

## **Spiritual Well-Being and Parenting Stress in Caring for Children with Neuro-Developmental Disorders**

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**ABSTRACT:** Caregivers of children's with neuro-developmental disorders face challenges starting from resistance and denial, and such challenges may be likely to impact their Well-being. The present study explores the relations between spiritual well-being and parenting stress when parents faced with a crisis like caring for children with neurodevelopmental disorders. A convenient sample of 38 parents who reared 3 to 12-year-old children diagnosed with neurodevelopmental issues was part of the study. Parental Stress Index -Short Form (PSI/SF; Abidin, 1995) and the Spiritual Well-Being Scale (SWBS; Ellison & Paloutzian, 2009) were used to obtain a measure of the variables chosen. Pearson's correlation coefficient was used to find out the significance of relations between spiritual well-being and parenting stress. Also, the significance of the mean difference between the gender groups in relation to spiritual well-being and parenting stress was analysed using Independent Sample 't' test. Findings reveal a significant negative correlation between spiritual wellbeing and parenting stress, and it also shows that there is no gender difference in relation to parenting stress and spiritual well-being among parents. The findings indicate that spiritual wellbeing might act as a buffer of parental stress and can play the role of a protective factor against parenting stress for life challenges. It also shows that there might be no gender differences in parents' experience of stress and spiritual wellbeing, but slight mean differences show a higher stress and spiritual wellbeing among mothers than fathers.

**Keywords:** Neuro-developmental disorders, Parenting Stress, Spiritual Wellbeing.

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### **I. INTRODUCTION**

The task of caregiving for chronic illnesses among family members has established as a pertinent field of interest to health psychologists in the contemporary era. Amongst these, parenting a child with a neurodevelopmental disorder, knowing that they would never develop like other children, is a 'plunge into an unknown world' for which parents feel they were given no forewarning (Scorgie et al., 2004). Reaching the stage of parental adjustment to their child's diagnosis is a tough process that begins with resistance and denial and at the final phase is followed by active, cognitive and emotional acceptance (Blacher, 1984). This evidence has similarities with Kubler-Ross' stages of grief and bereavement.

Neuro-developmental disorders onset in the developmental phases of the child and range from impairments in learning to social skills and intelligence (DSM-5, 2013). A good example of this would be Autism Spectrum Disorder and ADHD.

Autism Spectrum Disorder (ASD) has behaviourally defined with a marked deficiency in social interaction and communication, repetitive behaviours, desire for sameness and routine, etc. The challenging behaviours of these children's are externally self-destructive, non-compliant, and with problems in the sleep-wake cycles, lead to some of the distressing features of parenting. Due to difficulties in social interaction, especially with forming attachment bonds and reciprocating affection, parents are often denied essential and stimulating rewards of parenthood (Gupta & Singhal, 2005). Lack of emotional expressiveness lowers empathy between parents and child. ADHD is another disorder characterised by developmentally inappropriate patterns of inattention and impulsive/hyperactive behaviours and resulting in dysfunctions in social, academic and family life. The disruptive behaviours that these children's are exhibiting varies in degree and intensity but are nevertheless a source of stress and burden for parents imposing restrictions on social, mental and financial health (Johnson & Reader, 2002).

Parents being the primary caregivers of the child, the terms 'parents' and 'caregivers' will be used interchangeably throughout the present study. Individuals are not passive reactors to stressful life events but psychological beings who actively respond to the world outside. In this light, Lazarus and Launier (1978) proposed the Transactional theory of stress which employs terms such as Appraisal and Coping. Appraisal at a primary level is the assessment of what the event means to a person, and at a secondary level, the potentially stressful event is evaluated based on resources available to cope with the posed challenge. Coping is the cognitive and behavioural efforts engaged by a person to manage the demands (internal and external) of a situation appraised as taxing or exceeding one's coping resources. A child with a disability requires vital resources more than what parents expect to give like regular clinic appointments, expensive medications,

therapies, special education, special equipment, etc. These require the caregiver to (cognitively) reappraise the situation and seek support to cope with the challenges ahead (M.S. & Sridevi, 2014; Vidyasagar & Koshy, 2010). Hence cognitive appraisal and active coping play a vital role in delineating the relationship between stressor and adjustment (Trute & Hiebert-Murphy, 2001).

Cho and Kahng (2014) explored the predictors of life satisfaction among caregivers of children with developmental disabilities in South Korea. Availability of resources and the caregiver's perceived stress has been tested. It has reflected that the age of the child, age and gender of the caregiver, monthly income of the family, severity of disability, and the time demands involved in care for the child to be predictive indicators of life satisfaction.

Research studies have pointed out that the stress levels can be significantly different across different genders. In 2013, Aldosari explored that mothers had a higher stress level than fathers about the parent-child relationship. Being primary caregivers, mothers had more roles to play in helping the child's adaptation at various levels such as school, medical and therapy centres, managing studies and medications, contacting teachers, etc. Since the fathers took on a relatively passive role being more involved in financial matters, it has been found that majority of the burden lay with the mothers. Parent characteristics such as depression and support from the spouse are important determinants of levels of stress (Aldosari, 2013).

The word spiritual has derived from the Latin word 'spiritus' which means life, breath, courage, vigour or the soul (Hage, 2006). Aldwin (1994) mentions that while the primary goal of coping is a homeostatic function of restoring the former state of equilibrium, its most important role may be transformation. The human person is a being in relationship i.e. they are intrinsically spiritual. Hence an illness can be viewed as a disturbance in right relationships within the organism as well as outside it (Sulmasy, 2002).

The Bio psychosocial-Spiritual model (King, 2000) is a reformulation of earlier models with a spiritual component. The biological, psychological, social and spiritual are all distinct dimensions of a person that cannot disaggregate from the whole. Though measuring one's transcendent relationships is beyond spatiotemporal limits of empiricism, it is nonetheless found to be one of the major coping strategies known to man (Sulmasy, 2002).

As human beings, we have an innate drive and are therefore never complete without relationships. These can be with the people around us, but they also exist in a search for the Higher Being/the Transcendent (Pargament, 1999). Klein's object relations theory (1952) argues that the core of who we are is the outcome of our early relationships, especially those with the mother. Hence our early relationships internalise to form our concept of self which is a social construction and subsequently impacting our sense of self and relationships later in life (Gurney & Rogers, 2007). For a spiritual person, the concept of self seeks to identify itself in a relationship with a Higher Power and as Hill (2002) puts it, 'with a God that allows it to be known only in the form of relational engagement'.

Lamis et al. (2014) used a culturally informed risk-protective framework to inquire into the possible culturally relevant risk and protective factors in parenting stress for African American women. It has been found as hypothesised that neighbourhood disorder which is a culturally relevant risk factor has been associated with high levels of parenting stress. Both existential and religious wellbeing scales of the SWBS were found to correlate well with lower levels of parenting stress. The result is especially true for existential wellbeing as a protective factor to parenting stress as it encompasses a broader and internally focused sense of life satisfaction and purpose (Lamis et al., 2014). For the low-income African-American mothers, spirituality was a free resource available to them in times of need from which they could draw support and strength. This reduces stress and improves their overall quality of life including their parent-child interactions and care for the child's physical and emotional wellbeing.

Chandramuki, Shastry and Vranda (2012) explored the parental attitudes to children with Specific Learning Disorder (SLD). The study found differences in parental perceptions based on the child's gender. Boys are expected to have more academic rigour than girls, achieve higher education, hold better positions in society and support the family financially. They found a pattern of overprotection and rejection towards the child with learning disability (Chandramuki et al., 2012). There has been severely expressed emotion (EE) from significant others which would cause frustration in parents. The study found working with parents as an effective means to improve in their children (Chandramuki et al., 2012).

In a collectivistic culture like India, disability has still been viewed as a "tragedy" with the approach "better dead than disabled" (Gupta & Singhal, 2004). The idea is that it is not possible for people with a disability or their families to be happy or enjoy a good quality of life. India is also a country of high spirituality and a desire to reach out to the Transcendent. Gupta, Mehrotra and Mehrotra (2012) found that the majority of their respondents turned to God when all other avenues of hope were exhausted in times of crisis followed by surrender to the will of God. However, there is a dearth of literature on spiritual well-being and Indian parents' experiences of caring for children with developmental disabilities. Also, very few studies have focused on a comparative study of fathers and mothers and how they experience this stressful life event and the subsequent coping mechanisms to

face it. Mustering faith in an all-knowing and loving God and finding meaning and purpose to a 'catastrophe' or 'life event' enables one to be at peace with life circumstances. The present study tries to find out the relationship between spiritual well-being and parenting stress in caring for children with neurodevelopmental disorders. Also, the study tries to explore the gender differences with regards to spiritual wellbeing and parenting stress in those caring for children with neurodevelopmental disorders.

## **II. METHOD**

### **2.1 Sample**

This study comprised of 38 parents in Bangalore, Karnataka who have children with neuro developmental disorders. A non-probability convenience sampling technique has used with certain inclusion criteria. Inclusion criteria. To control certain extraneous variables on parenting stress: parents must have only one child with a neuro developmental disorder; the age of the child must be around 3-12 years and the parent around 30-45 years. The combined income of the family should be roughly around Rs.15000 to 60,000. Exclusion criteria. No single parents and parents with more than a single child facing neuro developmental disorders will be part of this study.

### **2.2 Tools/Measures**

The Parental Stress Index – Short Form (PSI/SF; 3rd Ed.; Abidin, 1995): is a 36 item self-administered test, which has the following dimensions – parental distress, parent-child dysfunctional interaction, and difficult child. The test is designed for parents with children of the age range 1 month to 12 years. It takes around 10 minutes to administer and has 5 point Likert scales ranging from 'strongly agree to strongly disagree'. Certain items will measure 'defensive responding' to rule out self-presentation or reduce its effect on the test. A score of ten or less indicates defensive responding and implies interpreting the test scores with caution. The Total Stress score has calculated by summing up the scores on the three dimensions. The reliability of the test ranged from .79 to .83 for the subscales.

The Spiritual Well-Being Scale (SWBS; Ellison & Paloutzian, 2009): is a 20 item self-administered test, which consists of two components, i.e. Religious Well-Being Scale (RWBS) and the Existential Well-Being Scale (EWBS). The RWBS measures the relationship with God or what they understand to be their spiritual Being. The EWBS measures their sense of satisfaction and purpose in life. The test takes around 10-15 minutes to administer, and it has a 6 point Likert scale ranging from 'strongly agree to strongly disagree'. It is not affected by age or sex. It has good face validity and is especially sensitive to lack of well-being. There is a range of scores to measure each of the scales including the overall SWB. Each subscale ranges from low, moderate to high. The overall SWB scores are as follows: 20-40 low SWB; 41-99 moderate SWB; and 100-120 reflects a sense of high SWB. The reliability for the entire scale is around 0.89 to 0.94. Internal consistency coefficient for the RWB ranges from .82 to .94 and for EWB from .78 to .86.

### **2.3 Ethical concerns**

The data collected will be used only for academic purpose. Participants who will agree and signs in the informed consent has selected for the research. Debriefing will be done to enable people to decide whether or not to participate as research subjects. Only initials of the participants have collected, and the information has conveyed in understandable language. Informed consent will give a summary of the nature of the study, the risk, benefit and the rights they have as research subjects. The confidentiality of the data has maintained. Any doubts from participants will be clarified.

### **2.4 Procedure**

The study conducted at two levels. First, data has collected from Astitva, a therapy centre for special needs children in Bangalore, Karnataka. The data collection has happened during the month of October 2015. An online survey method has adopted from December 2015 to January 2016. The consent form has given followed by a demographic sheet for screening and record purposes. Those who met the inclusion criteria has then administered the two questionnaires i.e. Parental Stress Index/Short Form (PSI/SF; Abidin, 1995) and the Spiritual Well-Being Scale (SWBS; Ellison & Paloutzian, 2009). The data was then analysed using statistical measures. A feedback form known as the Perceived Benefit of Spiritual Well-Being on Parenting was also taken from the subjects if they agreed.

### **2.5 Data Analysis**

The first hypothesis, a higher Spiritual well-being produces lower parenting stress in caring for children with neurodevelopmental disorders was tested using Pearson's correlational coefficient analysis. The later hypothesis, gender differences in the stress and spiritual well-being of parents caring for children with neurodevelopmental disorders, was analysed using an independent sample t-test.

### III. RESULTS

The demographics of the sample are predictive indicators of parenting stress while raising children with developmental disorders (based on numerous studies). The study sought to explore the objectives mentioned above, considering the demographic variables in the sample.

**Table I:** Correlation between Spiritual Wellbeing and Parenting Stress

	SWB	PSI
PSI	-.565**	1
SWB	1	.000

*Note.* PSI = Parental Stress Index; SWB = Spiritual Wellbeing

\*\* Correlation is significant at the 0.01 level (1-tailed)

Concerning Table I, it is evident that there is a statistically significant negative correlation between spiritual wellbeing and parenting stress ( $r = -0.565$ ,  $p < 0.01$ ) among parents caring for children with neuro-developmental issues. Hence the hypothesis is accepted. It has interpreted as higher spiritual wellbeing leads to lower parenting stress.

**Table II:** Mean and t-test of the Sample based on gender in Spiritual Wellbeing and Parenting Stress

Variables	Gender	N	Mean	t	df	Sig. (2-tailed)
SWB	F	20	90.35	0.76	36	.45
	M	18	85.78			
PSI	F	20	87.70	0.66	36	.51
	M	18	83.44			

*Note.* F= Female; M= Male; SWB = Spiritual Wellbeing; PSI = Parental Stress Index.

Concerning Table II, there is no significant difference between fathers and mothers in spiritual wellbeing and parenting stress. The hypothesis that gender differences exist in parenting stress levels and spiritual wellbeing has not proved. However, slight mean differences exist for both variables with mothers showing higher spiritual wellbeing and higher parenting stress levels than fathers.

### IV. DISCUSSION

The dimension of spirituality has identified as a crucial factor in health care. The sample of this study has classified on five prominent indicators of stress – age and gender of the parent, combined family income, age of the child and type of developmental issue. It has found that majority of the parents were in the settling down stage or midlife transition. In these stages, there is much soul searching and reflection followed by re-evaluation of goals and priorities in this stage (Levinson, 1978). There were 20 mothers and 18 fathers who could participate in the study. The combined family income of the parents indicates that majority of them were from relatively well-earning families. The age of the children reveals children were in their preschool/primary school years. Perhaps for a few of them, they would've just received the first formal diagnosis of their child. The majority of the sample has characterised by parents caring for children with autism followed by Down syndrome.

The relationship between spiritual wellbeing and parenting stress explored in the research revealed that a significant negative correlation exists between the two (Table I). In other words, a higher spiritual wellbeing can in fact possibly lead to lower parenting stress in those caring for children with neuro-developmental disorders. Spiritual wellbeing acts as a buffer to stress, and the perceived spiritual support one receives from their relationship with God (Maton, 1989) and their sense of satisfaction or purpose in life: perspectival transformation (Scorgie, Wilgosh & McDonald, 1996) is what sustains them through the roughest of times. The same may be the way they perceive their role as parents, their perception of the difficult child, and their interaction with this child (Abidin, 1995).

The research also sought to explore gender differences between fathers and mothers in perceptions of parenting stress and spiritual well-being. It has observed that both mothers and fathers do not differ significantly on any of the two variables and it has inferred that gender differences in spiritual wellbeing and parenting stress in caring for children with neurodevelopmental disorders might not exist. Ha & Hong (2008) explored the effect of caring for children with developmental or mental health issues on the mental and physical health of parents and the extent to which this varies by gender. In a sample of 163 parents, equally stressful were the developmental problems of the child on both mothers and fathers. Malhotra, Khan & Bhatia (2015) says that there were no statistically significant differences between mothers and fathers on the domains of parenting stress i.e. parental distress and difficult child and total stress.

One of the possibilities of why different researchers have found conflicting results on gender differences in parenting stress is because of the variances in sample characteristics. Parenting stress is a complex variable made up of multiple factors such as the ones explored in the demographics of the study. The lack of gender differences could be because even though mothers do perceive greater burden and stress than fathers, mothers also reap greater emotional gratification from parenting than men (Pruchno & Patrick, 1999). The same could balance out the perception of stress in both mothers and fathers. While mothers overburdened with parenting the child and helping them adapt to society, fathers overburdened with increased financial needs for medical and rehabilitation expenses for their child which can come in the way of mental health, parenting abilities and bonding with the child (Malhotra, Khan & Bhatia, 2015). However, it is also evident that slightly higher mean differences exist in mothers than fathers for parenting stress. The studies pointed out here shows that mothers do in fact have higher perceptions of stress than fathers, but this may/may not lead to a significant change.

In the case of gender differences in spiritual wellbeing, studies have shown different types of coping skills in fathers and mothers (Upadhyaya & Havalappanavar, 2008). While mothers use more of religion-faith and denial-blame coping strategies which are types of emotion-focused coping, fathers predominantly use acceptance-redefinition and social support which are types of problem-focused coping. Once again in this study, there have been no gender differences in spiritual well-being, but slight mean differences indicating higher spiritual wellbeing among mothers do exist.

The Perceived Benefit of Spiritual Wellbeing on Parenting (Feedback form) asked three major questions. What is spiritual wellbeing to you? Do you believe that your spirituality has helped you in parenting your child? Specify how this has impacted how you have seen yourself/your child/your interaction with your child? It has found that many of the parents used spirituality as an important source of coping with the stress. They believed that they had blessed with the child and 'everything happens for a reason'. They found that their trust in God/their new found purpose in life by caring for their special need child helped them to face the challenges of everyday parenting with confidence.

## **V. CONCLUSION**

"People are like stained glass windows. They sparkle and shine when the sun is out, but when the darkness sets in; their true beauty is revealed only if there is a light from within."

Kubler Ross (1975) – Pioneer of the hospice-care-movement

The findings of this study highlight the unique role that spiritual well-being plays in acting as a buffer to parenting stress. Higher the spiritual well-being of the parent, lower will be the level of stress they will experience. The sense of satisfaction or purpose parents had found in life with some sense of spirituality be it in the form of the strength they derive from their relationship with God and the strength drawn from their transformation. When they faced with any internal and external demands most parents identified spiritual ways to cope with the challenges/stressors rather than avoid it. The wellbeing derived from the spiritual dimension of a person is a protective factor against developing high parenting stress when neuro-developmental issues of the child act a risk factor to developing high life stress. The study also found that regarding gender differences; there was no significant difference between fathers and mothers in parenting stress and spiritual wellbeing. While many have tried to ascertain gender differences in parenting stress while caring for children with developmental issues, results have never reached consensus and have remained inconclusive. Spiritual wellbeing also reveals higher means in mothers than fathers. The results are consistent with previous studies that also have found mothers to use more emotion-focused and religion-faith coping style than fathers; while fathers use more of problem-focused coping and acceptance-redefinition to cope (Upadhyaya & Havalappanavar, 2008). The contributions of this study are not without flaws, and it must consider in light of the limitations. Firstly, while the study was able to control stress-impacting demographic variables like age of the child and parent, gender of the parent, exclusion of single parent homes and parents having more than one child facing developmental issues; it could not control for family socio-economic status based on combined income of the family. Secondly, the small sample size and time constraints have acted as a limitation.

In light of the present findings and limitations, future research would consider the need to control the combined income of the family in the sample, so that it is more representative of all classes or at least having the majority of middle-income families. Another option is to determine their perception of financial burden rather than attempt to classify them into the different socio-economic classes. Extending the sample size with an equal distribution of fathers and mothers will always be beneficial to learning more about the parental population who look after children with developmental issues. Also, it would be more enhancing to study the impact of concepts like spiritual coping/spiritual support in parenting stress than spiritual wellbeing. The researcher suggests a mixed method have an in-depth understanding of how parents use their spirituality in times of high life stress challenges.

While it is true that there is no such thing as stress-free parenting even for those with neuro-typical children, enhancing the wellbeing of the parent is essential for improving the quality of life. A stressful family environment can translate into poorer parent-child relationships, loss of self-esteem, and negative affect for both where children can internalise their disorders leading to poorer psychological well-being for them as they grow up.

There are several implications of this study which is beneficial for practice. The role of counsellors and other mental health professionals including special educators come in here. Both parents need an equal amount of spiritually sensitive training and guidance for a holistic care of their family environment. It is undeniable that in a conducive family environment, there is much scope for learning and overcoming some of the developmental issues of the child. A spiritually sensitive counselling and guidance encourage parents to draw strength from a non-financial resource such as prayer or meaning-making and acceptance-redefinition. The salutatory effects of faith in God on perceived parenting stress comes from knowing that He is in control and that one can draw support and guidance from Him anytime to face the challenges of each day. For those who derived their spirituality from existential-based transformation opportunity for personal reflection and reflective discourse with the child's therapist would enable parents to evaluate what this challenge means to them and how they can face it. Parents may not be aware of how useful these means of coping become when they faced with challenges. The use of logotherapy to find something constructive and positive in a tragedy should be an essential technique used by trained counsellors and psychiatrists. Parents must have opportunities for psycho-education on impacts of parenting stress on themselves and their child. Being aware of the parent's perceptions of spiritual support can help counsellors, psychiatrists and mental health professionals to have a soul reaching impact on the parents and improve their wellbeing.

### **ACKNOWLEDGEMENTS**

“And by the way, I'm wearing the smile that you gave me.”

- Unknown

This journey was the hardest I have ever yet taken, but in it, I've realised the value of relationships that stood by me through it all. My Jesus for being the strongest source of sustenance and guidance no matter how baffling or burdensome things got along the way. Besides I owe it all to Him for making my dreams of research come true.

My guide, Dr Sreenath K. for his invaluable guidance and constructive feedback that, got me through the entire course of this dissertation. I also thank my Head of Department, Dr Tony Sam George for the opportunity to conduct a quality research at the undergraduate level and enjoy the experience.

I am grateful to Astitva, a special education centre in Bangalore, for being open to my conducting research among parents there and helping me with it as well. I thank all the parents at the institute and those who were part of the online survey for their invaluable time spent being part of my study and sharing their thoughts through the feedback form.

My dearest family (Dad, Mom, Nikhil and Nehemiae) who sacrificed so much to help me get here and encouraged me with their love and prayers to believe that nothing is too hard when the Lord is on my side. My deepest thanks to Pastor Joji Thomas and Dr Mareena Susan Wesley for guidance that gave me direction and help in practical issues to begin this research.

Special mention to my friends, Selan and Rinnie who believed in me and gave a listening ear in times of uncertainty and lack of clarity. Their thoughtful feedback and support to me in times of distress can never match. Above all, they taught me to smile knowing that God is in control.

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