves of charity organizations which fund a wish for children with life-threatening illnesses; (3) Listserves of online and in-person support groups which provide grief support for parents (couples) of a child with a chronic illness diagnosis or terminal prognosis; (4) via University Listserves and University affiliated Facebook pages (e.g. ASU News, Counseling and Counseling Psychology Facebook Page, GPSA, etc.); (5) local children's hospitals (e.g., Phoenix Children's Hospital Palliative Care Unit, Banner Cardon Pediatric Oncology Unit, and Hospice of the Valley (Ryan's House for children); and (6) local camps for families of children with chronic illnesses (e.g., Camp Soaring Eagle and Arizona Lion's Camp). See Appendix B for a full list of recruitment sites.

Participants

Participants had to meet the following inclusion criteria in order to participate: (1) parents who have a child, under the age of 16, diagnosed with a chronic illness; (2) at least 3 months had passed since the child's diagnosis; (3) couples are in a committed relationship, and both parents (partners) were willing to participate; and (4) both parents (partners) spoke English fluently.

One hundred couples initially expressed interest in participating. Fourteen of the 100 couples did not meet the screening requirements, 15 did not complete the necessary screening measures, and 5 participants completed the research survey, but their partner

did not. Therefore, the final sample included 66 couples ($n = 132$ individuals), ranging in age from 21 to 65 years old ($M_{\text{men}} = 39.26$, $SD = 7.25$, $M_{\text{women}} = 36.94$, $SD = 6.33$). Of the 132 participants, approximately 81.8% of participants identified as White/European American, 9.8% identified as Hispanic/Latino(a), 3.0% identified as Black/African-American, 0.8% identified as Asian/Asian-American, 0.8% identified as Native American or Pacific Islander, and 2.4% identified as other. Nearly half of the participants reported having a bachelor's degree or higher. Specifically, of the 132 participants, 19.7% reported they had completed a graduate or professional degree, 26.5% completed a bachelor's degree, 31.1% completed some college, 5.3% a vocational or technical school degree, 4.5% an associate's degree, 10.6% having a high school diploma or equivalent, and 2.3% completed less than high school. Yearly household income ranged across the sample with 12.1% reporting annual earnings of \$0-\$25,000; 20.5% earning \$25,000-\$49,999; 28.8% earning \$50,000-\$74,999; 14.4% earning \$75,000-\$99,999; 13.6% earning \$100,000-\$149,999; and 10.6% earning greater than \$150,000 per year.

Relationship descriptives. On average, couples reported that they have known their partner for 15.20 years ($SD = 6.62$ years, range = 4 to 35 years), and have been in a relationship with their partner for an average of 13.28 years ($SD = 5.94$ years, range = 2 to 28 years). A majority of the couples (86.4%) reported being married, 9.1% reported being in a committed relationship and living together, and 4.5% reported being engaged and living together. Married couples reported being married for an average of 11.89 years ($SD = 5.70$ years, range = 2 to 27 years). Couples reported having an average of three children ($SD = 1.80$, range = 1 to 11 children). Twenty couples reported having a child (or children) from previous relationships (1.1%), and 11 of those couples (17.4%)

reported that the child (or children) live(s) with them 50% or more of the time (range = 1 to 2 children). See Table 1 for descriptive statistics reported by gender.

Chronic illness descriptives. A total of 17 couples (25.8%) have a child with cancer. Of this number, 6 couples (9.1%) have a child with metastatic cancer, 6 couples (9.1%) have a child with non-metastatic cancer, and 5 couples (7.6%) have a child with blood cancer (i.e., Leukemia). Twelve couples (18.2%) have a child with a neurological disease (e.g., cerebral palsy, epilepsy). Ten couples (15.2%) have a child with an autoimmune disorder (e.g., lupus, hypogammaglobulinemia). Nine couples (13.6%) indicated “other” and specified their child’s condition (e.g., omphalocele, type 1 neurofibromatosis, severe hemophilia, chronic lung disease). Six couples (9.1%) have a child with renal disease (e.g., kidney failure). Four couples (6.1%) have a child with mitochondrial disease, three couples (4.5%) with congenital heart disease, two couples (3.0%) with severe digestive disorder; two couples (3.0%) with spina bifida, and one couple (1.5%) reported having a child with cystic fibrosis. Of this total number, 33 couples (50.0%) have a child with a condition that limits the child’s lifespan (i.e., life-threatening or life-limiting), and seven couples (10.6%) have a child who has more than one chronic illness diagnosis. See Table 2 for frequencies of couples’ child’s chronic illness. The length of time since the child's diagnosis ranged from three months to 13.23 years ($M = 5.16$ years, $SD = 3.43$).

Procedure

Data collection took place in two parts: (1) screening questionnaire (see Appendix C) and (2) research survey (see Appendix D). Interested couples contacted the researcher via email, who provided them an overview of the study and an electronic copy of the

informed consent. Upon consent, couples were assigned a unique ID (ex: female 001, male 501) and a link to the online screening questionnaire. Participants who met eligibility requirements, as noted above, were redirected to the research questionnaire, which consisted of the measures below. Both questionnaires were hosted by a secure online website, Qualtrics. On average, participation took a total of approximately 20 minutes. Couples were compensated \$30 for their participations upon completion.

Measures

General stress. Stress was measured with the 7-item *stress* subscale of the Depression, Anxiety, Stress Scales (DASS-21; Henry & Crawford, 2005). Participants were instructed to respond to questions relating to their stress (e.g., “I tended to over-react to situations”) using a four-point rating scale (0 = “*Did not apply to me*”; 3 = “*Applied to me very much, or most of the time*”). High scores are indicative of greater severity or frequency of concerning emotional symptoms related to each subscale. Instructions were modified, asking participants to reflect on their current situation regarding their child with a chronic illness and to indicate how much the statement applies to them since their child’s diagnosis of chronic illness. The stress subscale showed good internal consistency for men ($\alpha = .88$) and women ($\alpha = .87$).

Stress related to the child’s illness. For the purpose of this study, 7 items were created to measure stress related to the child’s chronic illness to be consistent with the 7-item subscale of the DASS-21. Items were created based on Coffey’s 2006 meta-analysis which examined and identified the most frequent, core types of stress related to parenting a child with a chronic illness. Items were created to assess for the following “common” stressors: decision-making regarding the child’s treatment, intrusive thoughts related to

the child's health, financial stress, lack of quality time with one's partner, how to discuss the child's health with others, practical demands of child's treatment and care, and concern for how child is affected by the diagnosis. Sample items included, "I felt overwhelmed about making decisions regarding my child's treatment" and "I was preoccupied with the idea that my child's physical and/or psychological state is painful for him/her." Participants responded to the four items using a four-point rating scale (0 = "Did not apply to me"; 3 = "Applied to me very much, or most of the time"), similar to the DASS-21. This measure showed good internal consistency for men ($\alpha = .83$) and women ($\alpha = .82$).

Individual well-being (IWB). IWB was measured using the 7-item *depression* subscale and the 7-item *anxiety* subscale of the Depression, Anxiety, Stress Scales (DASS-21; Henry & Crawford, 2005) to examine IWB. For the purpose of this study, instructions were modified to fit the context of the child's health. Participants were instructed to respond to questions relating to common depressive behaviors (e.g., "I couldn't seem to experience any positive feeling at all") and anxious behaviors (e.g., "I found myself getting agitated") using the four-point scale stated above (DASS-21; Henry & Crawford, 2005). IWB was calculated by summing the total score all 14 items, (i.e., 7 items from both subscales) and averaging the total score. This instrument showed good internal consistency for men ($\alpha = .96$) and women ($\alpha = .93$). The depression and anxiety subscales showed a strong, significant correlation ($r = .85$), suggesting that the subscales are highly inter-related (Ohio University, 2013), supporting the use of this measure as a combined score.

Relational well-being (RWB). RWB was measured using the 7-item Relationship Assessment Scale (RAS; Hendrick, 1988). The RAS uses a five-point response scale to measure participants' relationship satisfaction, fulfillment of individual needs and expectations in the relationship, love for one's partner, and the prevalence of relationship problems. Sample questions include, "In general, how satisfied are you with your relationship?", and "How many problems are there in your relationship?" The RAS has been used widely in many relationship studies across various cultures (Hendrick et al., 1998). This instrument showed acceptable internal consistency for men ($\alpha = .71$ and women ($\alpha = .77$).

Dyadic coping. The English version of the Dyadic Coping Inventory (DCI; Randall, Hilpert, Jimenez-Arista, Walsh, & Bodenmann, 2015) was used to assess positive and negative forms of DC. This instrument uses a five-point scale (1 = "very rarely" to 5 = "very often) to measure how individuals perceive their own coping behaviors (perceived self), their partner's behaviors (perceived partner), and how they cope as a couple regarding certain positive and negative dyadic coping behaviors (common). The DCI includes 37 items and measures subscales of *positive DC* as well as *negative DC*.

Subscales tapped *emotion-focused* supportive DC (*EFSDC*), problem- focused supportive DC (*PFSDC*), and delegated DC (*DDC*). *EFSDC* consisted of six items, including perceived self (e.g., "I express to my partner that I am on his/her side"), perceived partner (e.g., "My partner shows empathy and understanding"), and common DC (e.g., "We help each other relax..."). *PFSDC* consisted of seven items, including perceived self (e.g., "I try to analyze the situation together with my partner in an

objective manner...”), perceived partner (e.g., “My partner helps me to see stressful situations in a different light”) and common DC (e.g., “We try to cope with the problem together and search for shared solutions). *DDC* consisted of four items, including perceived self (e.g., “When my partner feels he/she has too much to do, I help him/her out”) and perceived partner (e.g., “When I am too busy, my partner helps me out”; Bodenmann, 2008). The *negative DC* subscale included eight items (e.g., “My partner blames me for not coping well enough with stress” and “When my partner is stressed I tend to withdraw”; Bodenmann, 2008).

This study focused on male and female reports of *positive DC* (17 items; aggregated subscales of *EFSDC*, *PFSDC*, and *DDC*) to measure a total composite score of *positive DC* and reports of *negative DC* (eight items) to measure a total composite score of *negative DC*. *Positive DC* was measured by calculating a mean score for the subscales (*EFSDC*, *PFSDC*, and *DDC*), and *negative DC* was measured by calculating a mean score of a total of the eight *negative DC* items (Papp & Whitt, 2011).

The *EFSDC* subscale also showed good internal consistency for men ($\alpha = .81$) and women ($\alpha = .83$). The *PFSDC* subscale also showed good internal consistency for men ($\alpha = .83$) and women ($\alpha = .87$). The *DDC* subscale showed poor internal consistency for men ($\alpha = .58$) and women ($\alpha = .49$), which is inconsistent to reported levels in the English validation of the DCI (Randall, et al., 2015). Despite the low internal consistency for *DDC*, the composite measure of the *positive DC* subscale showed strong internal consistency for men ($\alpha = .89$) and women ($\alpha = .92$). Without the *DDC* subscale in the composite *positive DC* subscale, the internal consistency was the same for men ($\alpha = .89$)

and the same women ($\alpha = .92$). The *negative DC* subscale also showed good internal consistency for men ($\alpha = .87$) and women ($\alpha = .85$).

Grief. Participants' experience of grief was measured using a modified version of the 13-item Texas Inventory of Grief – Revised (TRIG; Faschingbauer, 1981). Participants were instructed to consider their present feelings concerning the state of the child's health and to respond to questions relating to various aspects of grief (e.g., acceptance, crying, intrusive thoughts) using a 5-point rating scale (1 = "*Completely False*" to 5 = "*Completely True*"). High scores are indicative of emotional distress. This scale was modified by the researcher by asking participants to reflect on "the child with a chronic illness/the child's diagnosis", rather than "the person who died" and to indicate how much the statement applies to him/her since the child's diagnosis, (e.g., "I still cry when I think about my child's diagnosis" and "Sometimes I miss the person my child was before his/her diagnosis"). The TRIG has been examined across diverse samples (Faschingbauer, 1981) and showed good internal consistency for men ($\alpha = .88$) and women ($\alpha = .87$) in this sample.

Control variables. As grief can have negative effects on well-being (Bonanno, 2001), grief was also controlled for when running all models that included IWB and RWB. The amount of time passed since the child's diagnosis of a chronic illness can affect couples' stress and outcomes. This can affect attitudes toward acceptance or denial of the illness and its implications, the level of adaptation to the practical changes required to care for the illness, attitudes of hope for positive outcomes, and caregiver burnout (Ostrowska, 2008). Thus, the length of time since the child's diagnosis was controlled.

Additionally, as the length of a relationship can also affect the way in which couples may cope with stressors (Badr, et al., 2010), relationship length was also controlled.

Data Analytic Plan

Dyadic data – data collected from two romantic partners – contains sources of interdependence due to partners’ shared experiences (Kenny, Kashy, & Cook, 2006). Therefore, to control for this level of interdependence, actor-partner independence models (APIMs) were utilized. Stress (independent variable) and dyadic coping (moderator) were grand mean centered prior to analyses. Because predictors in multi-level models contain sources of variability, interactions also have more than one source of variability. To produce unbiased estimates for both levels of the models, grand mean centering was used to rescale the predictors by subtracting the grand mean of the predictor using the mean from the full sample, thus centering the variables around the overall mean, which makes values more interpretable (Kreft & De Leeuw, 1998). All analyses were conducted using SAS Proc Mixed version 9.3 (SASInstitute, 2011).

A series of 12 separate multilevel models were run to test the hypotheses. Models 1 to 4 were used to investigate the four hypotheses related to RQ1 - the association between stress and well-being. *Model 1* examined the main effect of general stress on IWB, *model 2* examined the main effect of CI-related stress on IWB, *model 3* examined the main effect of general stress on RWB, and *model 4* examined the main effect of CI-related stress on RWB.

Models 5 to 8 were used to investigate the four hypotheses related to RQ2 - whether *positive DC* moderates the association between stress and well-being. *Model 5* examined the interaction between general stress and *positive DC* on IWB, and *model 6*

examined the interaction between CI-related stress and *positive DC* on IWB. *Model 7* examined the interaction between general stress and *positive DC* on RWB, and *model 8* examined the interaction between CI-related stress and *positive DC* on RWB.

Models 9 to 12 investigated the four hypotheses related to RQ3 - whether *negative DC* moderates the association between stress and well-being. *Model 9* examined the interaction between general stress and *negative DC* on IWB, and *model 10* examined the interaction between CI-related stress and *negative DC* on IWB. *Model 11* examined the interaction between general stress and *negative DC* on RWB, and *model 12* examined the interaction between CI-related stress and *negative DC* on RWB.

Each model included the controls (noted above), the independent variable (i.e., general stress and CI-related stress), the moderator (i.e., dyadic coping), and the interaction terms between the two types of stress and the moderators (i.e., general stress x *positive DC*, CI-related stress x *positive DC*, general stress x *negative DC*, CI-related stress x *negative DC*). When significant interactions were found, simple slope tests were conducted to decompose the interaction (Aiken & West, 1991). Significant interactions were decomposed using Preacher's (2016) online calculator to compute specific values needed to plot two-way interactions.

CHAPTER 3

RESULTS

Descriptives

Means, standard deviations, and reliabilities between genders on stress, IWB, RWB, positive, DC and *negative DC* can be found in Table 3.

Correlations among the variables general stress, CI-related stress, individual well-being, relational well-being, *positive DC*, and *negative DC* ranged from ($-.72 < r > .81$) for both genders. Overall, there were statistically significant correlations between general stress and IWB ($r = -.66$), CI-related stress and IWB ($r = -.29$), general stress and RWB ($r = -.29$), CI-related stress and RWB ($r = -.28$). Correlations were not significant for *positive DC* and IWB but were significant for *positive DC* and RWB ($r = .81$).

Correlations were not significant for *negative DC* and IWB but were significant for *negative DC* and RWB ($r = -.72$). Correlations were generally consistent across gender with one exception. The correlation between CI-related stress and IWB was significant for women but not men, (see Table 4).

Paired-samples t-tests were conducted to compare differences between men's and women's scores of general stress, CI-related stress, *positive DC*, and *negative DC* on IWB and RWB. There was a significant differences between men's and women's reports of RWB, $t(65) = 2.66$, $p < .01$ level, where men reported higher RWB than women. There were also significant differences between men's and women's reports of general stress, $t(65) = -4.82$, $p < .001$, and CI-related stress, $t(65) = -4.24$, $p < .001$, where men reported lower general stress and lower CI-related stress than women (see Table 3).

RQ and H1: Association between Stress and Well-Being

H1a: General stress and IWB. Consistent with prediction that general stress would be negatively associated with IWB, results showed a significant main effect of general stress on IWB, $F(1,61) = 59.86$ $p < .0001$, where couples who reported more general stress reported lower IWB, $b = -.60$, $p < .0001$. In other words, on average, there was a .60 unit decrease in IWB for each unit increase in general stress (see Table 5).

H1b: CI-related stress and IWB. Also supporting the prediction that CI-related stress would be negatively associated with IWB, there was a significant main effect of CI-related stress on IWB, $F(1,61) = 5.03$, $p < .05$, where couples who reported more CI-related stress reported lower IWB, $b = -.22$, $p < .05$ (see Table 6).

H1c: General stress and RWB. Consistent with predictions that general stress would be negatively associated with RWB, there was a significant main effect of general stress on RWB, $F(1,61) = 8.22$, $p < .0001$, where couples who reported more general stress reported lower RWB, $b = -.30$, $p < .0001$. As such, on average, for every unit increase in general stress there was a .30 unit decrease in RWB (see Table 5).

H1d: CI-related stress and RWB Additionally, consistent with predictions that CI-related stress would be negatively associated with RWB, there was significant main effect of CI-related stress on RWB, $F(1, 61) = 9.29$, $p < .01$, where couples who reported more CI-related stress reported lower RWB, $b = -.34$, $p < .01$. In other words, RWB scores decreased by .34 for each unit increase of CI-related stress (see Table 6).

RQ and H2: Moderating Effects of Positive DC between Stress and Well-Being

H2a: Positive DC on general stress and IWB. Contrary to the hypothesis that *positive DC* would moderate the association between general stress and IWB, there was

no interaction between general stress and *positive DC* on IWB, $b = .18$, $p > .05$ (see Table 7).

H2b: Positive DC on CI-related stress and IWB. Contrary to the hypothesis that *positive DC* would moderate the association between CI-related stress and IWB, there was no interaction between CI-related stress and *positive DC* on IWB, $b = .13$, $p > .05$ (see Table 8).

H2d: Positive DC on general stress and RWB. Additionally, contrary to the hypothesis that *positive DC* would moderate the association between general stress and RWB, there was no interaction between general stress and *positive DC* on RWB, $b = .01$, $p > .05$ (see Table 7).

H2d: Positive DC on CI-related stress and RWB. Contrary to the hypothesis that *positive DC* would moderate the association between CI-related stress and RWB, there was no interaction between CI-related stress and *positive DC* on RWB, $b = .03$, $p > .05$ (see Table 8).

RQ and H3: Moderating Effects of *Negative DC* between Stress and Well-Being

H3a: Negative DC on general stress and IWB. In contrast with the hypothesis that *negative DC* would moderate the association between general stress and IWB, there was no interaction between *negative DC* and general stress on IWB, $b = -.08$, $p > .05$ (see Table 9).

H3b: Negative DC on CI-related stress and IWB. In support of the hypothesis that *negative DC* would moderate the association between CI-related stress and IWB, there was a significant interaction between negative between CI-related stress and *negative DC* on IWB, $F(1, 61) = 5.33$, $p < .05$, where couples who reported high CI-

related stress and high *negative DC* also reported low IWB, $b = -.23$, $p < .05$ (see Table 10). This interaction was probed at one standard deviation above and below the means of the centered study variables (Aiken & West, 1991). This simple slope analysis revealed that, as predicted, CI-related stress was significantly negatively associated with IWB at low levels of negative DC ($b = -.043$, $p < .05$), as well as at high levels ($b = -.40$, $p < .01$; see Figure 1). Said differently, the results showed that *negative DC* exacerbated the detrimental association between CI-related stress and IWB.

H3c: Negative DC on general stress and RWB. Contrary to the prediction that *negative DC* would moderate the association between general stress and RWB, there was no interaction between general stress and *negative DC* on RWB, $b = .05$, $p > .05$ (see Table 9).

H3d: Negative DC on CI-related stress and RWB. Contrary to the prediction that *negative DC* would moderate the association between CI-related stress and RWB, there was no interaction between CI-related stress and *negative DC* on RWB, $b = -.07$, $p > .05$ (see Table 10).

CHAPTER 4

DISCUSSION

Over 25% of children in the US suffer from a chronic illness, and close to 70% of all childhood deaths are due to chronic illness (CDC, 2014). Statistical reports examining the prevalence of childhood chronic illness (both terminal and non-terminal) and chronic illness-related death rates convey that trends generally increase over time (CDC, 2014; Center for Managing Chronic Disease, 2014). As a result, the pervasiveness of couples faced with the stress associated with their child's chronic illness is also on the rise. These stressors (financial strain, caregiving demands, emotional distress, etc.) can have a negative effect on partners' individual and relational well-being. The goal of this study was to examine whether general stress and stress related to the child's chronic illness diagnosis (CI-related stress) were associated with reports of individual and relational well-being, and whether DC (*positive DC* and *negative DC*) moderated the associations between stress (general and CI-related) and well-being (individual and relational).

Effects of Stress on Well-being

Because stress can have a negative effect on individual and relational well-being, (Randall & Bodenmann, 2009), it was hypothesized that both types of reported stress (general and CI-related stress) would be negatively associated with individual well-being, as measured by total reported symptoms of depression and anxiety, as well as relational well-being, as measured by relationship satisfaction. As predicted, results showed a significant negative main effect between general stress and individual well-being meaning that when couples reported high general stress, they also reported low individual well-being. As predicted, results also showed a significant negative main

effect between CI-related stress and individual well-being. In other words, when couples reported high CI-related stress, they also reported low individual well-being.

Additionally, consistent with predictions, results revealed a significant, negative main effect between general stress and relational well-being, such that couples who reported high general stress also reported low relational well-being. Finally, also supporting the hypotheses, there was a significant, negative main effect between CI-related stress and relational well-being, meaning that couples who reported high CI-related stress also reported low relational well-being. Taken together, the results suggest there was a negative association between stress (general and CI-related) and well-being (individual and relational) for couples in this study, such that high stress is associated with low well-being. This is consistent with previous research examining the effects of stress on well-being (e.g., Badr et al., 2010; Bodenmann et al., 2011; Johnson & Sarason, 1978).

Moderating Effects of Positive Dyadic Coping on Stress and Well-Being

A second goal of the proposed project was to examine the moderating effects of *positive DC* on associations between stress and well-being. As *positive DC* can have a positive effect on individual well-being (Bodenmann et al., 2011) and relational well-being (Bodenmann, 2005; Bodenmann, et al., 2006; Bodenmann et al., 2007; Bodenmann et al., 2011), it was hypothesized that *positive DC* would moderate the associations between stress and well-being (both individual and relational). Specifically, it was hypothesized that *positive DC* would moderate relationships between general stress and individual well-being, CI-related stress and individual well-being, general stress and relational well-being, and CI-related stress and relational well-being. Contrary to hypotheses, results did not show a significant interaction of *positive DC* on the

association between general stress and individual well-being or on the association between CI-related stress and individual well-being. These findings do not support research demonstrating that *positive DC* has positive effects on individual well-being in terms of general stress (Bodenmann, 2006; Bodenmann et al., 2011) as well as health-related stress (Meier, et al., 2011). Also contrary to the hypothesis, results did not show a significant interaction of *positive DC* on the association between general stress and relational well-being or on the association between CI-related stress and relational well-being. Again, these findings do not support research exhibiting positive effects of *positive DC* on relational well-being in terms of general stress (Bodenmann, 2005) as well as health-related stress (Acitelli & Badr, 2005). Despite the lack of significant interactions, results revealed a significant main effect of *positive DC* on relational well-being, but not on individual well-being.

These results suggest that *positive DC* did not serve as a moderator between stress and well-being for this sample. Based on the aforementioned research supporting the moderating effect of *positive DC* on both types of stress and well-being, it is surprising that no significant interactions were found. However, given that couples were recruited for this study through various social support networks as well as the sample's high overall individual well-being, high relational well-being, and high *positive DC* (Falconier, 2015), these results may be influenced by variables outside of the study variables, such as social context. For example, although couples in this study reported high levels of stress, reports of high well-being could be associated with benefits of other supports couples receive outside of the relationship, such as a support group. Although supports from others do not have the same impact on well-being as support from a

romantic partner (Papp & Whitt, 2011), these results may be associated with one of the main commonalities shared by all couples in this study: access to and utilization of some form of support beyond that of partner support.

Moderating Effects of Negative Dyadic Coping on Stress and Well-Being

A third goal of the current study was to examine the moderating effects of *negative DC* on associations between stress and well-being. Because *negative DC* has shown to have a negative effect on individual well-being (Meier, et al., 2011) and relational well-being (Bodenmann, et al., 2011), it was predicted that *negative DC* would moderate the associations between stress and well-being. Specifically, it was hypothesized that *negative DC* would exacerbate the relationships between general stress and individual well-being, CI-related stress and individual well-being, general stress and relational well-being, and CI-related stress and relational well-being.

Consistent with the hypothesis that *negative DC* would moderate the association between CI-related stress and individual well-being, results revealed a significant interaction between *negative DC* and CI-related stress on individual well-being. This means that couples who reported high CI-related stress and high *negative DC* also reported low individual well-being. Supporting this prediction, simple slope analysis revealed that CI-related stress was significantly negatively associated with individual well-being at low levels *negative DC* as well as high levels *negative DC*. This means that, when CI-related stress is compounded with additional stress caused by *negative DC*, it exacerbates the association between CI-related stress and individual well-being. In other words, when the experience of CI-related stress is causing deficits to individual well-being, adding to the stress of engaging in *negative DC*, (at high or low levels of *negative*

DC) causes more deficits to individual well-being. This finding supports previous literature suggesting that *negative DC* has a negative effect on individual well-being in the context of health-related stress (Badr et al., 2010).

However, contrary to the hypothesis that *negative DC* would moderate the association between general stress and individual well-being, there was no significant interaction between *negative DC* and general stress on individual well-being. Also contrary to the hypothesis that *negative DC* would moderate the relationships between stress and relational well-being, results did not show a significant interaction between *negative DC* on the association between general stress and relational well-being or between CI-related stress and relational well-being. These findings do not support current research which indicates that *negative DC* has negative effects on individual well-being (Bodenmann et al., 2011) and that *negative DC* has negative effects on relational well-being in the context of general stress (Bodenmann et al., 2011) as well as health-related stress (Badr et al., 2010; Meier, et al., 2011). Despite the lack of significant interactions, results revealed a significant main effect of *negative DC* on relational well-being, but not on individual well-being.

These results suggest that *negative DC* has a negative effect on individual well-being (but not relational well-being) when couples are experiencing CI-related stress (but not general stress). This suggests that, in most cases, partners in this sample were not only able to cope with general stressors, they were also able to cope with CI-related stress, which is a more complicated stress (Kayser, 2005). However, partners were more affected by CI-related stress when engaging in *negative DC*. In other words, couples can

cope with the stress of their child's chronic illness except when additional stress is compounded on top of the existing stress.

For example, if partner A becomes disengaged to cope with CI-related stress, that partner will find that 1) engaging in *negative DC* (disengaged coping) will not be effective at decreasing his or her stress experience, 2) disengaging will also add to the couple's stress, and 3) by adding to the couple's stress, partner A will also be adding to his or her own stress and 4) this will harm partner's A's own well-being. Thus, *negative DC* not only fails to deal with the stressor, it also adds to stress, and this can affect the partner's individual well-being.

Limitations

Limitations of the current study must be noted. It is important to appreciate the ethnic and cultural diversity in the US, as this could have differential effects on both the experience of general levels of stress and parent's coping resources (Falconier, Randall, & Bodenmann, 2016). Specifically, a majority of individuals in this study identified as White/European American (82.3%), which limits the generalizability of the results to White and European Americans. The sample was also generally well educated, with approximately 30% having completed some college, over 27% with a bachelor's degree, and nearly 20% with a graduate or professional degree. Additionally, 32.5% of the 66 couples made less than 50,000 and 24.2% made over 100,000. Although the income brackets in between these highest and lowest brackets were distributed relatively evenly, resources available to the couples around the poverty line could differ from those on the high end of annual income (Federal Register, 2016). Importantly, results were based on a sample of couples who were recruited through various support networks,

which could have differentially affected the amount of stress parents (couples) reported compared to parents who are not affiliated with such networks. As such, this sample had greater access to resources for partners and couples (e.g., support groups), the child (e.g., day camps with opportunities to build coping skills and friendships with others with similar illnesses), and the family (e.g., hospital programs with mental health professionals). As social and emotional supports can have a positive effect on adjustment and well-being (Keese & Neimeyer, 2008), these factors may have an effect on the couples' outcomes. Given the demographic of the sample and these recruitment strategies, generalizability of the results may be limited and may generalize best to individuals with access to support network(s) that consist of mostly Caucasians in either the lower or the middle to higher range of socioeconomic status (Keese & Neimeyer, 2008). Future research should examine a more diverse sample, including couples of minority status, in lower socio-economic status, and other samples that may not have access to these resources.

Although the sample size of this study is consistent with other cross-sectional dyadic studies (Regan et al., 2014), the small sample-size limits the generalizability of these results for couples who have children with varying types of chronic illness and different levels of life-limitation. Participants were diverse in terms of the child's specific type of illness, the child's age, the participants' age, length of time couples have known each other, and relationship length. Without examining between-group differences, conclusions cannot be made regarding differences in stress experience for couples based on the child's prognosis (e.g., terminal versus non-terminal), the child's age (e.g., requiring full practical support from parents or some level of independence), and the

length of the couple's relationship (e.g., experience coping with dyadic stressors, comfort within the relationship, flexibility of coping patterns, etc). Additionally, as the sample of couples were in a relationship for a long time (unmarried $M = 13.24$ years; married $M = 11.90$ years), relative to many dyadic coping study samples, couples may have had ingrained patterns of coping with stress within the relationship (Badr et al., 2010). Because this study was unable to access DC patterns and behaviors before the child's diagnosis, whether couples' reports were specific to their coping with the child's illness exclusively or if they reflect patterns of coping with stress that existed before the stress related to the child's illness cannot be determined.

A longitudinal study would be useful in examining whether *positive DC* can mitigate the effect of stress on well-being at different stages, providing more context and meaning to such an association. Furthermore, this study did not ask couples to identify which of the two partners (or both) were considered the primary caregiver, which may provide insight into the utilization of the *delegated DC* scale as well as individual's stress and individual well-being. Studies show that, when fulfilling the caregiving role, individuals may report changes in individual well-being, such as general reduction in individual well-being, which in some cases can level out overtime due to the experience of caregiving as rewarding (Badr et al., 2010). Although this study had couples indicate their child's illness, it did not ask participants to rate their perceived severity or debilitation of the illness, level of responsibility for the child's health, or level of adjustment to the child's limitations, or specific prognosis. Results may differ if analyses compared prognosis (i.e., terminal versus non-terminal), and this is an area of exploration for future analysis. Future research may benefit from comparisons between couples

coping with a child's terminal illness and those coping with non-terminal illnesses to examine which DC strategies would be most (and least) beneficial in differing situations (Badr et al., 2010)

Although the *positive DC* composite of this measure had good internal consistency, the delegated DC subscale had an unacceptably low alpha. This may suggest that items related to delegated DC fail to capture elements of this type of coping as they relate to stress associated with a child's chronic illness. While the DCI has been utilized in health contexts in previous studies, it has not been used on samples consisting of couples with stress related to their child's health only (Falconier, et al., 2015). As the DCI measures general responses to stress, it may not necessarily be specific enough to assess how couples utilize particular techniques to cope with distinctive, CI-related stressors. Future studies should separate out perceptions of DC self, perceptions of DC partner, and common DC as well as separate out the *positive DC* subscales (emotion-focused, problem-focused, delegated) to examine further the coping behaviors of partners.

Future Directions

Stress can negatively affect reports of individual and relational well-being (Randall & Bodenmann, 2009), and as 132 partners coping with the stress related to their child's chronic illness also reported, stress specific to the child's illness also negatively affects individual and relational well-being. Despite some non-significant interactions in this study, prior research (Badr et al., 2011; Kayser, 2005; Meier et al., 2011) still points to the importance of teaching couples dyadic coping strategies to help them deal with stress in the context of their relationship. For example, the Couples Coping Enhancement

Training (CCET) program is a couple's coping intervention that provides psychoeducation and strategies for stress management and coping for couples dealing with various types of stress (Bodenmann & Shantinath, 2004). The purpose of CCET is to teach couples how to engage in and enhance their dyadic coping skills. Expanding on Bodenmann and Shantinath's (2004) CCET to focus on specific stressors, such as those related to a child's chronic illness diagnosis, could help couples understand their own and their partner's coping behaviors, learn how to provide dyadic coping to one another, and gain skills to cope with CI-related stress. As indicated by the sites contacted to recruit this sample, there are currently no coping intervention programs to help couples learn dyadic coping skills in the context of couples with chronically ill children. Therefore, future directions should focus on creating such an intervention for parents (couples) of this population. Research will be needed to examine the effectiveness of a couples' coping enhancement program for parents (couples) with children who have chronic, life-limiting, and terminal illnesses.

This study was the first to examine the effects of dyadic coping with stress related to a child's chronic illness on well-being. Overall, the results from this study add to the understanding of the negative associations between stress and well-being (Randall & Bodenmann, 2009), by specifically focusing on stress associated with a child's chronic illness. These findings have important implications for relationship researchers interested in constructs related to stress and coping and mental health counselors working with couples and families. Mental health counselors working with couples and families are encouraged to further explore the beneficial effect (positive) dyadic coping can have on partner's reports of individual and relational well-being (Falconier et al., 2015). As CI-

related stress appears to be experienced differently than general stress, counselors may benefit from conceptualizing CI-related stress as a dyadic stress, understanding how the couple copes as a unit, and differentiating individual coping and dyadic coping. To help the couple gain a better understanding of how they can cope together, counselors can examine the types of DC couples use (i.e., *positive DC*, *negative DC*) as well as how partners perceive their own and their partner's coping behaviors.

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APPENDIX A
TABLES

Table 1
Descriptive Statistics for Demographic Study Variables

	Men (n = 66)	Women (n = 66)
Racial/Ethnic Identification		
Asian/Asian-American	0%	1.5%
Black/African-American	6.1%	0%
Hispanic/Latino(a)	9.1%	10.6%
Native American or Pacific Islander	3.0%	1.5%
White/European American	80.3%	83.3%
Other	1.5%	3.0%
Education Level		
Less than High School	3.0%	1.5%
High School Diploma or Equivalent	9.1%	12.1%
Vocational/Technical School	7.6%	3.0%
Associate's degree	3.0%	6.1%
Some College	34.8%	27.3%
Bachelor's Degree	24.2%	28.8%
Graduate or professional degree	18.2%	21.2%
Yearly Household Income		
\$0-\$24,999	12.1%	12.1%
\$25,000-\$49, 999	24.2%	16.7%
\$50,000-\$74, 999	27.3%	30.0%
\$75,000-\$199, 999	10.6%	18.2%
\$100,000-\$149, 999	15.2%	12.1%
Greater than \$150,000	10.6%	10.6%
Number of Children		
One	12.1%	15.2%
Two	30.3%	28.8%
Three	28.8%	27.3%
Four	12.1%	15.2%
Five	7.6%	6.1%
Six	6.1%	4.5%
Greater than Six	3.0%	3.0%
Children from Past Relationships		
Living with couple > 50% of the time	15.2%	19.7%
Not living with couple	24.2%	15.2%

Table 2
Frequencies for Child's Chronic Illness by Couple

Child's Chronic Illness	Number of Couples	Percentage
Metastatic Cancer	6	9.1%
Non-Metastatic Cancer	6	9.1%
Blood Cancer (Leukemia)	5	7.6%
Cancer Total	17	25.8%
Autoimmune Disorder	10	15.2%
Cystic Fibrosis	1	1.5%
Neurological Disorder	12	18.2%
Severe Digestive Disorder	2	3.0%
Renal Disease	6	9.1%
Mitochondrial Disease	4	6.1%
Spina Bifida	2	3.0%
Congenital Heart Disease	3	4.5%
Other (Specified)	9	13.6%
TOTAL	66	100%
Life-threatening Total	33	50.0%
Multiple Diagnoses Total	7	10.6%

Table 3
Correlations among Study Variables

	1	2	3	4	5	6	7	8	9
1. General Stress		.43**	-.61**	-.25*	-.14	-.08	-.16	-.14	.18
2. CI Stress	.70**		-.19	-.27*	-.03	-.03	-.02	-.02	.24*
3. IWB	-.67**	-.56**		.07	.03	.03	.07	.03	-.06
4. RWB	-.27*	-.25*	.22		.76**	.70**	.68**	.58**	-.74**
5. <i>Positive DC</i>	-.20	-.15	.11	.84**		.88**	.91**	.77**	-.71**
6. Emotion- Focused DC	-.31*	-.30*	.17	.83**	.93**		.68**	.53**	-.62**
7. Problem- Focused DC	-.17	-.08	.07	.77**	.95**	.80**		.62**	-.65**
8. Delegated DC	-.00	-.01	.03	.70**	.84**	.72**	.72**		-.55**
9. <i>Negative DC</i>	.30*	.26*	-.18	-.70**	-.79**	-.78**	-.71**	-.67**	

Notes: CI Stress = Chronic illness-related stress (i.e., stress related to the child's chronic illness); IWB = individual well-being; RWB = relational well-being; *Positive DC* = positive dyadic coping; DC = dyadic coping

** indicates significance at the .01 level; * indicates significance at the .05 level. Men's correlations are presented above the diagonal and women's correlations are presented below the diagonal.

Table 4
Descriptive Statistics for All Study Variables by Gender

	Men				Women				Men-Women difference, t
	M	SD	α	Range	M	SD	α	Range	
IWB	1.54	.50	.92	.36-2.07	1.46	.41	.93	.50-3.14	1.18
RWB	3.83	.78	.78	2.14-5	3.57	1.04	.77	1.43-5	2.66**
General Stress	2.13	.61	.87	1.14-4	2.58	.66	.88	1.29-4	-4.82***
CI Stress	2.45	.65	.83	1.29-3.71	2.84	.66	.82	1.29-4	-4.24**
<i>Positive DC</i>	3.42	.57	.89	2.41-5	3.34	.71	.92	1.94-5	1.11
Emotion-Focused	3.32	.71	.81	2.18-5	3.23	.81	.83	1.83-5	1.11
Problem-Focused	3.43	.63	.83	2-5	3.33	.80	.87	1.29-5	1.12
Delegated	3.55	.63	.58	2.25-5	3.53	.66	.49	2.25-5	.32
<i>Negative DC</i>	2.23	.51	.87	1-4	2.40	.78	.85	1-3.88	-1.77

Note: IWB = Individual well-being. RWB = Relational well-being. CI Stress = Chronic illness-related stress (i.e., stress related to the child's chronic illness). DC= dyadic coping. Emotion-Focused= *Emotion-focused* dyadic coping. Problem-Focused= Problem-focused dyadic coping. Delegated = Delegated dyadic coping.

*** indicates significance at the .001 level; ** indicates significance at the .01 level; * indicates significance at the .05 level

Table 5
General Stress and Well-Being Model Results

	Individual Well-being				Relational Well-being			
	SE	<i>F</i>	<i>b</i>	<i>p</i>	SE	<i>F</i>	<i>b</i>	<i>p</i>
Intercept	.21		2.88	<.0001	.32		4.50	<.0001
<i>Controls</i>								
Grief	.06	1.68	-.08	.20	.08	2.43	-.13	.20
Time Since Diagnosis	.01	.33	.01	.57	.03	3.39	-.06	.57
Relationship Length	.01	.47	.01	.50	.02	.38	.01	.50
<i>Main Effects</i>								
General Stress	.08	59.86	-.60	<.0001	.10	8.22	-.30	<.0001

Notes: SE = Standard error; Time Since Diagnosis = time passed since child's CI diagnosis.

Table 6
CI-Related Stress and Well-Being Model Results

	Individual Well-being				Relational Well-being			
	SE	<i>F</i>	<i>b</i>	<i>p</i>	SE	<i>F</i>	<i>b</i>	<i>p</i>
Intercept	.26		3.25	<.0001	.33		4.40	<.0001
<i>Controls</i>								
Grief	.08	7.98	-.24	<.01	.09	.95	-.09	.33
Time Since Diagnosis	.02	.13	.01	.72	.03	2.92	-.05	.09
Relationship Length	.01	.99	.01	.32	.02	.55	.01	.46
<i>Main Effects</i>								
CI Stress	.10	5.03	-.22	.03	.11	9.29	-.34	<.01

Notes: SE = Standard error; Time Since Diagnosis = time passed since child's CI diagnosis; CI Stress = Chronic illness-related stress (i.e., stress related to the child's chronic illness)

Table 7
General Stress and Positive DC on Well-Being Model Results

	Individual Well-being				Relational Well-being			
	SE	<i>F</i>	<i>b</i>	<i>p</i>	SE	<i>F</i>	<i>b</i>	<i>p</i>
Intercept	.21		2.91	<.0001	.22		4.15	<.001
<i>Controls</i>								
Grief	.06	1.92	-.09	.17	.06	3.60	-.12	.06
Time Since Diagnosis	.01	.58	.01	.45	.02	6.27	-.05	.02
Relationship Length	.01	.36	.01	.55	.01	.48	.01	.49
<i>Main Effects</i>								
General Stress	.08	63.19	-.61	<.0001	.08	4.72	-.17	.03
Positive DC	.08	.27	-.04	.60	.08	177.26	1.04	<.0001
<i>Interactions</i>								
General Stress x Positive DC	.10	3.55	.18	.06	.10	.01	.01	.91

Notes: SE = Standard error; Time Since Diagnosis = time passed since child's CI diagnosis.

Table 8

CI-Related Stress and Positive DC on Well-Being Model Results

	Individual Well-being				Relational Well-being			
	SE	F	b	p	SE	F	b	p
Intercept	.26		3.21	<.0001	.22		4.01	<.0001
<i>Controls</i>								
Grief	.08	7.62	-.23	<.01	.07	.72	-.06	.40
Time Since Diagnosis	.02	.13	.01	.72	.02	6.29	-.04	.02
Relationship Length	.01	1.38	.01	.25	.01	.23	<.01	.63
<i>Main Effects</i>								
CI Stress	.10	4.82	-.22	.03	.08	10.62	-.26	<.01
Positive DC	.09	.16	.03	.69	.08	191.63	1.05	<.0001
<i>Interactions</i>								
CI Stress x Positive DC	.11	1.25	.13	.27	.10	.09	.03	.76

Notes: SE = Standard error; Time Since Diagnosis = time passed since child's CI diagnosis; CI Stress = Chronic illness-related stress (i.e., stress related to the child's chronic illness).

Table 9
General Stress and Negative DC on Well-Being Model Results

	Individual Well-being				Relational Well-being			
	SE	<i>F</i>	<i>b</i>	<i>p</i>	SE	<i>F</i>	<i>b</i>	<i>p</i>
Intercept	.22		2.92	<.0001	.25		4.12	<.0001
<i>Controls</i>								
Grief	.07	2.00	-.09	.16	.07	.18	-.03	.67
Time Since Diagnosis	.02	.27	.01	.60	.02	1.68	-.03	.20
Relationship Length	.01	.44	.01	.51	.01	1.43	.01	.24
<i>Main Effects</i>								
General Stress	.08	61.01	-.61	<.0001	.09	6.20	-.22	.02
Negative DC	.06	.34	-.04	.56	.07	84.43	-.68	<.0001
<i>Interactions</i>								
General Stress x Negative DC	.09	.83	-.08	.37	.10	.24	.05	.62

Notes: SE = Standard error; Time Since Diagnosis = time passed since child's CI diagnosis.

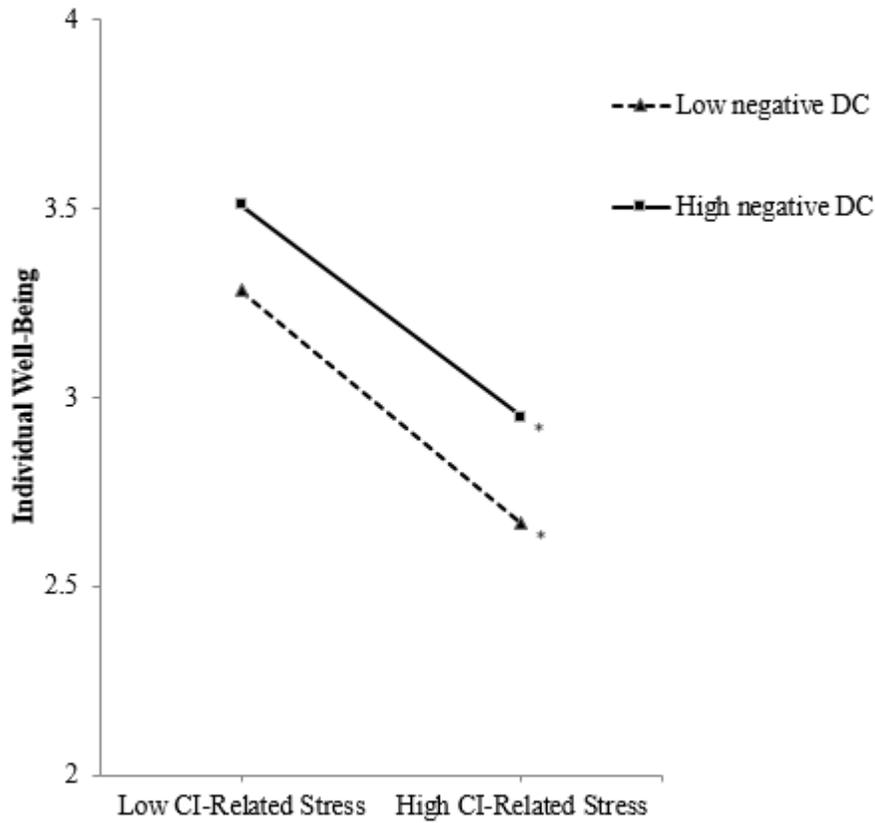
Table 10

CI-Related Stress and Negative DC on Well-Being Model Results

	Individual Well-being				Relational Well-being			
	SE	F	b	p	SE	F	b	p
Intercept	.26		3.24	<.0001	.26		4.12	<.0001
<i>Controls</i>								
Grief	.08	7.99	-.23	<.01	.08	.14	-.03	.71
Time Since Diagnosis	.02	.35	.01	.56	.02	1.13	-.02	.29
Relationship Length	.01	1.30	.01	.26	.01	1.62	.02	.21
<i>Main Effects</i>								
CI Stress	.10	5.00	-.22	.03	.10	3.69	-.19	.06
<i>Negative DC</i>	.07	.05	-.02	.82	.08	84.10	-.69	<.0001
<i>Interactions</i>								
CI Stress x <i>Negative DC</i>	.10	5.33	-.23	.02	.11	.41	-.07	.52

Notes: SE = Standard error; Time Since Diagnosis = time passed since child's CI diagnosis; CI Stress = Chronic illness-related stress (i.e., stress related to the child's chronic illness).

Figure 1
Interaction between CI-Related Stress and Negative DC on IWB



Notes: CI Stress = Chronic illness-related stress (i.e., stress related to the child's chronic illness); Negative DC = negative dyadic coping; * indicates significance at the .05 level.

APPENDIX A
RECRUITMENT SITES

Community Organizations' Listserves for Parents on National Health-related

Websites:

- The American Cancer Society
- National Cancer Institute
- Pancreatic Cancer Action Network
- Leukemia and Lymphoma society
- Leukemia Society of America
- Lupus Foundation of America
- Lupus Alliance of America
- Arthritis Foundation
- Crohn's and Colitis Foundation of America
- Cystic Fibrosis Foundation
- The Muscular Dystrophy Association
- National Institute of Neurological Disorders and Stroke (NINDS)
- Southwest Center for HIV/AIDS
- Spina Bifida Association
- Hope for Hypothalamic Hamartomas
- National Multiple Sclerosis Society
- Multiple Sclerosis Foundation
- Multiple Sclerosis Association of America
- ALS Association
- The American Heart Association
- Compassionate Care ALS, The DANA Foundation
- The National Children's Cancer Society
- The American Childhood Cancer Organization
- National Childhood Cancer Foundation
- Children's Hospital Association
- National Association of Children's Hospitals and Related Institutions (NACHRI)
- National Children's Center (NCC)
- Children's National
- American Children's Society
- Gastroparesis Patient Association for Cures and Treatments
- Gastroparesis and Dysmotilities Association
- Association of Gastrointestinal Motility Disorders (AGMD)
- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- The Elizabeth Glaser Pediatric AIDS Foundation
- Sickle Cell Disease Association of America
- American Liver Foundation
- Alternating Hemiplegia of Childhood Foundation (AHCF)

- American Autoimmune Related Diseases Association
- American Brain Tumor Association (ABTA)
- American Dystonia Society
- American Fibromyalgia Syndrome Association (AFSA)
- Association for Frontotemporal Degeneration (AFTD)
- Children's Tumor Foundation
- Childhood Brain Tumor Foundation
- Children's Brain Disease Foundation
- Children's Craniofacial Association
- Children's Hemiplegia and Stroke Association (CHASA)
- Pediatric Brain Foundation
- National Brain Tumor Society
- National Organization on Disability
- Pediatric Neurotransmitter Disease Association
- Pediatric Brain Tumor Foundation
- Reaching for the Stars (for Cerebral Palsy)
- United Cerebral Palsy (UCP).

Charity Organizations which Fund Wishes for Children with Life-threatening

Illnesses:

- Aladdin Foundation
- A Special Wish Foundation
- Believe In Tomorrow National Children's Foundation
- Children's Wish Foundation International
- Clayton Dabney Foundation, Dreams Come True Foundation
- Dreams Do Come True
- Hunt Of A Lifetime
- Jason's Dreams For Kids,
- Kidd's Kids
- Make-A-Wish Foundation of America
- Starlight Children's Foundation
- Wishes Can Happen Incorporated

Grief Support Groups for Parents of a Child with a Chronic or Terminal Illness

- Compassionate Friends
- Raising Special Kids
- Family Involvement Center
- Caregiver Action Network
- Grief Haven
- MISS Foundation

- Family Caregiver Alliance
- National Alliance for Caregiving
- National Family Caregivers Association
- Rosalynn Carter Institute for Caregiving
- Women's Health Information Center
- Catholic Charities
- Faith in Action
- Association of Jewish Family and Children's Agencies
- National Association of Christian Child and Family Agencies
- Arizona's Children Association
- Friend's Health Connection
- Mended Little Hearts Organization
- Neurofibromatosis Network of Arizona
- Special Needs Support Group of the North Valley
- National Center for Parents with Disabilities and their Families
- Through the Looking Glass
- The Wellness Community
- National Respite Network and Resource Center
- National Hospice and Palliative Care Organization
- National Hospice Foundation
- Hospice Foundation of America
- American Hospice Foundation
- Hospice of the Valley (Ryan's House)
- A-Better-Child.org
- AzParentalAdvocate.com
- Bridges4kids.org
- Cancer.net
- Caring.com
- ComfortZoneCamp.org
- Griefnet.org
- KidsHealth.org
- Kristies.org
- MSconnection.org
- NoahsChildren.com
- Our-Kids.org
- Recover-from-grief.com
- SupportingChildCaregivers.com
- HopeKids

APPENDIX B
SCREENING QUESTIONNAIRE

Screening Questionnaire

1. Are you and your partner both willing to participate in this study?
 - a. Yes
 - b. No

2. Are you and your partner the biological parents of a child under the age of 16, recently diagnosed with a chronic illness?
 - a. Yes
 - b. No

3. What languages do you speak fluently?
 - a. Please specify: _____

4. How long have you and your partner been dealing with the stress related to your child's diagnosis of a chronic illness?
 - a. ____ years
 - b. ____ months

5. Please indicate your child's chronic illness.
 - a. Metastatic cancer
 - b. Non-metastatic cancer
 - c. Blood cancer (e.g., leukemia)
 - d. Autoimmune disorder (e.g., juvenile rheumatoid arthritis, lupus)
 - e. Multiple sclerosis
 - f. HIV/AIDS
 - g. Cystic Fibrosis
 - h. Neurological Disease (e.g., multiple sclerosis, and juvenile fibromyalgia)
 - i. Digestive (e.g., Crohn's disease, gastroparesis, Hepatitis-C)
 - j. Diagnostician uncertain
 - k. Other (please specify) _____

APPENDIX C
RESEARCH SURVEY

Research Survey

1. How old are you?
 - a. Please specify: ____ years

2. What is your sex?
 - a. Male
 - b. Female
 - c. Other (please specify) _____

3. Which best describes your racial/ethnic background? (mark one or more):
 - a. Asian/Asian-American
 - b. Black/African-American
 - c. Hispanic/Latino(a)
 - d. Native American or Pacific Islander
 - e. White/European-American
 - f. Other (please specify)_____

4. What is your relationship status?
 - a. In a committed heterosexual relationship – not living together
 - b. In a committed heterosexual relationship – living together
 - c. In a committed same-sex relationship – not living together
 - d. In a committed same-sex relationship – living together
 - e. Engaged, in a heterosexual relationship, – not living together
 - f. Engaged, in a heterosexual relationship, –living together
 - g. Engaged, in a same-sex relationship, – not living together
 - h. Engaged, in a same-sex relationship, –living together
 - i. Married, in a heterosexual relationship
 - j. Married, in a same-sex relationship

5. What is the highest level of education you have completed?
 - a. Less than high school
 - b. High school diploma or equivalent (e.g. GED)
 - c. Vocational/technical school
 - d. Associate's degree
 - e. Some college

- f. Bachelor's degree
 - g. Graduate or professional degree (e.g. MA, Ph.D., MD, JD)
6. What is your typical yearly household income before taxes?
- a. \$0-\$25,000
 - b. \$25,000-\$49,999
 - c. \$50,000-\$74,999
 - d. \$75,000-\$99,999
 - e. \$100,000-\$159,999
 - f. Greater than \$150,000
7. How long have you and your partner known each other?
- a. ____ years
 - b. ____ months
8. How long have you and your partner been in a romantic relationship together?
- a. ____ years
 - b. ____ months
9. If you are married to your partner, how long have you been married?
- a. ____ years
 - b. ____ months
10. How many children do you have?
- a. Please specify: _____
11. Are any of these children from a relationship(s) other than your current relationship?
- a. Yes
 - b. No
12. If any of your children are from a previous relationship(s), do they live with you 50% or more of the time?
- a. Yes
 - b. No

Depression, Anxiety, Stress Scales
(DASS-21; Henry & Crawford, 2005)

The next items ask about different experiences people sometimes have. Please read each statement, consider your current situation in regard to your child with a chronic illness, and indicate how much the statement applies to you since your child's diagnosis of chronic illness.

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of the time
- 3 Applied to me very much, or most of the time

1. ____ I found it hard to wind down.
2. ____ I was aware of dryness of my mouth.
3. ____ I couldn't seem to experience any positive feelings at all.
4. ____ I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness
in the absence of physical exertion).
5. ____ I found it difficult to work up the initiative to do things.
6. ____ I tended to over-react to situations.
7. ____ I experienced trembling (e.g., in the hands).
8. ____ I felt that I was using a lot of nervous energy.
9. ____ I was worried about situations in which I might panic and make of fool of myself.
10. ____ I felt that I had nothing to look forward to.
11. ____ I found myself getting agitated.
12. ____ I found it difficult to relax.
13. ____ I felt down-hearted and blue.
14. ____ I was intolerant of anything that kept me from getting on with what I was doing.
15. ____ I felt I was close to panic.
16. ____ I was unable to become enthusiastic about anything.
17. ____ I felt I wasn't worth much as a person.
18. ____ I felt that I was rather touchy.
19. ____ I was aware of the action of my heart in the absence of physical exertion (e.g., sense

of heart rate increase, heart missing a beat).

20. ____ I felt scared without any good reason.

21. ____ I felt that life was meaningless.

Questions Pertaining to Specific Stressors Related to a Child's Chronic Illness

The next items ask about different stressful experiences people sometimes have when dealing with a child's recent diagnosis of a chronic illness. Please read each statement and indicate how much the statement applies to you since your child's diagnosis of a chronic illness.

- 0 Did not apply to me at all
 - 1 Applied to me to some degree, or some of the time
 - 2 Applied to me to a considerable degree, or a good part of the time
 - 3 Applied to me very much, or most of the time
-
- 1) I felt overwhelmed about making decisions regarding my child's treatment (e.g. doing independent research to learn about the disease, possible treatments, and side effects of treatments; consulting with physicians; obtaining second opinions, etc).
 - 2) I found it difficult to concentrate on anything without thinking about all of the ways my child's chronic illness may affect his/her future.
 - 3) I felt overwhelmed with the financial burden of health care and trying to get insurance approval to cover medical expenses (e.g., costs of medical testing, treatment and medication, doctor's appointments, etc).
 - 4) I felt that there has been no opportunity to spend quality time with my partner, as most of our conversations and time spent together related to the stress of our child with a chronic illness.
 - 5) I didn't know how to discuss my child's condition and the issues surrounding it with people other than my partner (e.g., family, friends, teachers and administrators at his or her school).
 - 6) I was concerned about the practical demands of treatment for my child (e.g., the availability of treatment in my area, cost of treatment, obtaining financial support for the treatment, time and scheduling demands, coordinating transportation, etc).
 - 7) I was preoccupied with the idea that my child's physical and/or psychological state is painful for him/her.

Relationship Assessment Scale
(RAS; Hendrick, Dicke, & Hendrick, 1998)

1. How well does your partner meet your needs?
 - a. Poorly
 - b. –
 - c. Average
 - d. –
 - e. Extremely Well
2. In general, how satisfied are you with your relationship?
 - a. Unsatisfied
 - b. –
 - c. Average
 - d. –
 - e. Extremely Satisfied
3. How good is your relationship compared to most?
 - a. Poor
 - b. –
 - c. Average
 - d. –
 - e. Excellent
4. How often do you wish you had not gotten into this relationship?
 - a. Never
 - b. –
 - c. Average
 - d. –
 - e. Very Often
5. To what extent has your relationship met your original expectations?
 - a. Hardly at All
 - b. –
 - c. Average
 - d. –
 - e. Completely
6. How much do you love your partner?
 - a. Not Much
 - b. –
 - c. Average
 - d. –
 - e. Very Much
7. How many problems are there in your relationship?
 - a. Very Few
 - b. –
 - c. Average
 - d. –
 - e. Very Many

Dyadic Coping Inventory
(DCI; Bodenmann, 2008)

Response Options

1. Very Rarely
2. Rarely
3. Sometimes
4. Often
5. Very Often

This section is about how you communicate your stress to your partner.

1. ___ I let my partner know that I appreciate his/her practical support, advice, or help.
2. ___ I ask my partner to do things for me when I have too much to do.
3. ___ I show my partner through my behavior when I am not doing well or when I have problems.
4. ___ I tell my partner openly how I feel and that I would appreciate his/her support.

This section is about what your partner does when you are feeling stressed.

5. ___ My partner shows empathy and understanding to me.
6. ___ My partner expresses that he/she is on my side.
7. ___ My partner blames me for not coping well enough with stress.
8. ___ My partner helps me to see stressful situations in a different light.
9. ___ My partner listens to me and gives me the opportunity to communicate what really bothers me.
10. ___ My partner does not take my stress seriously.
11. ___ My partner provides support, but does so unwillingly and unmotivated.
12. ___ My partner takes on things that I normally do in order to help me out.
13. ___ My partner helps me analyze the situation so that I can better face the problem.
14. ___ When I am too busy, my partner helps me out.
15. ___ When I am stressed, my partner tends to withdraw.

This section is about how your partner communicates when he/she is feeling stressed.

16. ___ My partner lets me know that he/she appreciates my practical support, advice, or help.
17. ___ My partner asks me to do things for him/her when he has too much to do.

18. ___ My partner shows me through his/her behavior that he/she is not doing well or when he/she has problems.
19. ___ My partner tells me openly how he/she feels and that he/she would appreciate my support.

This section is about what you do when your partner makes his/her stress known.

20. ___ I show empathy and understanding to my partner.
21. ___ I express to my partner that I am on his/her side.
22. ___ I blame my partner for not coping well enough with stress.
23. ___ I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.
24. ___ I listen to my partner and give him/her space and time to communicate what really bothers him/her.
25. ___ I do not take my partner's stress seriously.
26. ___ When my partner is stressed I tend to withdraw.
27. ___ I provide support, but do so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.
28. ___ I take on things that my partner would normally do in order to help him/her out.
29. ___ I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem.
30. ___ When my partner feels he/she has too much to do, I help him/her out.

This section is about what you and your partner do when you are both feeling stressed.

31. ___ We try to cope with the problem together and search for ascertained solutions.
32. ___ We engage in a serious discussion about the problem and think through what has to be done.
33. ___ We help one another to put the problem in perspective and see it in a new light.
34. ___ We help each other relax with such things as massage, taking a bath together, or listening to music together.
35. ___ We try to cope with stress by being affectionate with each other and making love.

This section is about how you evaluate your coping as a couple.

36. ____ I am satisfied with the support I receive from my partner and the way we deal with stress together.

37. ____ I find that, as a couple, the way we deal with stress together is effective.

Texas Revised Grief Scale
(TRIG; Faschingbauer, 1981)

Please read each statement, consider your current situation in regard to your child with a chronic illness, and indicate how much the statement applies to you since your child's diagnosis.

- 1 = Completely False
- 2 = Mostly False
- 3 = True and False
- 4 = Mostly True
- 5 = Completely True

1. ____ I still cry when I think about my child's diagnosis.
2. ____ I still get upset when I think about my child's diagnosis.
3. ____ I cannot accept my child's diagnosis.
4. ____ Sometimes I miss the person my child was before his/her diagnosis.
5. ____ Even now it's painful to recall memories of my child before his/her diagnosis.
6. ____ I am preoccupied with thoughts (often think) about the way my child was before his/her diagnosis.
7. ____ I hide my tears when I think about my child and his/her diagnosis.
8. ____ No one will ever take the place in my life of my child with chronic illness.
9. ____ I can't avoid thinking about my child's diagnosis.
10. ____ I feel it's unfair my child was diagnosed with his/her chronic illness.
11. ____ Things and people around me remind me of my child's diagnosis.
12. ____ I am unable to accept the effects my child's diagnosis.
13. ____ At times I feel the need to cry for my child with chronic illness.

APPENDIX D
IRB APPROVAL



APPROVAL: EXPEDITED REVIEW

Ashley Randall
 CLS - Counseling and Counseling Psychology
 480/727-5312
 Ashley.K.Randall@asu.edu

Dear Ashley Randall:

On 5/14/2015 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Coping with a Child's Chronic Illness Project
Investigator:	Ashley Randall
IRB ID:	STUDY00002692
Category of review:	(7)(b) Social science methods, (7)(a) Behavioral research
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • Couple's Coping CCI Measures_Final.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Couples' Coping CCI Recruitment RA Duties_Final.pdf, Category: Recruitment Materials; • Copy of Couples' Coping CCI Master List_Final.pdf, Category: Recruitment Materials; • Couple's Coping IRB Application_Final.docx, Category: IRB Protocol; • Couples' Coping CCI Flyer_Final.pdf, Category: Recruitment Materials; • Couple's Coping CCI Consent_Final.pdf, Category: Consent Form;

The IRB approved the protocol from 5/14/2015 to 5/13/2016 inclusive. Three weeks before 5/13/2016 you are to submit a completed Continuing Review application and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of 5/13/2016 approval of this protocol expires on that date. When consent is appropriate, you must use final, watermarked versions available under the "Documents" tab in ERA-IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc:

Courtney Johnson

APPENDIX E
IRB MODIFICATION



APPROVAL: MODIFICATION

Ashley Randall
 CLS - Counseling and Counseling Psychology
 480/727-5312
 Ashley.K.Randall@asu.edu

Dear Ashley Randall:

On 12/1/2015 the ASU IRB reviewed the following protocol:

Type of Review:	Modification
Title:	Coping with a Child's Chronic Illness Project
Investigator:	Ashley Randall
IRB ID:	STUDY00002692
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • IRB Appendices-modified 9-21.pdf, Category: Screening forms; • Copy of Couples' Coping CCI Master List_Final.pdf, Category: Recruitment Materials; • Couples' Coping CCI Recruitment RA Duties_Final.pdf, Category: Recruitment Materials; • Couple's Coping IRB Application-modified 9-21.docx, Category: IRB Protocol; • Flyer-PCH- Updated incentive.pdf, Category: Recruitment Materials; • FINAL Consent - modified 11-29-15.pdf, Category: Consent Form; • Flyer-Updated incentive.pdf, Category: Recruitment Materials;

The IRB approved the modification.

When consent is appropriate, you must use final, watermarked versions available under the “Documents” tab in ERA-IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc:

Courtney Johnson

APPENDIX F
INFORMED CONSENT

Title of research study: Coping with a Child's Chronic Illness: Effects of Dyadic Coping on Stress Associated with Ambiguous Loss

Investigator: Courtney Johnson (Primary Investigator) and Ashley K. Randall, Ph.D. (Faculty Primary Investigator)

Why am I being invited to take part in a research study?

We invite you to take part in a research study because you and your partner are the biological parents of a child, under the age of 16, who has been recently diagnosed (at least 3 months ago) with a chronic illness.

Why is this research being done?

Given the complexities of the challenges parents face in trying to navigate situations that are inherently complicated by uncontrollable variables, couples with chronically ill children are challenged with substantial stress. Dyadic coping (couples coping together) has been shown to have beneficial effects on mitigating experiences of stress for couples, while increasing individual and relational well-being. However, limited research exists on how engaging in dyadic coping can benefit couples experiencing stress regarding their child's chronic illness specifically. Thus, the purpose of this research is to gain a better understanding of how couples cope with stress associated to their child's illness.

How long will the research last?

This study will take place in 2 parts: (1) screening survey and (2) research survey. We expect that individuals will spend 5 minutes completing the screening survey, and 20 minutes completing the research survey.

How many people will be studied?

We expect about 60 couples (120 individuals) will participate in this research study.

What happens if I say yes, I want to be in this research?

You will be sent several electronic questionnaires to complete independent of your partner in this study. You will first complete a screening survey to ensure that you and your partner meet the requirements for this study. You will then be asked to complete a research survey, which should take no more than 20 minutes to complete and asks you to answer demographic questions and complete several questionnaires.

What happens if I say yes, but I change my mind later?

You can leave the research at any time, and it will not be held against you.

Is there any way being in this study could be bad for me?

Because some of the questions ask you to reflect on the stress of your child's illness, there is a very minimal probability that you may feel slight psychological discomfort, such as, mild feelings of anxiety or distress. However, if you experience any emotional discomfort during the study, it will probably feel similar or the same as the way you felt before starting the survey. It is unlikely that the questions in the study would increase your experience of stress, anxiety, or sadness.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, some participants may find it helpful to answer questions about how they cope together with their partner. A potential benefit may come from thinking about how you and your partner currently cope together and considering new ways you may be able to cope together with regard to challenges associated with your child's illness.

Results from this study may also help relationship researchers better understand how couples may cope with the stress of a child's illness which informs clinical training and intervention.

What happens to the information collected for the research?

All information from this study will be held confidential. Only the Primary Investigators will have access to your online responses to survey items. You will not be asked to provide any personal information, except for the information that is required for sending compensation (First Name, Last Name, and Address). To protect your anonymity, you will be assigned a unique ID number so that no one will be able to know who provided what responses to items on the survey. De-identified data may be shared with other researchers.

The aggregated results of this research study may be used in reports, presentations, and publications, but the researchers will not use any identifying information in these reports.

Who can I talk to?

If you have questions, concerns, or complaints, talk to the research team at parentsDCresearch@gmail.com. You may also contact the Primary Investigator, Courtney Johnson at Courtney.K.Johnson@asu.edu, and Faculty Primary Investigator, Dr. Ashley K. Randall at Ashley.K.Randall@asu.edu.

This research has been reviewed and approved by the Social Behavioral IRB. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

This form explains the nature, demands, benefits and any risk of the project. By checking the box below you agree knowingly to assume any risks involved. Remember, your participation is voluntary. You may choose not to participate or to withdraw your consent and discontinue participation at any time without penalty or loss of benefit. In checking the box below, you are not waiving any legal claims, rights, or remedies. A copy of this consent form can be sent to you upon request.

I have read the CONSENT FORM above and agree with all the terms and conditions. I acknowledge that by completing the survey, I am giving permission for the

investigator to use my information for research purposes. Additionally, you are also allowing other researchers access to your de-identified data (upon approval by the PIs, Courtney Johnson and Ashley K. Randall, Ph.D., Faculty Supervisor).

APPENDIX G
RECRUITMENT FLYER

Couples' Coping Project

- *Are you and your partner the parents of a child (aged 15 or younger), with a chronic illness or life-limiting condition?*
- *Have at least 3 months passed since the child's diagnosis?*
- *Would you and your partner be willing to participate in research on couples' coping and relationships?*



If you answered “yes” then you are eligible to participate in a research study on understanding how couples can cope with stress regarding a child's illness.

During this study you and your partner will complete:

- An online survey regarding your current relationship and stress associated with your child's health (~20 minutes to complete).

Upon completion of the study, couples will receive \$30, AND couples will also be entered to win one of three \$50 Visa gift cards.

To participate, please contact:
parentsDCresearch@gmail.com