

Relationship between Caregiver Burden and Spirituality in the Parents of Children with Chronic Illnesses

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Abstract— Jay Belsky's process of parenting model illustrates the significance of a parent in a young child's life, especially during the critical developmental stages. To fulfill the multitude of needs of a young child with chronic illness as a parent and a caregiver can mentally and physically overload an individual. This paper studies the burden felt by the parents of children with chronic illnesses residing in Chennai. It also assesses sleep quality as it is one of the most affected facets of life of a caregiver. During crises, meaning seeking through religion and spirituality has been recognized as a positive coping mechanism. Therefore, the aim of this paper was to understand the relationship between engagement in spiritual practices and the burden felt by the parents of children with chronic illnesses residing in Chennai. Through purposive sampling, 34 parents of children with different chronic illnesses currently residing in Chennai were approached and interviewed. After a week of rapport building, burden, sleep quality and spirituality were assessed by administering standardized questionnaires- Montgomery Burden Scale, Sleep Quality Scale and SpREUK-P and the data was quantitatively analyzed. The results indicate significant objective, subjective stress burden and moderate sleep disturbances felt by the parents and also shows that there was a significant negative relationship between engagement in spiritual practices and burden, demonstrating that spirituality might have a positive impact on caregiver burden. The narratives reported by the respondents helped better understand the numerical data acquired.

Index Terms—Caregiver burden, Children, Chronic illness, Parents, Sleep quality, Spirituality

Introduction

Watching one's own child in pain and illness can feel as though a part of themselves is being ripped apart. A parent as the primary caregiver of a child with chronic illness will have to not only help the child in the development for him/her to become an independent individual, but also treat and care their condition without letting it significantly affect the development.

Patients with chronic illnesses usually require care and treatment that focuses on managing the symptoms, obtaining practical support and having a good quality of life. Severe treatment

regimens lead to patients' dependency on their caregivers for several physiological and psychological needs, especially for a child. Caregiver is an individual who has the responsibility of meeting the physical and psychological needs of the dependent patient. The aspect of responsibility and major dependence characterizes a caregiver.

Studies demonstrate the centrality of the role of family caregivers in treatment. Among the terminally ill, 96% of caregivers are family members (Emanuel et al., 1999). The spouses of terminally ill patients may spend more than 100 hours a week in these activities (Haley et al., 2000). In India, family members are the natural caregivers for persons with mental or physical illnesses as family members are preferred, or even expected, for caring.

Furthermore, research has also clearly illustrated the toll that this intense role could have on an individual. Caregivers were seen to have higher levels of stress and depression as well as lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers (Pinquart & Sörensen, 2003). Family or spousal caregivers of hospice patients are at high risk for both psychological and physical health disorders (Haley et al., 2000). The evidence indicates that caregivers undergo tremendous objective and subjective stress.

Caregiving identity theory

The caregiver identity theory proposes that caregiving is a dynamic process of change. Caregiving is seen to be a systematic process of identity transformation of a familial relationship to a relationship of caregiving which is guided by factors grounded in family roles and culture (Montgomery, 2002; Montgomery & Kwak, 2008; Montgomery, Kwak, Kosloski, & O'Connell Valuch, 2011).

Caregiver burden describes the physical, emotional and financial toll of providing care. Multifactorial constraints and demands of providing care may result in caregivers making decisions that could have an adverse effect on how they competently manage their own health needs (de la Ceusta-Benjemea, 2010; Fargo & Bleiler, 2014; Zarit, Kim, Femia, Almeida, & Klein, 2014).

Caregiver burden is categorized in terms of objective burden (OB), subjective burden (SB) and demand burden (DB). Objective Burden is defined as the extent of disruptions or changes in various aspects of the caregivers' life and household. Subjective Stress Burden is defined as the caregivers' attitude or emotional reactions to the caregiving experience. It measures the emotional impact of caregiving on the caregiver. Subjective Demand Burden measures the extent to which the caregiver feels the responsibilities are overly demanding (Ampalam et al., 2012). These are the subscales measured in the parents of children with chronic illnesses in this current paper.

Importance of Sleep quality

Sleep quality is the individual's self-satisfaction with all the aspects of their sleep experience. Sleep is a restorative activity and good sleep quality has positive effects on the physical and mental health of the individual. Sleep debt, or deficit, is the difference between how much sleep you need and how much you actually get. The deficit can add up over time and can negatively impact your health. A study on estimating the optimal sleep duration (Kitamura et al., 2016) suggested that it takes four days to fully recover from one hour of lost sleep.

Amongst existing literature, sleep disturbances and insomnia are seen to be one of the major factors that affects caregivers. A systematic meta-analysis indicates that there is a significant difference in sleep quality between caregivers of patients with dementia and non-caregivers. The findings also suggest that caregivers acquire a sleep debt of up to 2.42 to 3.50 hours of sleep each week due to difficulties in falling asleep and maintaining sleep. Hospice family caregivers experience high prevalence of insomnia symptoms. It is also noted that the caregivers with insomnia symptoms report worse anxiety, depression, caregiver burden, QOL, self-rated health (Starr et al., 2022).

Children with chronic illness

As per Census 2011, children account for 13% of the total population in the country. Unfortunately, one mass portion of this population is affected by chronic illness. Chronic illness can be broadly defined as a condition that lasts for more than one year and may not have a cure. It requires continuous ongoing medical attention and limitations in daily activities. Around 10–15% of children worldwide suffer from chronic diseases.

Chronic diseases affect the child's life at every stage. During the neonatal and infant stage, children are unable to understand the disease but they may experience pain, separation anxiety, while going through treatment. This can have an impact on their attachment style and emotional well-being. A school-age child will start feeling the impact of limitations and restrictions in life. Adolescents understand their condition better but sometimes they would become defiant and ignore the advice of parents and treatment team.

In each of these stages, the parent/ primary caregiver should be equipped to deal with the limitations of the condition. They should attend to both the physical and psychological development and ensure healthy coping. Parents should be trained with communication and life skills and be empathetic to the child's perspective and guide them accordingly.

Coping and meaning-seeking in caregivers

Caregiving for a loved one can drain an individual mentally and physically. However, humans tend to find their way to understand and cope even in such severe circumstances. Caregivers utilize various coping strategies to show great resilience and stay strong, to help themselves and their loved ones.

Coping is defined as the person's constant changing cognitive and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the person's resources (Folkman and Lazarus, 1984). Coping can be referred to as thoughts and behaviors that are mobilized to manage internal and external stressful situations.

Positive emotion-based coping strategies such as meaning making, savoring, optimism, hope and humor are seen to be utilized to promote healthy coping strategies and alleviate negative consequences. Meaning making especially, through the 'just world theory' or religious or spiritual beliefs is seen to provide a sense of cognitive coherence for the caregivers.

Spirituality as a coping mechanism

In terms of its spiritual origin, seeking of meaning is universal, but the expression and experience of meaning are culturally based (Baumeister 2005; Baumeister et al. 2013).

According to Joseph et al. (2017, p. 506), spirituality should be understood as “a more general, unstructured, personalized, and naturally occurring phenomenon, where a person seeks closeness and/or connectedness between him/herself and a higher power or purpose”. Spirituality as a coping mechanism has been observed to be a powerful resource in the provision of comfort, peace, and resolution.

Emmons, 1999, emphasized that spiritual intelligence enables the individual to deal with the problems of life and its issues and also show virtuous behavior such as humility, compassion, gratitude, and wisdom. Personal and meaning centered activities that people engage in are referred to as spiritual practices.

Sodestrom and Martinson (1987) postulated that the direct-action mode of coping may be through spiritual practices such as reflection. The ‘inward turning’ of such practices helps the individual to get to know the complexity of their inner self as a spiritual phenomenon (Lane 1987). Therefore, effective spiritual coping strategies and practice may facilitate meaning or purpose seeking in situations of illness, that can result in self-empowerment to cope with the stress.

The neurological basis of the effect of spirituality is also widely studied. The evidence from preliminary studies points towards the involvement of the prefrontal and parietal cortex during spiritual practices and activation of the frontal attentional network during meditation especially (Mohandas, 2008).

Durkheim (1915) presented the sociological perspective on the influence and importance of religion and spirituality. His social and cognitive cohesiveness hypotheses explain the effect of religion in the societal level and a personal level. While religion focuses on a macro-level, institutional reality, spirituality deals with the individual's inner experiences and understanding of the supernatural. An accumulation of findings suggests that functional, need-based, social support is uniquely beneficial for individuals under high levels of recent life event stress.

In the field of philosophy, the evidence of humans attempting to understand the meaning and purpose of life, dates far back. This indicates that throughout evolution, in sickness and in health, humans coped and wished to understand the purpose of life. While understanding the significance of a parent in caregiving and how important their mental and physical health is, it is important to understand their indulgence in healthy coping strategies such as spiritual practices.

Literature Review

Caregiver burden, sleep quality and spirituality are three variables that have been widely studied across different populations and the findings are seen to be rather similar and consistent across all the prevalent studies. Careful consideration of the methods and limitations of the prevalent studies in this field helped in formulating the appropriate methodology.

The data on the effect of burnout among health professionals is seen to be very extensive across different countries and cultures. Burnout affects 30% to 78% of physicians and residents, 2–4 and can lead to an increased prevalence of suicide, divorce, depression, loss of income, and disruptive behaviour in the workplace. A meta-analysis by De Diego-Cordero et al., 2022 indicated that nurses tended to use S/R as a coping strategy to alleviate burnout in their clinical practice and there was a wide array of evidence of the influence of spiritual and

religious beliefs on burnout symptoms. Findings of Doolittle et al., 2013, consistent with various studies, illustrated the significance of burnout in health care workers and the positive impact of spirituality as a coping mechanism in reducing burnout. Family caregiving, on the other hand, is a completely different ordeal from professional health care practice.

Caregiver Burden

Parents, without any knowledge, understanding or anticipation of medical conditions, deal with the unfortunate and unforeseen circumstances thrown at them especially, can have high levels of emotional distress considering the fact that it is their own child with a condition. The findings of existing literature unanimously show the high intensity of psychological and physical impairments in parents of children with illnesses.

Lopes-Júnior et al., 2022, meta- analysis findings revealed that the health outcomes of parents caring for children with chronic illness reported depression more significantly when compared to the parents of healthy children. The study explained the role of the immune system, cortisol, the activity of Natural Killer cells and the proliferation of T cells during times of stress and how it acts as a biomarker of stress in parents, especially mothers, of children with special health needs.

Malm-Buatsi et al., 2015, findings showed that, consistent with most previous studies, mothers were seen to have reported more stress and anxiety than fathers. The parenting trait that was seen to have strong positive correlation with stress was protectiveness indicating the more protective the parent is of their child, more stress and burden they report.

Cohn et. al, 2019, findings suggest that parental caregiving for a chronically ill child is associated with worse overall mental health compared with parental caregiving of healthy children, particularly anxiety and depression. The findings support the need for developing and evaluating interventions targeting the health and well-being of parents of chronically ill children. A meta-analysis of 18 studies published in 2006 reported a similar effect size to our report for depressive symptoms among mothers. The findings also suggested that the studies done on fathers are narrow and limited.

It is interesting to note that all studies emphasize more on the mother and the findings on fathers consistently stays narrow and less significant.

Teixiera and Pereira, 2012 tested the mediating role of social support in the relationship between psychological morbidity and caregiving burden. The findings stress that adult children who feel distressed/traumatized, but sufficiently satisfied with their social support resources, experience less caregiving burden.

Sleep quality and disturbances

Rihm et al., 2022, this study focused on the psychosocial situation of families caring for children with rare diseases during the COVID-19 pandemic through a cross-sectional online survey. The distress level among the family caregivers was high ($M = 6.84$, $SD = 2.43$) and 89.6% of the sample reported clinical distress (≥ 4). Everyday problems including sleep problems, fatigue, being out of shape, fears, feeling tense or nervous, and worry were seen to be frequent. This indicates the poor quality of life of parents and family caregivers of children

with rare diseases. The significant distress levels might indicate high caregiver burnout and sleep disturbances.

Fuerboeter et al., 2021, findings indicated that the mothers of children with rare pediatric surgical diseases had significantly lower QoL and significantly higher impairment in mental health than a control group and norm data due to the pandemic and the COVID lockdown measures. The fathers were also seen to have significantly lower quality of life.

Brandt et al. 2022, conducted a meta-analysis of several studies on spinal muscular atrophy (SMA). Most of the studies found moderate to high levels of caregiver burden and also emphasize on physical and mental health symptoms including sleep disturbances in the parents of children with SMA.

Feeley et al., 2014, the mothers reported to get an average of 5.8 hours of sleep per night. This is considered to be similar to other studies of caregivers of children with a chronic illness. According to the PSQI scale, this cuts off as clinically disturbed sleep (Buysse et al., 1989) suggesting that providing care for a child with Bronchopulmonary Dysplasia can result in poorer sleep quality and disturbances.

The studies again, unanimously show that the burnout and the sleep disturbances in caregivers is significantly high in primary or family caregivers of children or even adults with chronic illnesses. They are seen to be at risk for various physical and mental conditions due to their responsibilities and levels of stress that are associated with their role.

Considering that caregiving does have a negative impact on the mental and physical health of an individual, it is necessary to discover healthy coping mechanisms for them.

Religion and spirituality

Analysing spirituality as a way of coping in literature has found that suffering, illness or death initiates a sense of meaning seeking in individuals. If this meaning seeking is successful, it can help the individual gain strength and help cope with their situation better. Family caregivers reported less pain and distress and enhanced coping when they were given spiritual care and support (Sloss et al, 2012; Delgado-Guay et al, 2013). Religion and religious practices were dominant ways of coping, whereas other aspects of spirituality such as art, music and socialization are given less weight. Some studies have found that spirituality and religious beliefs decrease distress in caregivers (Hosseini et al. 2016; Koenig 2015) and can be used as coping strategies in dealing with stressful events (Chafiri et al. 2017).

Weaver & Flannelly, 2004, discuss the role of religion/ spirituality for cancer patients and their caregivers. Religiosity and spirituality significantly contribute to psychosocial adjustment to cancer and have a positive effect on the quality of life of patients as well as their caregivers. Relying on religious and spiritual beliefs is associated with active coping and acceptance of their illness and dealing with the illness in a positive and purposeful manner. This article disagrees with Freud's ideology that viewed religious coping as a kind of defence mechanism that is a regressive, passive and avoidant psychological phenomenon. The feeling that one has a positive relationship with God can give an individual a sense of self-acceptance and belonging and also provide a sense of emotional comfort when faced with a life-threatening illness. This indicates that just the belief in higher power might not be adequate for positive coping. A perception of a positive relationship with God that begins or continues even after the diagnosis,

might be an important role for this coping mechanism to have a positive impact on the patients and caregivers.

Lalani et al., 2018 evaluated and synthesized studies on spirituality among palliative care. The findings suggested that despite the challenges that comes with caregiving for a family member, it was considered to be a meaningful, satisfying and rewarding act. The culture and traditions of different regions were seen to have a significant effect on the meaning and understanding of spirituality.

Bernard et al., 2014 suggested that families who belong to a religion or faith group have different experiences with respect to end-of-life care than those who belong to non-faith community groups. Spirituality transcended known and unknown fears of caregiving and assists them in their decision-making abilities during palliative care.

Yeh & Bull, 2009, found that the caregivers, of elders with heart failure, who used constructive action or problem focused coping strategies experienced fewer depressive symptoms than those who used escape avoidance coping strategies. The findings extend the work of the previous studies that found religiosity was associated with less depression for family caregivers of loved ones with dementia.

Chang et al., 1998, findings showed that religious/ spiritual coping affected caregivers' psychological distress indirectly through the quality of the relationship between the caregivers and the care recipient. It was found to be associated with lower levels of depression and role submersion.

Anum & Dasti, 2015, results indicated that the caregiver burden was negatively correlated with the psychological well-being and the domains of spirituality, while the psychological wellbeing and spirituality were positively correlated in parents of patients with thalassemia. These results highlighted the role of spirituality upon the psychological well-being of caregivers, which could be utilized to prevent pathological influences (such as hard feelings, hopelessness, depressed mood, anxiety, and relationship problems) of caregiver burden and enhance psychological well-being through spiritual counselling.

Rafati et al., 2019, focused on the caregivers of hemodialysis patients in Kerman, Iran. Results showed a significant inverse relationship between caregiver burden scores and spiritual well-being scores ($p < 0.001$, $r = -0.41$). The paper presents suggestions for how the findings of the study can be used to implement programs such as, introducing strategies to promote spirituality, such as spiritual self-care, to reduce the burden of caregivers and proposes the utilization of appropriate spiritual resources and support in designing simple, cost-efficient and effective interventions for caregivers.

Lai et al., 2017 finding suggests that people with higher intrinsic spirituality spend a long time assisting their terminally ill relative with a consequent severe restriction of time to devote to themselves. The correlation analysis showed that the burden of caregivers was positively associated with the psychological outcome variables such as increased levels of anxiety, depression and risk of complicated grief. Moreover, the caregivers with more intimate spiritual belief seem to experience lower negative feelings and, consequently, fewer emotional distress toward him.

Despite it not being within the scope of the current study, one interesting finding of this article was the role of spirituality in grief is that the believers had higher levels of clinical

symptoms of anxiety and risk for complicated grief than non-believers. This result was shown to be consistent with a previous study (He et al., 2014) on a sample of bereaved Chinese adults which showed that Buddhists subjects experienced a higher level of complicated grief symptoms than those who had no religious beliefs. Another study in a German community sample showed that religious beliefs were positively associated with the risk of complicated grief even years after the loss (Schaal, Richter, & Elbert, 2014). The research does not attempt to understand why this happens. This was a relatively novel study that tried to understand the impact of burden on spirituality, specifically in family caregivers of terminally ill patients.

In most studies, spirituality is seen to be a positive factor in case of caregiving. Even in studies that explore spirituality in patients with acute and chronic illnesses, the perception of pain and fatigue itself is seen to be different. Spirituality is an extremely abstract and individualistic concept, yet it is almost always seen to be a positive factor in any type of illness.

Rationale behind current study

Objective and subjective burden can have a direct and significant impact on the physical and mental health of individuals. Most studies that attempted to assess caregiver burden, sleep quality and spirituality in caregivers showed similar results that indicated that family caregivers, especially parents of children with chronic illness have moderate to high burnout. Lower QoL and sleep disturbances have been frequently reported. All studies that focused on sleep quality of the caregivers showed a significant decrease in sleep quality and increase in experiences of sleep disturbance in primary caregivers of patients with chronic illnesses.

In existing literature, the perception of spirituality and religion is widely varied across different populations yet, consistently seen to have a negative correlation with burden indicating that more indulgence in spirituality might lead to less burden felt by the individual. The theoretical reasoning for such a relationship is also established and discussed widely. Spirituality is seen to have a psychological, social and even neurological basis on coping and mental wellbeing.

Through this paper, the researcher attempts to understand the prevalence of burden, sleep quality and spirituality in parents of children with chronic illness residing in Chennai and corroborate the consistent findings of the studies that were presently reviewed.

Understanding the burden of parents will help design necessary programs for the welfare of the caregivers. This study attempts to not only understand burden, but also offers to assess the correlation between spirituality and burden. This might allow an indication of the significance of spirituality as a coping mechanism in primary caregivers of chronically ill children in Chennai, India and help in formulating and implementing an extended biopsychosocial model of intervention focusing more on spiritual and religious practices for the wellbeing of caregivers.

Methodology

Is there a significant correlation between caregiver burden and spirituality in parents of children with chronic illness residing in Chennai?

Research design:

The research utilizes a quantitative research design as it allows a more reliable and accurate measure of the chosen variables through numerical data from standardized questionnaires. A correlational statistical analysis design is used to answer the research question and to present the relationship between the 2 variables- caregiver burnout and spirituality.

Sample design:

Since this study requires a special population of parents of children with chronic illnesses in Chennai, the researcher employed a non-probability sampling method- purposive sampling. Also referred to as judgmental sampling, it involves the researcher to select a sample that is most useful to the purposes of the research. The final sample size of this study is 34.

Data collection process:

The researcher approached children's palliative facilities and NGOs in Chennai. Since the area of study is sensitive, the researcher took a week to build rapport with the potential respondents. The drop out percentage was above 50%. Once the respondents were ready, they were given a consent form after which they were asked to fill a form that collected their socio-demographic details and the responses for the 3 tools- Montgomery Borgatta Caregiver Burden Scale, Sleep Quality Scale and SpREUK-P questionnaire. After administering the questionnaires, the researcher spoke to them about how they felt and ensured that they were not triggered by any of the questions.

Tools used:

1. Montgomery Borgatta Caregiver Burden Scale a 14-item questionnaire with 5 item responses to each question; each response was given a score from 0 to 5. Of the 14 items in the questionnaire, a set of 6 questions measure Objective Burden(OB), 4 questions measure Subjective Stress Burden (SB) and 4 questions measure Subjective Demand Burden (DB).

Psychometric properties indicated high internal consistency and reliability across the three subscales with Chronbach's alpha ranging between .84 to .87 (Montgomery, 2002; Montgomery & Kwak, 2008; Montgomery et al., 2011; Savundranayagam, Montgomery, & Kosloski, 2011).

2. Shortened SpREUK-P Questionnaire- SF17 (Büssing et al., 2012) was designed to measure the engagement frequencies of a large spectrum of organized and private religious, spiritual, existential and philosophical practices. It avoids the intermix of cognitive / emotional attitudes and convictions on the one hand with the engagement in forms of practice (action, behavior) on the other.

The shortened SpREUK-P SF17 has 17 items and 5 factors, i.e.: Religious (alpha=.82), i.e., praying, religious events, religious symbols; Humanistic (alpha = .79), i.e., help others, consider their needs, do good, connectedness; Existentialistic (alpha =.77), i.e., self-realization, spiritual development, meaning in life, turn to nature; Spiritual (mind body) (alpha = .72), i.e., meditation, rituals, reading spiritual/religious books; and Gratitude / Awe

($\alpha = .77$), i.e., feeling of gratitude, awe, experience beauty. The internal consistency estimates range from .72 to .82 (17 item version) and correlate strongly with Trust in Higher Guidance.

3. Sleep Quality Scale (SQS) consists of 28 items, the SQS evaluates six domains of sleep quality. Total scores can range from 0 to 84, with higher scores denoting more acute sleep problems. The scale has been validated in individuals aged 18–59 years. An initial psychometric evaluation conducted by Yi and colleagues, found an internal consistency of .92, a test-retest reliability of .81. The SQS is strongly correlated with results obtained on the Pittsburgh Sleep Quality Index

Plan for analysis:

The scoring was done based on the guidelines provided by the manual of each of the scales. The subscales and total sum of Montgomery-Borgatta Caregiver Burden Scale and SpREUK-P was calculated. The total sum of Sleep Quality Scale was calculated. This numerical data was analyzed using SPSS. Both descriptive data and inferential data about the variables was acquired. Interpretations were made and presented using the norms provided by the standardized scales. The normality of the scores of the variables was measured using the Shapiro-Wilk test. Based on the normality score of the data acquired, the correlation coefficient was calculated using the Spearman correlation test, which is a non-parametric test. Kruskal Wallis test was also conducted to see the relationship between sociodemographic variables and burden, sleep quality and spirituality.

Findings

The following section presents the results of the data that was collected from the sample through the questionnaire and analysed using SPSS. The descriptive data of all the socio demographic details and the variables is as follows.

The mean age of the sample is seen to be 33.91 with a standard deviation of 9.14. As seen in Figure 2, there are a few outliers within the age range of 50-60. Since the standard deviation is low, the distribution of data is not widely distributed. Therefore, the mean score is a reliable aggregate of the age of the sample.

With regard to the sex, only 2 of the respondents were male and 32 out of the 34 respondents were female. That is only 5.8% of the sample was male or fathers and an extremely high portion of 94.2% of the sample was female or mothers of the children with chronic illnesses.

The mean score of the average income of the families per month is seen to be Rs. 15,250. The standard deviation is significantly high indicating that the income of this sample is widely distributed. The highest reported average monthly income is Rs.60,000 and the lowest average monthly income is Rs. 2000. Therefore, the mean score might not be a reliable aggregate of the average monthly income of this sample.

With regard to the religion the respondents identified with a huge portion of this sample (76.5%), follow Hinduism, portion of respondents following Christianity (14.7%) and a very small portion of the sample follows Islam (5.9%). One female respondent reported to be secular.

Table 1
 Frequency Table on Educational qualification of sample

Educational level	No. of respondents
No formal education	3
5th standard	1
8th standard	2
9th standard	6
10th standard	10
12th standard	5
Bachelor of Arts	2
Bachelor of Sciences	1
Bachelor of Engineering	1
BABL	1
Bachelor of Commerce	1
Master of Commerce	1

Table 1 shows the educational qualification of the sample. Three respondents did not receive formal education. It is seen that the majority (63.33%), that is 22 of the respondents, did not complete their formal high school education and 5 of the respondents (14.7%), completed their formal high school education and did not pursue anything further. Only 20.5%, that is, 7 out of the 34 respondents have pursued and acquired a degree. Notably, both the male respondents were part of the 7 respondents who acquired a degree.

The next section presents the descriptive data of the variables- dimensions of caregiver burden, sleep quality and dimensions of spiritual practices.

Table 2
 Descriptive data on Scores of sample on Montgomery Borgatta Caregiver Burden Scale and subscales

Variable	Mean	Median	SD	Range	Shapiro-Wilk Significance
OB	23.17	23.0	5.07	22.0	-

SB	14.7	16.0	4.59	16.0	-
DB	7.82	6.0	4.24	14.0	-
Total Caregiver Burden	45.79	48.0	10.08	43.0	.320

Table 2 presents the descriptive data of the subscales and the total score of the sample on the Montgomery Borgatta Caregiver Burden Scale.

The mean score of Objective Burden (OB) of this sample is 23.17 and this score, in comparison to the norms provided, indicates a significantly high level of objective burden. The standard deviation is 5 (lower than 7.723- 1/3rd of mean) indicating that the objective burden scores are not widely distributed in this sample.

The mean score of Subjective Stress Burden (SB) of this sample is 14.7 and this score, in comparison to the norms provided, indicates a significantly high level of subjective stress burden. The standard deviation is 4.59 (lower than 4.9- 1/3rd of mean) indicating that the subjective stress burden scores are not widely distributed in this sample.

The mean score of Subjective Demand Burden (DB) of this sample is 7.82 and this score, in comparison to the norms provided, indicates an extremely low level of demand burden. The standard deviation is 4.246 (higher than 2.6-1/3rd of mean) indicating that the subjective stress burden scores are widely distributed in this sample.

The total burnout score, that is, the sum of the subscales was also calculated. The total score acquired a p-value of 0.320 in the Shapiro-Wilk test. The p-value .320 ($p > 0.05$) indicates that the total scores might have a moderately normal distribution. The mean total burden score of this sample was 45.79. The standard deviation is 10.08 and is significantly low (lower than 15.2- 1/3rd of mean), indicating that the total burnout scores of this sample are not widely distributed. Therefore, the mean score is a reliable aggregate of the total Caregiver Burden scores of this sample.

The sum of the norm values given for the subscales was used to assume the norm average of the total score. With this assumption of the norm average of the total score, the mean score of this sample might indicate moderate to high burden within this sample ($45.79 < 51.5$).

Table 3
 Descriptive data on Sleep Quality Scale scores of the sample

Variable	Mean	Median	SD	Range	Shapiro-Wilk Significance
SQS	36.97	37.0	18.88	73.0	.393

Table 3 presents the descriptive data of the total scores of the sample in SQS. The p-value being greater than 0.05 indicates that the total scores might have a moderately normal distribution. The mean score (36.97) indicates very mild sleep disturbances in this particular

sample. The standard deviation (18.89) and range (73) indicate that the sleep quality scores of this sample is widely distributed. Therefore, the mean score might not be a reliable aggregate of the scores of this sample.

Table 4
 Descriptive data on Scores of the sample on SpREUK-17 Scale and subscales

Variable	Mean	Median	SD	Range	Shapiro-Wilk Significance
Religious	7.98	8.0	3.44	12.0	-
Humanistic	8.85	9.5	3.30	12.0	-
Gratitude	6.55	7.0	2.61	8.0	-
Existential	4.14	4.0	2.5	9.0	-
Spiritual	3.08	2.5	2.9	9.0	-
Total SpREUK-P	30.63	31.25	8.3	40.0	.892

With regard to the subscales and total score in SpREUK-P17, as seen in table 4, the p-value from the Shapiro-Wilk test of the spirituality scores of this sample indicates that the data is not normally distributed. The mean of the total SpREUK-P17 score is 30.63, the standard deviation is 8.3 and the range is 40. The standard deviation is low indicating that the mean is a reliable aggregate of the total SpREUK-P17 scores of this sample. In comparison to the norms provided, this mean score indicates that the sample rarely engages in spiritual practices (mean < 50).

Each subscale assesses different dimensions of spiritual practices. In this sample, spiritual practices have the lowest mean score (3.0882), followed by existential practices (4.1471), gratitude (6.5588), religious (7.9853) and humanistic practices have the highest mean score (8.8529). This indicates that there is higher indulgence in humanistic practices such as thinking and doing good for others, helping ones in need, etc. than in any other dimensions of spiritual practices.

The relationship between the total burden scores and the sociodemographic categorical variable of the native place of the sample was analysed to see if traveling from outside Chennai for the purpose of treatment had a significant difference on the level of burden.

Table 5
 Mean Ranks of total Caregiver Burden scores of sample from different native places

Native place	N	Burnout Mean Rank
Chennai	7	7.57
From Tamil Nadu	20	19.90
Outside Tamil Nadu	7	20.57

The Significance score (.012) indicates that the difference between the burden scores of respondents from Chennai, from within Tamil Nadu and from outside Tamil Nadu was moderately significant.

Even though the difference is not significant, the mean rank of total burden score of respondents from Chennai (7) is 7.57, of respondents from within Tamil Nadu (20) is 19.90 and of respondents from outside Tamil Nadu (7) is 20.57. The burden scores are seen to increase if they travelled from outside of Chennai.

The correlation between the average monthly income reported by the respondents and the three main variables was also analysed. Table 6 presents the Spearman's rho correlation coefficient with the significant score.

Table 6
 Spearman's Rho Correlation coefficient of average monthly income and variables

Variables	Correlation Coefficient	Significance (2-tailed)
SQS-Income	-.138	.437
Total Burden score- Income	.067	.706
Total SpREUK-17 score- Income	-.265	.130

The correlation between the monthly average income and the variables is not significant in this sample. Despite the insignificance, the nature of the relationship can be noted. Sleep quality is seen to have a very small, negative correlation with monthly income. This indicates the higher the average income reported, the lower the sleep disturbances.

Table 7

Spearman's Rho Correlation coefficient of subscale and total scores on Caregiver Burden Scale and total scores on Sleep Quality Scale

<i>Variables</i>	Correlation Coefficient	Significance (2-tailed)
OB-SQS	.308	.076
SB-SQS	.480**	.004
DB-SQS	.093	.600
Total Burden Score- SQS	.444**	.009

**Correlation is significant at the 0.01 level (2-tailed)

Table 7 presents the correlation coefficient between the total caregiver burden and the subscales. The objective burden score was seen to have a moderately significant, positive and low relationship with the sleep quality score indicating that the more sleep disturbances, the more objective burden score among this sample. The total burden score and the subjective stress burden score are both seen to have a significant, positive and moderate correlation with the sleep quality scores of this sample. This indicates that the more sleep disturbances, the more subjective stress burden and total burden score among this sample.

Table 8

Spearman's Rho Correlation Coefficients of subscale and total scores on SpREUK-17 and total scores on Sleep Quality Scale

<i>Variables</i>	Correlation Coefficient	Significance (2-tailed)
Religious- SQS	-.052	.772
Spiritual- SQS	-.108	.544
Existential- SQS	-.250	.153
Humanistic-SQS	.388*	.023
Gratitude- SQS	-.105	.554
Total SpREUK-P17 score- SQS	-.077	.663

**Correlation is significant at the 0.01 level (2-tailed)

Table 8 presents the correlation coefficient between the total SpREUK-P17 score and the subscale scores and the sleep quality scale scores. Except the humanistic practices subscale, all the spirituality subscales have an insignificant correlation with sleep quality of this sample. It is notable that despite the insignificance, the relationship between sleep quality scores and religious (-.052), spiritual (-.108), existential (-.250), gratitude (-.105) and total SpREUK-P17 score (-.077) are seen to have a negative and low correlation. The correlation coefficient between humanistic subscale scores and sleep quality scores of this sample is significant (.388), and is seen to indicate a significant, moderate and positive relationship between the same.

Table 9

Spearman's Rho Correlation coefficient of subscales and total scores on Caregiver Burden Scale and subscales and total scores on SpREUK-P17

Variables	Correlation Coefficient	Significance (2-tailed)
Total Caregiver burden- Total SpREUK-17 score	-.247	.159
OB- Religious	-.040	.820
OB- Spiritual	.048	.786
OB- Existential	-.304	.080
OB-Humanistic	-.019	.913
OB- Gratitude	-.522**	.002
SB- Religious	-.199	.260
SB- Spiritual	.063	.722
SB- Existential	.040	.823
SB-Humanistic	.098	.580
SB- Gratitude	-.275	.115
DB- Religious	-.527**	0.01
DB- Spiritual	.012	.948
DB- Existential	.279	.111
DB-Humanistic	-.103	.562

DB- Gratitude

-.050

.777

**Correlation significant at the 0.01 level (2-tailed)

To answer the research question, the correlation between the total caregiver burden scores and the total SpREUK-P17 scores analysed. Considering the fact that the subscales of the particular scales utilized in this study are reliable, the correlation between the subscales of both the questionnaires were also analysed.

Table 9 presents the correlation coefficient between the total caregiver burden score and the total spirituality score in this sample and it is insignificant. Despite the insignificance, the total scores are seen to have a low and negative correlation. However, as previously mentioned the total scores are certainly not the most reliable. The subscale scores of the standardized scales used are seen to be much more reliable and accurate than the sum total.

The correlation coefficient between the SpREUK-17 subscales and the Montgomery Borgatta Caregiver burden subscales are also shown in table 9. These correlation coefficients answer the research question and show that specific dimensions of spiritual practices have a significant relationship with specific types of burden. Religious practices have a significant strong, negative relationship with subjective demand burden (-.527) and Gratitude practices have a significant strong, negative relationship with objective burden (-.522) at 99% confidence interval. This significant, strong and negative correlation indicates that the higher indulgence in certain spiritual practices, the lower the burden felt.

Discussion

Considering the sensitivity of this field, the researcher indulged in a week's period of rapport building with respondents that further shed light on the intensity of their emotions. This chapter presents the common narratives and themes from the experiences and emotions shared by the respondents which help better understand the numerical data.

Demographics and Bi-polarity of sexes

All the respondents were in their middle adulthood. Except two out of the 34 respondents, were females. In the current study, the male caregivers were not open to responding and they usually directed the researcher to the mother of the child. The 2 male respondents in this study also considered the mother to be a better representative of the primary caregiver of the child because they spent more time with the child directly. The most reported comment was that the father is more focused on the finances and talking to the doctors than taking direct care of the child. As pointed out by Cohn et. al, 2019, the findings on fathers are extremely narrow and limited and this pattern persists in this current study as well. The traditional bi-polar socialization model illustrates a psychological perspective in which caring for and nurturing others is more central to women's identity than it is to men. Men are seen to experience a feeling of awkwardness or discomfort with either the intimacy that will be shared or the tasks which must be performed in the primary caregiver role (Hirsch, 1996). In the current study, the mothers also reported to always prioritize their child and family over their own health and well-being and were more expressive of their emotions, feelings and problems than the fathers.

Malm-Buatsi et al., 2015, also shows that mothers of children with illnesses are more prone to show more depressive symptoms than fathers. However, Fuerboeter et al., 2021, indicated that fathers have objectively lower QoL. Both of these findings are similar to the findings of the current study. While the mothers were more expressive and open to show their vulnerability, the fathers also had a high level of burden and responsibility, especially the financial toll that majorly fell on them.

The respondents predominantly followed Hinduism. The religious composition of this sample is very uneven, yet could be quite representative of the uneven distribution of religion throughout India (Kramer, 2021). According to Census of India, 1951-2011, Hindus make up 79.8% of India's population and Muslims account for 14.2%; Christians, Sikhs, Buddhists and Jains account for most of the remaining 6%. This distribution is very similar to the one of this current study.

With regard to educational qualifications, 63.3% of the respondents did not complete their high school graduation as seen in table 1. This indicates that formal education is significantly low in this sample. Both the male respondents of this study were seen to have not only completed their formal high school education, but also pursued and acquired undergraduate degrees. The only respondent in this study to have a postgraduate degree was one of the two male respondents. This could again be a representative distribution of the unequal distribution of education between the two sexes in India (Hayat, 2021).

Both the male respondents had a current occupation. All the female participants were either currently housemakers or worked irregularly for a daily wage. A few of the respondents who reported to be housemakers had discontinued their job because they had to take care of their child. This calls back the bipolar socialization model and the influence of stereotyped gender roles in caregiving (Hirsch, 1996). She is expected to fulfil her role as a primary, nurturing caregiver for the child over her aspirations. These women were expected to give up their education and career for their families even before their marriage and this belief was seen to be deeply ingrained in respondents. The expected pattern for women is to meet the needs of others before meeting her own needs and this was evident in the sample of the current study.

The respondents reported to be from the lower to middle class socioeconomic status with an average of Rs. 15,250. Taking into account the average income of different socioeconomic status in India, the cost of living in Chennai and the cost of treatment procedures, the range of average monthly income of this sample is significantly low. This low-income level could potentially be a factor affecting the financial toll on the parents.

Chronic illnesses and Caregiving time

The children of the respondents, with the chronic illnesses, were between the age range 2-16. They were diagnosed with Chronic Kidney Disease (CKD), different degrees of Acute Lymphoblastic Leukemia (ALL), Fancouis Ananine, Oostero Sarcoma, Ewing Sarcoma, pancreatic conditions or other cardiovascular diseases. All of these conditions require intense, periodic medical interventions such as haemodialysis, for which they needed to be in the hospital. The treatment regime included regular and continuous medication which was usually administered by the parents.

Among these respondents, 64.3% of the mothers spent their whole days taking care of their child. They reported that they spend 24 hours a day with their child and their daily lives, duties and responsibilities revolved around the child and the treatment. Since most of the children diagnosed could not go to school to acquire formal education, the parents were also responsible for providing a certain kind of informal education in addition to the daily chores and treatment interventions. It should again be noted that both the male respondents reported to spend about 4-6 hours a day with the child after their work hours. There is evidently a significant difference between the amount of time spent with the child among the mothers and fathers. This finding speaks more to the bi-polar socialization model and primary caregiving being more central to the identity of the mothers than the fathers.

The respondents also had other children to take care of. On an average, the respondents had one to three children, including the child diagnosed with the chronic illness. The other children were either separated from the parents because of the condition and treatment procedures of the child or the siblings helped out the parents in the caregiving process. The researcher met several siblings who sat with the patient during their treatment procedure. The respondents elicited a lot of guilt and resentment for not fulfilling their role as a parent to their other children. Their focus and attention was completely on the child that was ill and they expressed their guilt for not being able to take care of all their children equally. This could be another factor that was impacting their objective and subjective burden scores.

Intensity of Caregiver Burden

With regard to burden, as seen in table 2, the mean scores of the objective burden (OB) and subjective stress burden (SB) are significantly high. The standard deviation for the both is also low indicating that the mean scores are a reliable aggregate of the sample's scores. The narratives provided by the respondents during the rapport building shed light on the intensity and dimensions of burden and emotions felt by the parents. The level of privacy and time for themselves was almost non-existent. It needs to be noted that the mothers were unbothered by the lack of privacy and time for themselves. Upon questioning about why they feel that their personal space is not of priority, the mothers reported that this was the "norm" for all mothers. A few of them even said that this is how it has been even before marriage and therefore, the concept of personal interests, space and time did not affect them as much now. One of the more concerning common narratives from the mothers was the suicidal ideations. Most mothers consistently reported that they would end their lives if anything happened to the child with the medical condition. This is a notable theme that will require more attention and help. Mothers also expressed feelings of guilt, anxiety, fear and even anger. Each parent had their own unique issues that could have majorly affected their objective burden and subjective stress burden. The intensity of emotions felt by these parents was very severe. Similar to the findings reported in the meta-analysis (Lopes-Júnior et al., 2022), the narratives elicited by a majority of the parents of children with chronic illnesses in this current study showed symptoms of depression including various physical, behavioural and emotional changes. Most commonly seen symptoms were excessive guilt and feelings of worthlessness, depressed mood, loss of interest, fatigue and change in sleep patterns. Preoccupations about all their problems and anxiety about what the future holds were also predominantly reported by almost all the respondents. The

extremely high scores on objective and subjective stress burden were corroborated by these narratives. Therefore, hypothesis one and two have been accepted.

The mean score of the subjective demand burden (DB) was seen to be significantly low. This indicates that the parents did not feel manipulated or irritated by the demands made by their child. The parents did not feel that the wants and needs made by the children were unreasonable or burdensome. However, the standard deviation of the subjective demand burden scores of this sample is considerably higher indicating that the scores are widely distributed. This could be reasoned by the dichotomy of narratives given by the parents. On one hand, it was considered to be part of the parental role to fulfil the wants and needs of young children and therefore requests made by the children were not considered to be a 'burden' to the parent. At the same time, parents were also frustrated that sometimes, the children do not understand the implications of their conditions on their desires. This could be one of the reasons for the distributed scores in the subjective demand burden. Despite the distribution of the scores, the range of scores in DB indicates low to moderate subjective demand burden. Since the subjective demand burden scores are low, the third hypothesis has been rejected.

Role of Relocation in burden

The sample included parents who are currently residing in Chennai. However, it is seen that 7 of the respondents are originally from Chennai. The rest of the respondents reported to have travelled from outside the city or state even, for the purpose of the child's treatment only. As presented in table 5, the mean total burden score of the sample is seen to increase for when they travelled outside Chennai and increases furthermore, when the respondents reported to have travelled from outside the state. All the respondents reported to have travelled solely for treatment purposes. Mothers reported to feel guilty about the family left behind in their native place without their care. Mothers also reported that the siblings of the patient were growing up back in their native place, without parental care because of the intense treatment regime of their other child and this brought intense guilt among the mother. Therefore, this guilt along with the lack of stability, the uncertainty of an unknown place, financial burden, etc. could have led to the increase of burden scores. The satisfaction with social support resources in experiencing less caregiving burden is also seen to be important (Teixeira and Pereira, 2012). Therefore, lack of social support in a new city might be another contributing factor for the increased burnout in parents that travelled from outside of Chennai.

Sleep disturbances with Subjective Stress

The mean sleep quality score indicates moderate sleep disturbances within the sample. However, it needs to be considered that the sleep quality scores of this sample are widely distributed. Majority of the parents reported problems with having deep sleep. They reported that they were never able to get deep sleep because they had to be alert to detect any triggers of the child's illness. However, unlike in the study of Feeley et al., 2014, the parents did not have any significant acute, clinical symptoms of sleep disturbances. While the parents of children with chronic illness reported consistent sleep debt, they did not report any acute, high degree of sleep disturbances and this is corroborated by the mean score in the sleep quality scale. Therefore, the fourth hypothesis has been rejected.

Consistent with several studies, the sample is seen to have high burden accompanied by sleep disturbances (Brandt et al. 2022, Feeley et al., 2014). Parents reported to stay up sometimes for specific night treatment procedures for low blood sugar etc. Rihm et al., 2022, studied psychosocial situations of families caring for children with rare diseases and the results showed high distress among the sample and also showed the frequency of everyday problems such as sleep problems, fatigue, fears, feeling tense or nervous and worry which is similar to that of the current study as well. As seen in table 8, sleep quality is also seen to be significantly correlated with subjective stress burden score and total burden score. This indicates that the more burden felt by the parents, the more sleep disturbances the experience. High emotion-focused coping has seen to be significantly predictive of reduction in sleep time (Sadeh, A., Keinan, G., & Daon, K., 2004; L. Drake, Pillai & Roth, 2014). The preoccupations about their child's condition and the intensity of emotions and stress might have affected the sleep patterns of the parents.

Meaning seeking through Spirituality and Religion

Discussions about spirituality and religion brought out a lot of emotions. It is important to note that the religion followed by the sample was a very common theme that came up during conversations about spirituality. This indicates the intertwined relationship of religion and spirituality. It was also seen that even for the people who did not follow the practices of their religion, religion and spirituality was an important topic.

There was a spectrum of emotions and attitudes towards spirituality. Most commonly, there was anger and disappointment. The mothers felt that their "higher power" had put them in this particular situation or did not save them from it. Therefore, the parents had "given up" on their beliefs on higher power or started to form a negative relationship with it. Rage stemmed from the injustice of an innocent, young child having to go through so much. They attributed this "injustice" to have been "inflicted by God". A few mothers also felt as though "the higher power" was punishing them for their past sins by inflicting pain and illness on their loved one. These were a few negative narratives reported by the parents. On the other end of the spectrum, there were also a few parents who said that the illness was happening for a reason. They said that they could feel "God" communicating with them more frequently. They found comfort in the signs they perceive to be from their higher power.

Though the range of emotions are wide and varied, the just world phenomenon perspective is seen to have brought meaning and a sense of cognitive cohesiveness for the parents.

Indulges in Practices of Spirituality

To understand spirituality as an active coping strategy, the engagement with practices of gratitude, existential, humanistic meaning seeking, religion and spirituality was measured. The total mean score in SpREUK-P indicates that the sample had significantly low and rare engagement in such practices. Within this low and rare indulgence, spiritual practices have the lowest mean score (3.08), followed by existential practices (4.14), gratitude (6.55), religious (7.98) and humanistic practices have the highest mean score (8.85). This evident ascending order of mean scores shows that the sample more frequently indulges in the social facets of spirituality and religion such as helping their neighbours, praying, visiting the temple, etc.,

while the personal facets such as “inward turning”, self-actualization, mind-body practices have not been widely explored.

One of the reasons for rare indulgence in practices could be the negative attitudes towards higher power. The parents reported that the rigid time schedules that revolve around the child sometimes stopping them from attending religious events. However, the parents also reported to not understand or not “see the point” of indulging in individualistic practices such as meditation, reflection, mind-body practices considering their child’s condition. These reports show that there is still preference for more indulgence in social, external facets than personal, internal facets of spiritual practices.

The perception of a positive relationship with God or higher power is an important factor that impacts the process of coping (Weaver & Flannelly, 2004; Lalani et al., 2018). The predominantly negative narratives and themes around spirituality might be a factor affecting the low engagement in spirituality and also the high subjective burden.

Spirituality correlates with Sleep and Burden

Humanistic practices are seen to have a significant positive relationship with the sleep quality scores. This indicates that the higher the parent indulges in humanistic spiritual practices (such as helping other people and fulfilling the needs of others), the more their sleep disturbances. This particular finding is rather distinct and unique and there are no explanations in existing literature to be found for this particular correlation. It needs to be noted that the relationship between sleep disturbances and all the other dimensions of spirituality practices is seen to be negative, but insignificant. This negative nature of relationship indicates that the higher the spirituality, the lesser the sleep disturbances. This brings back the effect of subjective perceived stress in sleep quality and how spirituality as a positive coping strategy might influence the same.

As shown in Table 9, the total burden score does not have a significant correlation with the total spirituality score. Despite the insignificance, the nature of the correlation is seen to be negative. This indicates that the higher engagement in spiritual practices, the lower the burden felt. Since the standardized scales utilized in this study emphasize more on the interpretations made from the subscales than the sum total, the correlation between the subscales of caregiver burden and the subscales of spiritual practices was calculated to present a more accurate and holistic analysis of the relationships.

There is a significant strong negative relationship between specific spiritual practices and specific burden felt by the parents and these findings are consistent with previous studies on the same (Lai et al., 2017; Bernard et al., 2014; Lalani et al., 2018; Anum & Dasti, 2015). However, it was not within the scope of this study to understand why the specific types of spiritual practices have a significant relationship with specific types of burden. No explanations for such particular relationships were found in the reviewed literature as well.

It is seen that religious practices have a significant strong, negative relationship with subjective demand burden (-.527) and Gratitude practices have a significant strong, negative relationship with objective burden (-.522) at 99% confidence interval. While this strongly indicates that the more spiritual practices, the less burden felt by the parents of children with chronic illness, it is not understood why religious practices specifically correlates with DB and

gratitude specifically correlates with OB. Regardless, this significant and high correlation between variables answers the research question of the current study and the fifth and final hypothesis can be accepted; there is a significant negative correlation between caregiver burden and engagement in spiritual practices.

Limitations

This current study has limitations that can be considered for future studies. The standardized scales did not elicit the intensity of emotions and dimensions of burden that was reported by the respondents during the informal rapport building stage. To understand the abstract concept of spirituality and religion, a mixed method of research design could have been utilized to elicit and record more structured narratives and themes. This would have helped understand the relationships between the different variables much better. The distribution of sex could have been more focused and the limited primary findings about fathers as caregivers could have been explored.

Conclusion

This current study focused on a very specific and special population of parents of children with chronic illnesses residing in Chennai. It found out that there was a significant level of objective and subjective burden felt by this particular sample. The sample was also seen to have moderate levels of sleep disturbances that could be impacting their mental and physical health and that was also seen to have significant correlation with subjective stress and spiritual practices. Answering the research question, the findings of this study also proved that there is a significant negative relationship between indulging in specific types of spiritual practices and subjective and objective burden felt by the parents.

The scope for further study in this particular field is immense. There are several dimensions of the findings in this study that can be delved into. Given that the relationship is negative, the effect of spiritual practices could also be studied using an intervention research design. Furthermore, the sample could be made more diverse in terms of the sociodemographic factors and the relationship and even the effect of it on burden and spirituality could be studied. The sample could be extended to the primary caregivers of patients and the burden and spirituality could be studied to see if the effect is significant among a broader population. Furthermore, the gender stereotypes in caregiving that were found to be extremely intense and ingrained with the culture and norms of India could be explored in depth.

With findings that are more large-scale and significant that proves that spiritual practices have a positive impact on coping with caregiving, interventions could be designed to help in a biopsychosocial model of spiritual and active coping for the welfare of the mental and physical health of the caregivers.

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