12-2017

Parental Quality of Life Among Parents in the NICU: Examining Moderators of Change Over Time

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Recommended Citation

Lima, Evan, "Parental Quality of Life Among Parents in the NICU: Examining Moderators of Change Over Time" (2017). *Loma Linda University Electronic Theses, Dissertations & Projects*. 432.
https://scholarsrepository.llu.edu/etd/432

LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

Parental Quality of Life Among Parents in the NICU: Examining Moderators of Change Over Time

by

Evan Lima

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Clinical Psychology

December 2017

Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy in Clinical Psychology.

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ACKNOWLEDGEMENTS

First and foremost I want to thank God, without whose blessings I would never have been able to make it through this crazy process.

I would like to express my deepest gratitude to Dr. Cameron Neece, whose guidance, encouragement, and overall support, I am incredibly thankful. Thank you for providing me with so many opportunities throughout my time at LLU. Your guidance, encouragement, feedback, patience and support have meant so much to me throughout this process. I have learned so much from working with you, and look forward to continued collaborations in the future.

Thank you to my parents, Greg and Teri Lima, for their continued support as I made my way through my educational endeavors. Thanks also to my father for reading through this document as it was in the editing phase. Thanks for the late night and early morning runs to SeaTac Airport, and ensuring there was caffeinated coffee in the house when I came to visit.

To my beautiful nieces, Annin, Ashlen, and Adelyn. You ladies are the three most precious and beautiful girls I know. I always look forward to making goofy faces, having picnics and tea parties, reading books, hiking, and swimming. Spending time with you is always the highlight of my trip, and I love all three of you very much.

Thank you to Dr. Anita Hamilton and Dr. Kenneth Hartline from the Neuropsychology Program at Children's Hospital Los Angeles, and Dr. Joy Nichols from the Pediatric NeuroAssessment Program at the Loma Linda University Children's Hospital. Thank you all for taking the time to teach me the art of neuropsychological

assessment in the pediatric population. I have learned so much from, and have such great respect for all of you.

An extra special thanks to the close guy friends I have made while in Loma Linda. Josh Hivale, Phil Hivale, Calvin Chuang, Kris Baughman, Miguel Serrano, Chris Petr, Justin Mirande, Shawn Koh, RoyLyn Palmer-Coleman, and Shama Williams, you have all been with me through laughter, tears, holidays, and so much more. From late night Frappes and Fries runs, night before Thanksgiving slumber parties involving 3am runs to whatever happens to be open and cheesy 90s style family photos, Sabbath afternoon potlucks, game nights, and movies. I can always count on a good laugh with you all. The life long friendships we have cultivated are invaluable. Finally, thank you to the Lady Girls for keeping all us guys in line, and putting up with our nonsense, including the title Lady Girls.

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ABBREVIATIONS

LLUCH	Loma Linda University Children's Hospital
NTISS	Neonatal Therapeutic Intervention Scoring System
NICU	Neonatal Intensive Care Unit
PICU	Pediatric Intensive Care Unit
QOLI	Quality of Life Inventory

ABSTRACT OF THE DISSERTATION

Parental Quality of Life Among Parents in the NICU: Examining Moderators of Change Over Time

by

Evan Lima

Doctor of Philosophy, Graduate Program in Clinical Psychology
Loma Linda University, December 2017
Dr. Cameron Neece, Chairperson

Having a child is both an exciting and overwhelming time for parents (Wigert et al., 2006; Cooper & Pells, 2015). While having a child is an exciting time, approximately 10% of infants are born prematurely and admitted into the Neonatal Intensive Care Unit (NICU), with additional infants being admitted for other reasons (e.g., sickness, low birth weight, etc.) (March of Dimes, 2015). Overall, parents of children admitted to the NICU have consistently reported experiencing lower quality of life than prior the their child being admitted to the NICU (Rosenbaum et al., 2011). Previous research has found anxiety, depression, and posttraumatic stress disorder to negatively moderate parental quality of life (Shaw et al., 2006; Vanderbilt et al., 2009; Fonseca et al., 2012). Additionally, research points to three potential moderators of parental quality of life of parents whose child has been admitted to the NICU, (1) spirituality, (2) coping, and (3) social support (Kim et al., 2008; Hexen et al., 2011; Lavasani et al., 2011). The current study aims to further explore quality of life among parents whose child is admitted to the NICU by investigating potential moderators of change in parental quality of life over the NICU stay. Specifically, we aimed to (1) investigate the change, overt time, in the quality of life in parents of children in the NICU, and (2) to investigate potential moderators of the quality of life in parents of infants in the NICU. Data was collected from parents who had an infant admitted to the Loma Linda University Children's Hospital NICU. We conducted a paired sample t-test to assess change in parental quality of life over time. We conducted multiple moderation analyses to assess (2a) spirituality, (2b) social support, (2c) coping style, and (2d) overall severity of infant illness as moderators in parental quality of life over time. Results indicated that parental quality of life does not change significantly, over time, when their infant was in the NICU ($p > .05$). Results also indicated that none of the assessed moderators significantly moderated parental quality of life over time, when their infant was in the NICU ($p > .05$).

CHAPTER ONE

INTRODUCTION/LITERATURE REVIEW

Introduction

Having a child is both an exciting and overwhelming time for parents (Wigert et al., 2006; Hoffenaar, van Balen, & Hermanns, 2010; Cooper & Pells, 2015). Though having a child is reportedly an exhilarating time, there is a body of research, which suggests that parental marital satisfaction declines after the birth of a child, with one of the major moderators in the first year being the child's crying (Meijer & van den Wittenboer, 2007; Moller et al., 2008). Furthermore, research indicates that having a child in the Neonatal Intensive Care Unit (NICU) further exacerbates negative feelings such as depression, anxiety, and acute stress disorder (Doering, Moser, & Dracup, 2000; Lefkowitz, Baxt, & Evans, 2010).

It has been reported that more infants, many of whom were admitted to the NICU, die in the first 28 days of life than during any other period of childhood (Moura et al., 2011). In 2015, nearly 10% of infants born in the United States were categorized as premature (March of Dimes, 2015). Infants are admitted to the NICU, many times upon their birth, with specialized care provided for infants born sick, premature, and/or at a very low birth weight (Child Health USA, 2013). Further research reported that more than seven percent of infants admitted to the NICU stayed for more than six days for a various number of reasons, with the most common reasons being (1) pre-mature birth, (2) low birth weight, and (3) sickness such as intraventricular hemorrhage and infections (Russell et al., 2007; Hoque et al., 2011; Child Health USA, 2013; March of Dimes, 2015). Moreover, admission rates to NICUs in the United States are rising, with the most common cause being pre-mature birth (Stein, 2015; March of Dimes, 2015).

Upon admission to the NICU, infants are categorized into one of three levels, (1) healthy babies who require stabilization before being transferred for specialized services, (2) babies who were born over 32 weeks or are recovering from a more serious complication and require assisted ventilation, or (3) babies with a serious illness and/or congenital defect (Nemours Foundation, 2015; American Academy of Pediatrics, 2004).

Affects of Having a Child in the NICU on Parents

It is well-established that having a child in the NICU is a stressful time for parents (Wigert et al., 2006). There is a body of literature that indicates it is common for parents of infants admitted to the NICU to have significantly more symptoms and higher levels of depression, anxiety, and acute stress disorder (Carter, Mulder et al., 2007; MacDonald, 2007; Vanderbilt et al., 2009; Lefkowitz, Baxt et al., 2010). Additionally, having a child in the NICU causes some families' significant financial burdens (Argus et al., 2009). Financial worries come from hospital bills, food, and often paying to stay closer to the hospital (Argus et al., 2009). Furthermore, parents with an infant admitted to the hospital report higher levels of stress associated with having to pay for medical treatment (Argus et al., 2009). Parental stress is compounded when there are other children at home who need to be cared for, and often leaving one spouse to care for additional children at home (Argus et al., 2009). Overall, parents of children admitted to the NICU have consistently reported experiencing lower quality of life than prior to the their child being admitted to the NICU (Rosenbaum et al., 2011).

Parental Quality of Life

While there are many articles discussing the negative changes that take place following the birth of a child (e.g., reduced sleep, reduced relationship satisfaction, etc.), there are also positive changes that are reported. Some new parents report that their overall mood increased and that their depression decreased following the birth of their child (Groskop, 2011). Additionally, many new parents find that they are able to meet new people and make new friends after having a baby (Cohen, 2016). Having and caring for a baby takes up a lot of time, which some new parents find helps them in setting routines and schedules, and completing tasks in a more time-efficient manner (Cohen, 2016).

With new parents noting both positive and negative changes to take place following a child’s birth, it is important to explore any changes in parental quality of life (Landsem et al., 2015). Quality of life has been defined as an individual’s “ability to enjoy normal life activities” (Medicine Net, 2015). While the majority of people report wanting to have children, a number of studies indicate that parental quality of life decreases following the birth of a child (Moller et al., 2008; Lawrence et al., 2009; Dew et al., 2011). Additionally, researchers have also reported that, as additional children are born, parental quality of life continues to decline (Witting et al., 2008). Having a medically compromised infant further reduces parental quality of life (Fowlie & McHaffie, 2004). Parents who have a child admitted to the NICU consistently report that their quality of life decreases (Lawrence et al., 2009; Lefkowitz, Baxt, & Evans, 2010). Rosenbaum and colleagues (2011) found that 73% of parents who have a child in the NICU reported that they found prayer, faith, access to care from clergy, and belief in the quality of the parent-child relationship to be most helpful in effectively coping with having a child in the NICU.

Previous research has established that parents of children in the NICU report significant decreases in quality of life (Wiggert et al., 2006; Lawrence et al., 2009). Further research into specific aspects of the parental experience of having an infant in the NICU have reported that, while parental quality of life has been found to be negatively moderated by symptoms of various mood disorders (e.g., posttraumatic stress disorder, depression, anxiety), there may be additional moderators, aside from mood disorders, that significantly and negatively affect parental quality of life (Shaw et al., 2006; Vanderbilt et al., 2009; Fonseca et al., 2012). Researchers have reported that psychosocial support, spirituality, and copying style significantly and positively moderate parental reported quality of life in parents of children receiving palliative care, and parents of infants in the NICU (Hexen et al., 2011; Davidson, Jones, & Bienvenu, 2012). Assessing psychosocial support, spirituality, and coping style as moderators of parental quality of life will help to more effectively work with parents of children in the NICU throughout the infants' stay.

Spirituality as a Moderator of Parental Quality of Life

Although the physical care of infants in the NICU is important, spiritual care is an important component to provide to parents of infants in order to provide full support to parents during the difficult time of having a child admitted to the hospital (Rosenbaum et al., 2011). One study reported that nine out of 10 people believe in God or a higher power, with that number increasing to 95% when faced with an illness (Robinson et al., 2006). It is common for individuals to turn to spiritual matters in extreme circumstances, such as illness, with a reported 85% of patients utilizing religious beliefs to cope (Holland et al., 1998; Gall et al., 2005). Many healthcare professionals are uncomfortable in approaching parents and family members to discuss topics of spirituality (Rosenbaum et al., 2011). The lack of professionals (e.g., doctors, nurses, etc.) discussing spiritually based topics with parents has reportedly led to 60%-80% of parents of hospitalized children having unmet spiritual needs (Robinson, 2006). Rosenbaum and colleagues (2011) further reported that while the majority of pediatricians (76%) agree that addressing a families spiritual and religious needs is important, most (51%) never or rarely talk with families, and few (10%) do so as part of a routine. Robinson and colleagues (2006) found that not only did 60% to 80% of parents report having unmet spiritual needs, 73% of parents reported spiritual/religious themes (e.g., prayer, access to clergy, etc.) were most helpful to them. The main reason reported for the lack in hospital personnel discussing spiritually based topics with families is that there is a feeling of incompetence due to lack of training (Rosenbaum et al., 2011). This results in parents, caregivers, and family members being at increased risk for depression, anxiety, and trauma related symptoms for, at times, several years after the infant is no longer being hospitalized (Shaw et al., 2006; Davidson et al., 2012).

Spiritual and religiously themed matters have been found to have a positive influence on parents and families of ill children (Meert, Thurston, & Briller, 2005; Hexen et al., 2011). Having specific spiritual beliefs has been found to help reduce reported levels of depression (Holland et al., 1998). Parents have reported that even though they often experienced feelings of powerlessness and frustration, they felt the connection with their child was maintained through spirituality (Meert, Thurston, & Briller, 2005).

Spirituality has been reported to play a significant role in meaning making (Gall et al., 2005). One research study reported that individuals who had specific spiritual/religious beliefs, when faced with a life threatening illness, reported less depression, anxiety, and a greater ability to collaborate with hospital staff (Holland et al., 1998). More specifically, the research has consistently reported that individuals who report being spiritual have a higher quality of life (Sawatzky et al., 2005; Laudet et al., 2006; Tarakesherwar et al., 2006). There appears to be a lack of research studying the moderating effect of spirituality on parental quality of life of parents whose child is in the NICU. Given that there is a body of literature discussing the positive influence that spirituality has on parental quality of life, it is likely that spirituality influences the trajectory of quality of life among parents of infants in the NICU, such that parents with a lack of spiritual ties will report lower quality of life than parents with spiritual ties (Gall et al., 2005; Meert, Thurston, & Briller, 2005; Hexen et al., 2011).

Social Support as a Moderator of Parental Quality of Life

Spirituality, while the most widely researched, is not the only variable found to significantly moderate quality of life. There is a large body of literature in which it is reported that having a strong social support system buffers against a decline in mental status, which increases perceived quality of life (Jackson, 2006; Lavasani et al., 2011). A broad and accepted definition of social support is "…a range of interpersonal relationships or connections that have an impact on the individual's functioning, and generally includes support provided by individuals and by societal institutions (Barker, 2007). Social support has been found to increase an individual's health promoting behavior (e.g., exercise, healthy diet) and decrease health-compromising behaviors (e.g., inadequate sleep, substance abuse) (Jackson, 2006). One research study found that mothers who spoke about their feelings during the admissions process of their infant into the NICU had reduced posttraumatic stress disorder symptoms at follow up (Davidson, Jones, & Bienvenu, 2012). Another study reported that 32% of parents met criteria for acute stress disorder following the admittance of their infants into the NICU (Lefkowitz, Baxt, & Evans, 2010). Mothers of newborns who perceived high levels of social support reported higher quality of life than mothers who perceived low levels of social support (Webster et al., 2011). More specifically, individuals with higher levels of perceived social support reported less physical and mental complaints, and had lower levels of self-reported stress, compared to individuals with lower levels of perceived social support (Lovell, Moss, & Wetherell, 2012). Recent research has reported that there is no referral for psychosocial family support or support group for families of an infant being hospitalized (Moura et al., 2011).

The literature has consistently reported that individuals with more social support generally process and cope with crisis and traumatic events more effectively and in less time (Shaw et al., 2006; Eden & Callister, 2010). Moreover, parents of children admitted to the NICU report that having hospital staff inform them as to what to expect, emotional support, and having physical contact with their child to be helpful in the process of coping with having a child hospitalized (Eden & Callister, 2010; Hexen et al., 2011). Additionally, Eden and Callister (2010) reported that support to parents from NICU staff (e.g., nurses, doctors, etc.) helped to improve parent's decision making and grieving, particularly concerning the end of an infant's life. Furthermore, it has been reported that family members who experienced more social support had less anxiety (Davidson, Jones, & Bienvenu, 2012). Providing parents with parent and peer support programs, which allow parents the opportunity to debrief after having a child become hospitalized, may serve to reduce stress (Shaw et al., 2006).

Coping Style as a Moderator of Parental Quality of Life

Regardless of mental status (e.g., mentally healthy, anxious, depressed, etc.), it is necessary to cope effectively with the everyday stressors of life in order to maintain a positive mental state (Tugade & Fredrickson, 2007). Coping are "thoughts and behaviors used to manage the internal and external demands of situations that are appraised as stressful" (Folkman & Moskowitz, 2004). There is a large body of research assessing different ways of coping, two such ways have consistently been reported on and studied, emotion-focused coping and problem-focused coping (Herman & Tetrick, 2009; McKinley, 2013). Emotion-focused coping involves attempting to reduce one's negative response to a situation by concentrating on minimizing the emotional outcomes of the problem (e.g., anxiety, frustration), while problem-focused coping takes more practical ways to deal with stress (e.g., time management, social support) (Herman & Tetrick, 2009; Simply Psychology, 2015). Problem-focused coping has been reported to be a more effective way to long-term cope, more so than emotion-focused coping (Penley, Tomaka, & Wiebe, 2002; Herman & Teterick, 2009). It has been reported that women tend to be more successful in using emotion-focused coping, while men are more successful in using problem-focused coping (Baker & Berenbaum, 2007). The difference in response to emotion-focused and problem-focused coping is believed to be due to the fact that problem-focused coping aims to reduce stress by specifically reducing the effects of the stressor that causes the emotional reaction, whereas emotion-focused coping focuses on thoughts and/or feelings that result from stress without attempting to alter any environmental causes (Herman & Tetrick, 2009).

Coping style has consistently been shown to moderate quality of life (Grey et al., 2000; Kershaw et al., 2004; Kennedy, Lude, & Taylor, 2006; Kim et al., 2008). One study on men with human immunodeficiency virus (HIV), found that positive coping was associated with slower disease progression (Deichert & Fekete, 2008). Furthermore, Shaw and colleagues (2013) found dysfunctional coping to be positively associated with elevated risk of posttraumatic stress disorder in mothers of infants who had been in the NICU. Research has reported that problem-focused coping results in better adjustment to dealing with a sick child (Cobiella, Mabe, & Forehand, 1990; Seideman, 1997; Weiss et al., 2012). A study consisting of parents whose child was admitted to the pediatric intensive care unit (PICU) or the NICU found that problem-focused coping was associated with more improved psychological outcomes than emotion-focused coping (Shaw et al., 2013).

The Current Study

The current study aims to further explore the quality of life of parents whose child is in the NICU as well as explore specific moderators of changes in quality of life over the course of the NICU stay. Specifically, we aimed to investigate (1) the change over time in the quality of life in parents of infants in the NICU, and (2) potential moderators of the quality of life in parents of infants in the NICU. Specific hypotheses were formulated for the current study as well. It was hypothesized that (1a) parental quality of life will decrease over time, in parents whose infant is in the NICU, (2a) parents whose infants had less severe health problem will have no change in quality of life, while parents of infants with more severe health problems will have a greater decline in quality of life, (2b) those with high levels of perceived social support will have no change in quality of life, while those with low levels of perceived social support will have a greater decrease in perceived quality of life, (2c) those who utilize problem-focused coping will have no change in perceived quality of life, while those who use emotion-focused coping will have a greater decrease in their perceived quality of life, and (2d) life those who are more spiritual will have no change in perceived quality of life, while those who are less spiritual will have a greater decline in perceived quality of life.

CHAPTER TWO

METHODS AND MATERIALS

Participants

Participants were families recruited from the Loma Linda University Children's Hospital (LLUCH) Neonatal Intensive Care Unit (NICU) (see Table 1 for demographic information).

All infants enrolled in the study required the highest level of care, as determined by one of the pediatric surgeons who were part of the research team. Loma Linda's NICU is equipped with 84 licensed beds to treat the most critically ill infants (Loma Linda Health, 2015). The average number of infants per day in 2014 was 80, with an average length of stay of 21.3 days (E. Tagge, M.D., personal communication, November 4, 2015). The Loma Linda University Children's Hospital is one of the only level four NICUs in Southern California (E. Tagge, M.D., personal communication, June 30, 2016). Therefore, it is not uncommon for infants to be transferred to the LLUCH NICU from surrounding hospitals for treatment, with 58 of 1,214 (5%) patients being transferred to LLUCH NICU in 2014 (E. Tagge, M.D., personal communication, November 4, 2015). Of the 1,214 infants that stayed in the LLUCH NICU in 2014, 39 (3%) died (E. Tagge, M.D., personal communication, November 4, 2015). The emphasis of the LLUCH is developmentally appropriate care of neonates and, at the same time, to be culturally sensitive as individuals from many ethnic and religious backgrounds come through their doors (Loma Linda Health, 2015).

Table 1. Loma Linda University NICU Subject Recruitment Data

Variable	N	%	M	SD
Parents who completed first assessment	142			
Parents who completed second assessment	31			
Race				
Female Parent	29	74.4	3.48	.99
African American	1	2.6		
Caucasian	14	35.9		
Hispanic	11	28.2		
Asian	1	2.6		
Other	29	74.4		
Male Parent	25	64.1	3.76	1.36
African American	2	5.1		
Caucasian	7	17.9		
Hispanic	10	25.6		
Asian	1	2.6		
Other	4	10.3		
Marital Status				
Mother	28	71.8	2.57	1.48
Married	12	30.8		
Separated/divorced	2	5.1		
Never Married	14	35.9		
Father	26	66.7	2.35	1.47
Married	13	33.3		
Separated/divorced	2	5.1		
Never Married	11	28.2		
Income	25	64.1	2.80	2.10
$0 – 15,000	11	28.2		
$15,001 – 25,000	4	10.3		
$25,001 – 35,000	1	2.6		
$35,001 – 50,000	2	5.1		
$50,001 – 70,000	4	10.3		
$70,001 – 95,000	1	2.6		
Greater than $95,000	2	5.1		
Quality of Life at Time Point One	29	74.4	50.69	9.81
Quality of Life at Time Point Two	30	76.9	47.63	13.45
NTISS	31	100	17.16	8.03
Score 0-10	9	29.0		
Score 11-20	12	38.7		
Score 21-30	8	25.8		
Score 31-40	2	6.5		
Score 41-50	0	0		

Nursing and research staff approached and informed parents about the study if they met the selection criteria and signed a consent to be contacted that was collected by

NICU administrative staff. Inclusion criteria for the current sample were as follows: (1) all infants admitted to the LLUCH NICU who were identified as staying at least three weeks. Exclusion criteria were as follows: (1) Non-English speaking families, and (2) infants who were identified as staying less than three weeks. The criteria were chosen in order to provide an accurate and broad representation of characterization of parental mental health at infant NICU admission. Additionally, at the time, we did not have translations of the questionnaires in any other language besides English.

The study consisted of 31 parents who agreed to enroll in the study and completed questionnaires at initial admission and three weeks later. At the first time point, 142 parents completed questionnaires. However, due to a variety of reasons (e.g., discharge, death, unable to get in contact), only 31 parents competed both questionnaires at both time points. The majority of parents, who completed questionnaires at both time points, identified as Caucasian (38%). Additionally, a large proportion of the patients' parents were married (40.8%) and fell in the low-income level ($0 to $15,000) (23.9%). A majority of parents endorsed a high school diploma as their highest degree attained (42.3% of mothers and 46.5% of fathers). In terms of infant demographics, 58.1% (N = 18) were male while 41.9% (N = 13) were female, with the mean gestational age being 34.59 weeks (SD = 4.04) and the mean birth weight of 2,353.01 grams (SD = 850.49 grams).

Procedures

Personnel at the front desk in the NICU at LLUCH notified the research team about new cases that were admitted into the NICU. A neonatologist or other NICU staff obtained parents' consent to be contacted by the research team. If consent to contact was obtained, the research team was notified and a member of the research team contacted the family to set up an intake assessment. The intake interview was targeted to be completed within 48 hours of the child being admitted to the NICU. During the intake interview, research staff obtained informed consent and administered the first set of questionnaires to the parent(s). If all questionnaires were not completed at the intake, parents were permitted to take the questionnaires home and asked to return the measures within the next 24 hours. Research staff made phone calls to remind parents to return questionnaires. In addition, infant outcome measures from daily patient records tracked by the nursing staff and physical therapist were obtained at infant NICU admission. Three weeks after packets were returned, a second set of questionnaires was administered in order to clarify the feasibility of collecting longitudinal data. A member of the research team extracted data from PowerChart. All data was entered and stored in SPSS 21.0 (IBM, 2012). Data from the 31 longitudinal participants were used in order to run preliminary correlations in order to look at the size of the relationship (see Table 2).

Table 2. Correlation between Moderator Variables

	QOLI_T1	QOLI_T2	PFC	EFC	NTISS	Social Support	Spirituality
QOLI_T1	-						
QOLI_T2	.60*	-					
PFC	-.02	.28	-				
EFC	-.04	.06	.34	-			
NTISS	.24	.29	-.14	-.04	-		
Social Support	-.31	-.42**	.18	-.28	-.29	-	
Spirituality	.15	.28	.29	.46**	.07	-.12	-

**$p < .001$, *$p < .05$

Measures (see Table 3)

Table 3. Measures for NICU Project

Measures for NICU Project			
Measure	**Description**	**Type of Measure**	**Variable**
Process Variables			
Demographics questionnaire	Demographic data was collected by a questionnaire that parents will be asked to complete called the Development History Questionnaire. In addition, questions about prenatal history and infant diagnosis will be asked.	Parent Interview	This questionnaire assessed potential confounding variables such as a history of prenatal counseling, whether or not the infant is a transfer patient, whether the parents have had a previous child in the NICU, if the NICU admission expected, the appearance of infant, number of parent visitations to NICU, parental feelings of hope, amount of parental participation in their child's care, amount of social support, family financial situation, and family's spirituality and beliefs.

Independent Variable Measures of Parental Stress and Overall Parental Functioning			
Brief COPE Scale	The Brief COPE Scale is a 28-item measure used to assess different ways in which people respond to stress. It consists of five scales with four items each measuring distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that are less useful (focus on and venting of emotions, behavioral disengagement, mental disengagement). Each item was measured using Likert scales ranging from 1 (“I don’t do this at all”) to 4 (“I do this a lot”). The Brief COPE Scale showed fairly good reliability and validity (Yusoff, Low, & Yip, 2010).	Parent Report	All subscales of this scale was used to identify coping styles used by parents in the NICU.
Quality of Life Inventory (QOLI)	The QOLI assesses an individual’s quality of life through self-report of the importance they attach to each of the 16 domains on a 3- point scale. In addition, it assesses current satisfaction with each domain on a 6-point rating scale. Importance scores are multiplied by satisfaction scores for each domain, and then these scores are summed to determine an overall current quality of life for each individual. The QOLI possesses good internal consistency (.79) and two week test-retest (.73) reliability. Good convergent validity has been demonstrated between QOLI total score and both the Satisfaction With Life Scale (.56) and the Quality of Life Index scores (.75) (Frisch, 1992).	Parent Report	The total scale of this measure was used to look at other aspects of parents’ lives that may contribute to or protect from distress.
Measure	**Description**	**Type of Measure**	**Variable**
Outcome Measures of Infant Vitality			
Chart Review	Information from patient charts in the program called “Powerchart” will be extracted including weight, temperature, length of stay, head circumference, length, and other vitality measures tracked by NICU staff.	NICU staff Observation which are charted daily for all patients	Information was used to calculate the NTISS score.
Measure	**Description**	**Type of Measure**	**Variable**
NTISS	The NTISS is a scoring system for ICU and surgery patients in the NICU. It is a therapy-based severity of illness assessment index with scores ranging from 0 to 47 and is a modification of the TISS score of Cullen et al (1974) suitable for use in neonatal intensive care. The minimum score for a NICU infant is 4 because there are 4 procedures mandated for a NICU baby at Loma Linda Medical Center (Frequent vital signs, Cardiorespiratory monitoring, Noninvasive oxygen monitoring, Quantitative intake and output), each of which is one point. The NTISS measures severity by quantifying the intensity and complexity of care received by a patient by assigning score points from 1 to 4 for various intensive care therapies including respiratory, drug therapy, cardiovascular, monitoring, transfusion, metabolic/nutrition, and vascular access.	Chart Review	This measure was used to assess for infant severity.

Demographics

Demographic data was collected by a questionnaire that parents were asked to complete called the Development History Questionnaire. In addition, questions about prenatal history and infant diagnosis were asked. This questionnaire also assessed potential confounding variables such as a history of prenatal counseling, whether or not the infant was a transfer patient, whether the parents have had a previous child in the NICU, if the NICU admission was expected, the appearance of infant, number of parent visitations to NICU, parental feelings of hope, amount of parental participation in their child's care, amount of social support, family financial situation, and family's spirituality and beliefs.

For the current study, level of social support was measured using the six-point Likert scale question "I get the emotional help and support I need from family and friends", ranging from 1 (strongly agree) and 6 (strongly disagree). Additionally, level of spirituality was measured using the eight-point Likert scale question "I consider myself a spiritual person", ranging from 1 (Definitely False) and 8 (Definitely True). Both questions were taken from the demographic questionnaire, which was completed by parents at the first time point.

The QOLI assesses an individual's quality of life through self-report of the importance they attach to each of the 16 domains on a 3- point scale. In addition, it assesses current satisfaction with each domain on a 6-point rating scale. Importance scores are multiplied by satisfaction scores for each domain, and then these scores are summed to determine an overall current quality of life for each individual. The QOLI possesses good internal consistency ranging from (.77 - .89) and two-week test-retest ranging from (.80 - .91) reliability (Frisch, 1992). Good convergent validity has been demonstrated between QOLI total score and both the Satisfaction With Life Scale (.56) and the Quality of Life Index scores (.75) (Frisch, 1992). The total scale of this measure was used to look at other aspects of parents' lives that may also contribute to distress. The reliability obtained in our sample for the total scale, at both time points, was α =.81 at admission and α =.86 three-weeks later. The T-score from each of the two time points of the QOLI was utilized when running the t-test.

The Brief COPE Scale is a 28-item measure used to assess different ways in which people respond to stress. It consists of 14 scales with two items each measuring distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that are less useful (focus on and venting of emotions, behavioral disengagement, mental disengagement). Each item was measured using Likert scales ranging from 1 ("I don't do this at all") to 4 ("I do this a lot"). The Brief COPE Scale showed fairly good reliability and validity (Yusoff, Low, & Yip, 2010).

Due to unsatisfactory reliability levels (.59) within the scales of the measure, we ran an item if deleted analysis in SPSS 21.0, and deleted items in which it was indicated that doing so would increase reliability to the greatest potential, and repeated until reaching acceptable levels of reliability (see Table 4 for subscale breakdown and unused items) (IBM, 2012).

Table 4. Breakdown of Subscales and Unused Items of Brief COPE

Subscale	Item Name
Problem-Focused Coping	I've been concentrating my efforts on doing something about the situation I'm in.
	I've been taking action to try and make the situation better.
	I've been getting help and advice from other people.*
	I've been trying to get advice or help from other people about what to do.*
	I've been trying to come up with a strategy about what to do.
	I've been thinking hard about what steps to take.
Emotion-Focused Coping	I've been accepting the reality of the fact that it has happened.*
	I've been learning to live with it.*
	I've been getting emotional support from others.
	I've been getting comfort and understanding from someone.
	I've been making jokes about it.*
	I've been making fun of the situation.*
	I've been trying to see it in a different light, to make it seem more positive.
	I've been looking for something good in what is happening.
	I've been trying to find comfort in my religion or spiritual beliefs.
	I've been praying or meditating.
Less Useful Coping	I've been giving up trying to deal with it.*
	I've been giving up the attempt to cope.*
	I've been saying to myself "this isn't real."
	I've been refusing to believe that it has happened.
	I've been turning to work or other activities to take my mind off things.*
	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.*
	I've been criticizing myself.
	I've been blaming myself for things that happened.
	I've been using alcohol or other drugs to make myself feel better.*
	I've been using alcohol or other drugs to help me through it.*
	I've been saying things to let my unpleasant feelings escape.*
	I've been expressing my negative feelings.*

*Variable deleted in order to increase reliability.

Reliability obtained in our study for each subscale was: problem-focused coping (.78), emotion-focused coping (.74), and less useful coping (.81). All subscales of this scale were used to screen parents for any protective or risk factors that may make them more or less prone to experiencing high levels of stress. We only utilized problem-focused coping and emotion-focused coping for our moderation analyses.

The NTISS is a scoring system for ICU and surgery patients in the NICU. It is a therapy-based severity of illness assessment index with scores ranging from 0 to 47 and is a modification of the Therapeutic Intervention Scoring System (TISS) score of Cullen et al (1974) suitable for use in neonatal intensive care. NTISS measures severity by quantifying the intensity and complexity of care received by a patient by assigning score points from 1 to 4 for various intensive care therapies including respiratory, drug therapy, cardiovascular, monitoring, transfusion, metabolic/nutrition, and vascular access. As such, the minimum score for a NICU infant at Loma Linda University Medical Center is 4 because there are 4 procedures mandated for NICU admission there (Frequent vital signs, Cardiorespiratory monitoring, Noninvasive oxygen monitoring, Quantitative intake and output), each of which is one point. It is based on the assumption that given similar philosophies or styles of care, that therapeutic intensity is a direct correlate of illness severity. This measure was used to assess for infant severity. Time point one of the NTISS was collected at admission.

For the study, due to the medical knowledge necessary to score the NTISS, a medical student and a pediatric surgeon were recruited for the purpose of coding and scoring each NTISS measure. Cohen's k was run to determine if there was agreement between the pediatric surgeon and medical student on measures of infant severity in the NICU. There was almost perfect agreement between the pediatric surgeon and medical student, (k = .99; $p < .01$).

Data Analytic Plan

In order to test our hypothesis that the quality of life in parents who have an infant in the NICU decreases over time (Hypothesis 1a), a Paired-Sample *t*-test was performed.

Multiple linear regression using and a hierarchical stepwise technique was used for the moderator analyses, following the guidelines of Baron and Kenny (1986), using model one in the PROCESS syntax for SPSS 21.0 (IBM, 2012; Hayes, 2013). The variables were entered in a stepwise procedure (independent variable, moderator variable, interaction term). The interaction term was created by multiplying the independent variable and the moderator variable after both variables had been centered to a mean of zero (Baron & Kenny, 1986). If the interaction term was significant, the moderation was supported. Significant interactions were to be probed using the guidelines of Baron and Kenny (1986) to describe the moderator effect.

For Hypothesis 2a, the independent variable of the regression equation was the first time point of the quality of life, the moderator variables was the infants severity score (NTISS), and the interaction term was the independent variable of the first time point of parental quality of life. The dependent variable was the second time point of parental quality of life.

For Hypothesis 2b, the independent variable of the regression equation was the first time point of the quality of life, the moderator variable was the level of social support, and the interaction term was the independent variable of the first time point of parental quality of life. The dependent variable was the second time point of parental quality of life.

For Hypothesis 2c, the independent variable of the regression equation was the first time point of the quality of life, the moderator variables were problem-focused coping and emotion-focused coping, and the interaction term was the independent variable of the first time point of parental quality of life. The dependent variable was the second time point of parental quality of life.

For Hypothesis 2d, the independent variable of the regression equation was the first time point of the quality of life, the moderator variable was the level of spirituality, and the interaction term was the independent variable of the first time point of parental quality of life. The dependent variable was the second time point of parental quality of life.

Mean and standard deviation for all moderators were run (please see Table 5 for a full report of means and standard deviations).

Table 5. Mean and Standard Deviation for All Moderator Variables

Moderator	Mean	Standard Deviation
Severity	17.16	8.03
Spirituality	5.93	2.56
Social Support	1.68	1.14
Emotion-Focused Coping	22.42	4.72
Problem-Focused Coping	9.52	2.72

CHAPTER THREE

RESULTS

A paired-sample *t*-test was run in SPSS 21.0 to assess whether self-reported levels of parental quality of life would increase or decrease three weeks after their infant's admission into the NICU (IBM, 2012). The study hypothesized that parental quality of life would decrease over time (Hypothesis 1a). Results indicated that parents with children in the NICU reported similar levels of quality of life at the initial intake (M = 50.32, SD = 9.79) and at the three week follow up (M = 47.61, SD = 13.88). Results of a paired-samples *t*-test indicated that there was no significant difference between quality of life at intake and quality of life at the three-week follow up ($t(27) = 1.28$, $p > .05$; $d = .24$).

A moderation analysis was conducted using model one of the PROCESS macro for SPSS to assess whether infant severity moderated parental quality of life over time in parents who have an infant in the NICU (Hypothesis 2d) (Hayes, 2013). Results indicated that the infants overall severity did not significantly moderate change in parental quality of life over time ($p > .05$) (see Table 6 for full report of results).

Table 6. Results of Infant Severity as a Moderator of Parental QOL

Model	B	se	*t*	*p*	95%CI
Infant Severity					
Constant	47.79	2.73	17.50	.000*	[42.16, 53.43]
NTISS	.238	.309	.773	.447	[-.398, .875]
QOLI	.784	.275	2.85	.009**	[.217, 1.35]
Intercept	-.009	.042	-.204	.840	[-.094, .077]

**p*<.001, ***p*<.01

A moderation analysis was conducted using model one of the PROCESS macro for SPSS to assess whether self-reported levels of spirituality moderated parental quality of life over time in parents who have an infant in the NICU (Hypothesis 2a) (Hayes, 2013). Results indicated that self-reported levels of spirituality did not significantly moderate change in parental quality of life over time (*p* > .05) (see Table 7 for full report of results).

Table 7. Results of Spirituality as a Moderator of Parental QOL

Model	B	se	*t*	*p*	95%CI
Spirituality					
Constant	47.75	2.57	18.59	.000*	[42.43, 53.06]
NTISS	1.05	1.34	.78	.441	[-1.73, 3.83]
QOLI	.777	.291	2.67	.014**	[.174, 1.38]
Intercept	-.052	.157	.332	.743	[-.376, .272]

**p*<.001, ***p*<.01

A moderation analysis was conducted using model one of the PROCESS macro for SPSS to assess whether self-reported levels of social support moderated parental quality of life over time in parents who have an infant in the NICU (Hypothesis 2b) (Hayes, 2013). Results indicated that self-reported levels of social support did not significantly moderate change in parental quality of life over time (*p* > .05) (see Table 8 for full report of results).

Table 8. Results of Social Support as a Moderator of Parental QOL

Model	B	se	*t*	*p*	95%CI
Social Support					
Constant	46.55	3.24	14.36	.000*	[39.86, 53.24]
NTISS	-3.62	6.66	-.544	.592	[-17.36,10.12]
Social Support	.744	.377	1.97	.060	[-.034, 1.52]
Intercept	-.207	.349	-.592	.560	[-.928, .515]

**p*<.001, ***p*<.01

Two moderation analyses were conducted using model one of the PROCESS macro for SPSS to assess whether problem-focused coping is more effective than emotion-focused coping on perceived quality of life among parents who have an infant in the NICU (Hypothesis 2c) (Hayes, 2013). Results indicated that problem-focused did not significantly moderate change in parental quality of life over time (*p* > .05). Additionally, results further indicated that emotion-focused coping did not significantly moderate change in parental quality of life over time (*p* > .05). Therefore, our hypothesis that those who utilize problem-focused coping will have no change in perceived quality of life, while those who use emotion-focused coping will have a negative change in their perceived quality of life was not supported (see Table 9 and Table 10 for full report results).

Table 9. Results of PFC as a Moderator of Parental QOL

Model	B	se	*t*	*p*	95%CI
PFC					
Constant	47.01	2.26	20.83	.000*	[42.34, 51.68]
NTISS	1.70	1.18	1.45	.162	[-.731, 4.13]
PFC	1.24	.391	3.18	.004**	[.433, 2.05]
Intercept	-.186	.155	-1.20	.242	[-.506, .134]

**p*<.001, ***p*<.01

Table 10. Results of EFC as a Moderator of Parental QOL

Model	B	se	*t*	*p*	95%CI
EFC					
Constant	47.55	2.34	20.31	.000*	[42.72, 52.39]
NTISS	-.003	.545	-.005	.995	[-1.13, 1.12]
EFC	.816	.229	3.57	.002**	[.344, 1.29]
Intercept	-.045	.053	-.863	.397	[-.154, .063]

**p*<.001, ***p*<.01

CHAPTER FOUR

DISUSSION

We tested whether or not parental quality of life significantly changed over time when their infant was in the NICU. It was hypothesized that parental quality of life would decrease over time (Hypothesis 1a). We reviewed the results of our paired samples t-test and determined that our hypothesis was not supported ($p > .05$). Additionally, we tested whether change in parental quality of life was significantly moderated by spirituality, social support, or the overall severity of the infant. Our hypotheses were that spirituality, social support, and overall severity of the infant would significantly moderate change in parental quality of life over time. We reviewed the results of our moderation analyses and determined that spirituality, social support, and overall severity of the infant did not significantly moderate change in parental quality of life over time ($ps > .05$). More specifically, we tested whether or not individuals who utilized problem-focused coping or emotion-focused coping would have a significant change in quality of life over time. Our hypothesis was that individuals who used problem-focused coping would report no change in quality of life over time, while individuals who used emotion-focused coping would report a negative change in quality of life over time. We reviewed the results of our moderation analyses and determined that our hypothesis was not supported ($ps > .05$).

Because of our small sample size ($N = 31$), the study was underpowered. We conducted power analyses in G*Power and discovered we needed a sample size of 34, and a sample size of 68 to detect a medium effect size for our first and second aims, respectfully (Faul, Erdfelder, Bychner & Lang, 2009). The study had a sample size of 31, which fell short of the calculated sample size needed for either aim, more significantly for our second aim. Post-hoc power analyses were conducted in G*Power to assess power based on our sample size (Faul, Erdfelder, Bychner & Lang, 2009). It was found that, for our study, our first aim had a power of .77, and our second aim had a power of .36. Lack of power increases the possibility of Type II error. Increasing the sample size would decrease the possibility of committing Type II error. However, despite the lack of power for our second aim, we had medium effect sizes for each hypothesis ($f^2 = .20$ - .37), and we can therefore conclude that there is a moderate possibility that increasing our sample size to achieve adequate levels of power would not result in significant findings for any of the moderators tested in our study.

Aside from the lack of power, the small sample size likely caused reliability levels within the Brief COPE to be low ($\alpha < .60$). Due to the low observed reliability levels, we had to perform an item deleted analysis in SPSS 21.0 leading to the deletion of multiple items from each scale (IBM, 2012). Deleting multiple items from a scale can cause the measure to no longer measure what it was originally designed to measure. A follow-up study would be essential in order to examine the psychometric validity of the adjusted scales to ensure they are still measuring the constructs of interest, mainly for less useful coping as more than half of the items were deleted in order to attain adequate reliability. It is important to note that less useful coping was not utilized in any of the statistical analyses. Increasing the sample size would also likely increase levels of reliability within the scales, allowing all items within each scale to be utilized, thus ensuring that the validity and reliability of the measure remains intact. Further, using all items within the scale would give deeper insight into the experience of parents who have a child in the NICU.

We found that quality of life among parents who have a child in the NICU did not significantly change over a three-week period of their infant's hospitalization ($p > .05$). Despite the small sample size (N = 31) the lack of significant findings was likely not due to lack of power as we had a power of .77, with a small effect size ($d = .24$). Therefore, it is likely that increasing the sample size would not increase our chances of finding significance in quality of life. Post-hoc t-tests were completed to assess all 16 domains that the QOLI measures. Results indicated that parents in the NICU reported higher levels of self-esteem at intake (M = 3.11, SD = 2.27) than at three-week follow-up (M = 2.36, SD = 2.82). Results of the paired-samples *t*-test indicated that there was a significant difference between self-esteem at intake than at three-week follow up (t(27) = 2.14, $p = .042$; $d = 24$). All other domains of the QOLI measure were not significant, *ps* > .05 (Table 11 for full report of post-hoc t-tests).

Table 11. Quality of Life Inventory Post-Hoc t-Tests

Predictor	Mean	SD	*t*	*p*	95%CI
Health	.07	3.43	.110	.913	[-1.26, 1.40]
Self-Esteem	.75	1.86	2.14	.042*	[.029, 1.47]
Goals & Values	.25	2.84	.47	.645	[-.850, 1.350]
Money	.36	1.95	.97	.341	[-.398, 1.11]
Work	-.30	2.60	-.59	.559	[-1.32, .732]
Play	.46	3.53	.70	.493	[-.906, 1.834]
Learning	-.07	3.41	-.11	.913	[-1.40, 1.25]
Creativity	.29	2.73	.55	.585	[.517, -.774]
Helping	.67	2.76	1.26	.221	[.531, -.425]
Love	.82	2.91	1.50	.146	[.549, -.306]
Friends	-.18	2.37	-.40	.694	[.449, -1.10]
Children	.78	2.86	1.41	.169	[.550, -.354]
Relatives	.50	2.65	1.00	.326	[.500, -.526]
Home	.54	3.34	.85	.403	[-.759,1.83]
Neighborhood	.81	2.77	1.49	.150	[-.312, 1.93]
Community	-.14	2.46	-.307	.761	[-1.10, .811]

*$p < .05$

Several explanations can be used to explain why parental quality of life did not change over time in our study. First, there is some research to suggest that perceived quality of life is generally stable over time (Michalos & Kahke, 2010). Specifically, while having a child in the NICU may cause changes in aspects of quality of life (e.g., anxiety, stress, etc.), research suggests that parents of infants admitted to the NICU appear to adapt relatively successfully (Carter et al., 2005). That said, it may not be that parental quality of life does not decline when they have an infant admitted to the NICU, but that it initially declines upon admittance and then returns to their individual baseline level as time passes, and as their infant's strength increases and gets closer to discharge. Additionally, 21 days is short term and changes in QOL may be seen over a longer period of time, specifically after infant discharge. It is a well-documented fact that, generally speaking, parents focus on their newborn infant (Cohen, 2016). One can speculate that having an infant admitted to the NICU would cause parents to further focus on their infant. Therefore, it is possible that parents of children admitted to the NICU are so focused on their infant that they do not realize that their quality of life has indeed declined. Further, parental level of education may have contributed to our findings. Specifically, parents who are less educated may not fully understand the dangers of their child being in the NICU and may be too trusting of doctors to help. Another possibility for our findings is that the QOLI may be more a measure of trait and state dependent, as the wording may tap into the acute aspect of change rather than stable aspects. More specifically, the QOLI measure may capture QOL in a dynamic phase (changing) rather than static (stable) phase. Having a change in perceived quality of life while your infant is admitted in the NICU is understandable and, therefore, may not be an accurate representation of one's stable, or static, quality of life. Therefore, testing parental QOL more frequently, and after the infant's discharge, may posit a more accurate picture of parental quality of life. Additionally, we found significant variability in the change in parental QOL over time, thus highlighting the need to look at moderators of parental QOL. Finally, we tested changes in parental perceived overall quality of life over time. We did not test potential change in various aspects of quality of life over time (e.g., family, work, financial, etc.). It is possible that, while overall quality of life does not change over time, aspects of quality of life do change.

The study found that the overall severity of infant illness did not significantly moderate parental quality of life over time ($p > .05$). Though we were underpowered for this hypothesis, we had an observed effects size of ($f^2 = .20$), which is considered a medium effect size. This is an interesting finding as it would be logical to think that the severity of an infants' illness would significantly moderate parental quality of life. Researchers have consistently found that having a child admitted to the hospital is a stressful time for parents, often resulting in clinical levels of several psychological disorders (e.g., acute stress disorder), some over the course of the infants' stay, but more so post-discharge (Jackson, 2003). This reported increase in experienced symptoms might be due to the fact that, once discharged, support from medical personnel decreases significantly. While in the hospital, infant care is provided mainly by hospital staff, leaving parents to focus on their child and each other. Once discharged, parents are left to care for the infant. Caring for an infant is a challenging thing, which has been found to decrease various aspects of parental quality of life (e.g., marital, friend, etc.) (Doering, Moser, & Dracup, 2000; Lefkowitz, Baxt, & Evans, 2010). Furthermore, caring for a medically fragile infant adds to the already difficult task of caring for an infant (Holditch-Davis & Miles, 2000). While overall parental quality of life may not change due to the severity of infant illness over the course of their infants' stay in the NICU, it may significantly moderate parental quality of life post-discharge.

Spirituality also did not significantly moderated parental quality of life over time ($p > .05$). Though we were underpowered for this hypothesis, we had an observed effects size of ($f^2 = .37$), which is considered a medium effect size. Further examination of the simple slopes revealed that, at both average and high levels of reported spirituality, parental quality of life was significantly and positively moderated over the course of their infants' stay in the NICU ($ps < .05$). This finding suggests that further research assessing levels of spirituality as potential moderators of change over time is needed. Previous research has reported that spiritually based themes have been helpful in buffering against depression, anxiety, and other psychologically related disorders, with an increase in belief in God when faced with an illness being observed (Robinson et al., 2006). However, no research has been done in the NICU assessing effects of spirituality over the course of the infants stay, nor what specific mechanisms of spirituality moderate parental quality of life. Spirituality in itself is a subjective experience, with many different beliefs, experiences, and needs. There are those that believe negative life experiences occur as a punishment for choices made by the individual, while others believe that experiences are not correlated to personal choices. Therefore, depending on an individual's belief, spirituality may positively or negatively moderate quality of life. The current study utilized an eight-point Likert scale ranging from "Definitely False" to "Definitely True" to assess individual levels of spirituality. Using a more in-depth measure to assess various aspects of spirituality and individual experiences with spiritual based themes would give researchers insight to not only level of spirituality, but also what characteristics of spirituality may or may not moderate parental quality of life.

Findings indicated that reported parental level of social support did not significantly moderate parental quality of life over time ($p > .05$). Though we were underpowered for this hypothesis, we had an observed effects size of ($f^2 = .27$), which is considered a medium effect size. One reason for this finding may be related to an individual's baseline social support. Panayitou and Karekla (2013) found that, while perceived social support does help, it does not buffer against the negative impact of anxiety disorders on quality of life and perceived stress. Therefore, while social support does have a direct and positive effect on quality of life, it may not be enough to significantly moderate parental quality of life over time. Additionally, people have differing levels of social need. Someone who is more of an internal processor and introverted is going to have less of a need for interacting with others. Moreover, someone who is more of an external processor and extroverted is going to have a much higher need to talk with other individuals. However, it is also possible that parents of children admitted to the NICU are interacting with each other or medical staff (e.g., doctors, nurses, etc.), and thus getting their social needs related to their infant met. Research has shown communication with hospital medical staff is one of the greatest needs communicated by parents (Kowalski et al., 2006). Therefore, it is possible that parents in our study felt as if their social needs were being met by talking with hospital staff about their child.

Concerning our final hypothesis, neither problem-focused nor emotion-focused coping significantly moderated parental quality of life over time ($p > .05$). Though we were underpowered for this hypothesis, we had an observed effects sizes of for problem-focused coping (f^2 =.32) and emotion-focused coping (f^2 = .28), which are both considered medium effect sizes. Assessing the effectiveness of an individual's way of coping is difficult. For our study, we utilized a self-report measure known as the Brief COPE, which is a measure completed by the patient. Though previous research has found fairly good reliability, there is no way to be certain that individuals are always going to answer in a reliable manner (Yusoff, Low, & Yip, 2010). Since the individual completes the measure, there is no way to be certain that the individual completing the measure is being 100% honest with their answers, which may account for the initially poor reliability (α = .59), particularly within the less useful coping subscale, within our sample. Further, the measure does not assess whether or not the reported ways of coping are perceived as helpful or not by the individual in coping with their perceived stress and/or anxiety. We can logically conclude that, if someone does not find their means of coping to be helpful, that it will likely not moderate change in quality of life over time. Conversely, if an individual perceives their means of coping to be helpful, that it would likely moderate change in quality of life over time.

The current study is not without limitations. The first and foremost potential limitation that must be discussed is the lack of power due to the small sample size (N = 31). Though we were underpowered for the study, observed effect sizes were medium, or approaching medium, for all moderators tested. Additionally, there is a discrepancy between the number of parents completing measures at time point one (N = 142) and again at time point two (N = 31). The major reason for lack of parent follow through with longitudinal data is that, even though infants were screened to ensure admission would span three weeks, infants were often discharged from the hospital prior to contact being made by a member of the research team. Secondly, due to the unavailability of Spanish copies of the measures used, lack of a Spanish-speaking member on the research team, and a lack of funding, any parent who was not fluent in English was not enrolled into the study. Further, the LLUCH is located in Southern California, in the greater Los Angeles area, which is an area containing many non-fluent English speaking individuals, many of whom are monolingual Spanish speakers. Allowing monolingual Spanish speakers to take part in the study would be beneficial in that it would give a more complete picture as to the population of the LLUCH NICU. Given our finding after examining the simple slopes of spirituality as a moderator of quality of life, further research assessing levels of spirituality as moderators is warranted. Finally, researchers did not conduct any kind of post-discharge interview to assess parental quality of life after leaving the NICU and having spent some time at home with their infant and without the support of hospital staff. Understanding the experience of parents post discharge will give a more complete picture of the trajectory of parental quality of life, thus helping researchers and clinicians conclude whether the creation and implement an intervention is necessary for parents whose child is in the NICU.

Future research with this population should include non-English speaking parents to participate in the study would give not only insight into another culture, but also give researchers the ability to infer the findings are generalizable to the human population. Researchers wishing to conduct similar studies may also consider incorporating qualitative data and a post-discharge component after parents have spent some time at home with their infant, to more fully understand each parent’s unique experience (e.g., alternative means of coping) and how to effectively work with parents whose infant is in the NICU not only while their infant is hospitalized, but post-hospitalization as well.

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APPENDIX A

PARENT MEASURES

1. Brief COPE
2. Demographics Questionnaire

Measures not included due to copyright protection

1. QOLI

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out your child would be in the NICU. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

____1. I've been turning to work or other activities to take my mind off things.
____2. I've been concentrating my efforts on doing something about the situation I'm in.
____3. I've been saying to myself "this isn't real."
____4. I've been using alcohol or other drugs to make myself feel better.
____5. I've been getting emotional support from others.
____6. I've been giving up trying to deal with it.
____7. I've been taking action to try to make the situation better.
____8. I've been refusing to believe that it has happened.
____9. I've been saying things to let my unpleasant feelings escape.
____10. I’ve been getting help and advice from other people.
____11. I've been using alcohol or other drugs to help me get through it.
____12. I've been trying to see it in a different light, to make it seem more positive.
____13. I’ve been criticizing myself.
____14. I've been trying to come up with a strategy about what to do.
____15. I've been getting comfort and understanding from someone.
____16. I've been giving up the attempt to cope.
____17. I've been looking for something good in what is happening.
____18. I've been making jokes about it.
____19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
____20. I've been accepting the reality of the fact that it has happened.
____21. I've been expressing my negative feelings.
____22. I've been trying to find comfort in my religion or spiritual beliefs.
____23. I’ve been trying to get advice or help from other people about what to do.
____24. I've been learning to live with it.
____25. I've been thinking hard about what steps to take.
____26. I’ve been blaming myself for things that happened.

____27. I've been praying or meditating.
____28. I've been making fun of the situation.

Demographics Questionnaire

I will be asking you some specific questions about yourself as well as your child's early history, as we would like as accurate a picture as possible. Remember, this information is strictly confidential and it will not be shared with <u>anyone</u> outside of this project.

<u>I. Child's Information</u>

1. Child's Full Name:
____
(Last, First, Middle)

2. Child's Birthdate: ___ ___ / ___ ___ / ___ ___

3. Sex: (Please circle one)
1 = Female
2 = Male

4a. Child's race: (Please circle one)
1 = African American
2 = Asian
3 = Caucasian (White)
4 = Hispanic
5 = Native American
6 = Other (Please specify: _____________________________)

<u>II. Female Parent's Information</u>

5. Full Name:
____
(Last, First, Middle)

6. Race: (Please circle one)

7. Birthdate: ___ ___ / ___ ___ / ___ ___

1 = African American
2 = Asian
3 = Caucasian (White)
4 = Hispanic
5 = Native American
6 = Other (Please specify: _______________________________)

8. Monolingual Spanish-Speaking?
1 = Yes 0 = No

III. Male Parent's Information

9. Full Name:
____
(Last, First, Middle)

10.Race: (Please circle one) 11. Birthdate: ___ ___ / ___ ___ / ___ ___

1 = African American
2 = Asian
3 = Caucasian (White)
4 = Hispanic
5 = Native American
6 = Other (Please specify: _______________________)

12. Monolingual Spanish-Speaking?
1 = Yes 0 = No

IV. Current Family Living Arrangements

13. Home Address:
____
(Street Address)

____
(City) (State) (Zip)

14a. Home
Phone:____

14b. Work Phone:
(Dad)____

(Mom) ____

14c. Mobile Phone:
(Dad)____

(Mom) ____

14d. Email:
(Dad)____

(Mom) ____

14e. Preferred Method of
Contact:____

V. Emergency Contact

15. In case you move or change your phone number before the project is completed, we would like to have the name, address, and phone number of two people who will always know where you are.

Contact 1: ______________________________ ____________________
(Last, First, Middle) (Relation to interviewee)

____
Street Address City

____
State Zip Area Code + Phone Number

Contact 2: ______________________________ ____________________
(Last, First, Middle) (Relation to interviewee)

____
Street Address City

____
State Zip Area Code + Phone Number

I give permission to The NICU Study staff to contact the persons listed above in order to locate me.

____
PRINT NAME (Last, First, Middle)

____ ______________
SIGNATURE DATE

VI. Mother's Employment and Education Information:

16. Current marital status: (Please circle one)

1 = Married
2 = Separated/Divorced
3 = Widowed
4 = Never Married

17a. Currently (or during the last 12 months) employed full-time or part-time outside of the home: (Please circle one)

1= YES
2 = NO

17b. What is the longest period of time worked at the same job in the last 12 months? (If at the same job for longer than one year, please enter 12)

____
(# of months)

17c. Please describe the kind of work, including job title/position, name of company/employer, job responsibilities, and what employer makes or sells:

____

____

____

____

17d. Number of hours worked per week, on average: ___________ (# of hours)

17e. What are the work hours:

(Please circle one)

1 = DAY (8 am to 5 p.m.)
2 = EVENING (after 5 p.m.)
3 = NIGHT (after 11 p.m.)
4 = VARIABLE (hours change)

18. Highest educational degree attained:

(Please circle one)

1 = None
2 = High School Diploma or GED
3 = Associate's Degree
4 = Vocational Degree
5 = Bachelor's Degree
6 = Master's Degree
7 = Ph.D., M.D., J.D., etc

19. Highest grade completed in school: (Please circle highest on scale)

……

5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

Or fewer High School College Or more

20. Current marital status: (Please circle one)

1 = Married
2 = Separated/Divorced
3 = Widowed
4 = Never Married

21a. Currently (or during the last 12 months) employed full-time or part-time outside of the home: (Please circle one)

1= YES
2 = NO

21b. What is the longest period of time worked at the same job in the last 12 months? (If at the same job for <u>longer</u> than one year, please enter 12)____________ (# of months)

21c. Please describe the kind of work, including job title/position, name of company/employer, job responsibilities, and what employer makes or sells:

____

21d. Number of hours worked per week, on average: ___________ (# of hours)

21e. What are the work hours: (Please circle one)

1 = DAY (8 am to 5 p.m.)
2 = EVENING (after 5 p.m.)
3 = NIGHT (after 11 p.m.)
4 = VARIABLE (hours change)

22. Highest educational degree attained: (Please circle one)

1 = None
2 = High School Diploma or GED
3 = Associate's Degree
4 = Vocational Degree
5 = Bachelor's Degree
6 = Master's Degree
7 = Ph.D., M.D., J.D., etc

23. Highest grade completed in school: (Please circle highest on scale)

……

5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Or fewer High School College Or more

VIII. Family Information:

24. What is the total gross annual income for your household, considering all sources of income and support together (e.g., job earnings, interest from savings, investment or rent income, unemployment or disability insurance, alimony, child support, and support from extended family)?

Please Circle One:

	Yearly	Monthly Estimates	Weekly Estimates
01/A=	$0 to 15,000	0 to 1250	0 to 288
02/B=	$15,001 to 25,000	1251 to 2083	289 to 480
03/C=	$25,001 to 35,000	2084 to 2916	481 to 673
04/D=	$35,001 to 50,000	2917 to 4166	481 to 961
05/E=	$50,001 to 70,000	4167 to 5834	962 to 1346
06/F=	$70,001 to 95,000	5835 to 7917	1347 to 1827
07/G=	> $ 95,000	> 7918	> 1828

25. Parents are currently: (Please circle one)

1 = Married (Number of years married? ______ / ______)
Years Months

2 = Living Together (Length of time together? ______ / ______)
Years Months

IX. Pregnancy

1. Was the pregnancy planned? 1 = Yes 0 = No
2. How was the mother's health during the pregnancy?

   1 = Poor 2 = Fair 3 = Good 4 = Very Good
3. How much prenatal care did the mother receive during pregnancy?

   1 = None 2 = Some 3 = A Lot
4. Did mother receive prenatal counseling?

   1 = Yes 0 = No
5. How much (if at all) did the mother smoke during pregnancy?

   ____

6. How much (if at all) did the mother drink during pregnancy?

____

7. Were any medications/drugs taken during pregnancy?

____

X. Birth

1. Was the baby full-term? 1 = Yes 0 = No

If not, how many weeks early was the baby? ___________

2. Would you say the delivery was:

1 = Easy 2 = Average 3 = Difficult

3. Were there any complications during delivery?

____

4. What was the baby's weight at birth? _____lbs _____ozs

5. Reason for NICU admission?

____

6. Did you know beforehand that your infant would be admitted to the NICU?

1 = Yes 0 = No

7. Infant’s diagnosis

____

8. Have you had any previous children in the NICU before?

1 = Yes 0 = No

9. Was your child transferred to Loma Linda Medical Center from another hospital’s NICU?

1 = Yes 0 = No

If you answer to the above is yes, please answer the following questions:

9a.Which hospital was your child transferred from?

____

9b. What was the reason for the transfer?_

____

9c. How old was your child when he/she was transferred to Loma Linda Medical Center?

____

10. Baby is:

1 = Bottle fed 2 = Breast-fed (on breast) 3 = Breast-fed (through bottle) 4 = Mixed

XI. Other

1. How many times (on average) have you visited your infant in the NICU since your child was admitted to the NICU?

1 = Once a week
2 = Twice a week
3 = Almost everyday of the week
4 = Every day of the week

2. How will you being paying for your child's NICU stay?

1 = Insurance
2 = Medicaid
3 = Out of pocket
4 = Loans
5= Unsure
6 = Other

3. How stressful is the financial aspect of your child's NICU stay?

1 = Not at all stressful
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful

4. How much physical contact do you get to experience with your infant?

1= I have no physical contact with my infant
2 = I have physical contact with my infant a 1-2 times a day
3 = I have physical contact with my infant several times a day.

5. What kind of physical contact are you able to have with your infant?

1 = I am only able to touch my infant through the isolette
2 = I am able to hold my infant
3 = I am able to hold my infant and also have skin-to-skin contact with my infant

How much do you agree with the following statements:

6. "I get the emotional help and support I need from family and friends."

1 = Strongly agree
2 = Agree
3 = Slightly agree

4 = Slightly disagree
5 = Disagree
6 = Strongly disagree

7. Which of the following describes how your baby looks and behaves? Circle all that apply.

1 = My baby has tubes or equipment on or near him/her
2 = My baby has bruises, cuts, or surgical incisions
3 = My baby has unusual color (for example looks pale or jaundiced)
4 = My baby has unusual or abnormal breathing patterns
5 = My baby is small in size
6 = My baby has a wrinkled appearance
7 = My baby has a machine (respirator) breathing for him/her
8 = My baby has a swollen or enlarged body part, such as abdomen, head, limb

8. Which of the following describes your role in the care of your infant in the NICU? Circle all that apply.

1 = I participate in the feeding of my infant by myself
2 = I am not able to participate in the feeding of my infant by myself
3 = I am able to participate in the bathing of my infant
4 = I am able to participate in the diapering of my infant
5 = I am not able to bathe my infant
6 = 5 = I am not able to diaper my infant
7 = I am able to hold my infant when I want
8 = I am not able to hold my infant when I want
9 = I am able to have alone time with my infant
10 = I do not get to have alone time with my infant
11 = I am able to take my infant's temperature

9. Even when others get discouraged, I know I can find a way to solve the problem.

1 = Definitely False
2 = Mostly False
3 = Somewhat False
4 = Slightly False
5 = Slightly True
6 = Somewhat True
7 = Mostly True
8 = Definitely True

10. I consider myself a spiritual person.

1 = Definitely False
2 = Mostly False
3 = Somewhat False
4 = Slightly False
5 = Slightly True
6 = Somewhat True
7 = Mostly True
8 = Definitely True

APPENDIX B

INFANT MEASURES

1. Neonatal Therapeutic Intervention Scoring System (NTISS)

Ressources et utilitaires

Scoring systems for ICU and surgical patients:

NTISS (Neonatal Therapeutic Intervention Scoring System)

NTISS = SUM (points for activities performed) = 0

Abstraction guidelines

Superscript letters represent mutually exclusive variables.