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Spiritual Well-Being and Caregivers' Strain in Dementia Caregiving

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ABSTRACT

The present paper examined the relationship between spiritual well-being and strain among caregivers of persons living with dementia. A cross-sectional descriptive study was conducted among 182 family caregivers of persons with dementia. The Spiritual Health and Life Orientation Measure (SHALOM) and Caregivers' Strain Index (CSI) were used to assess family caregivers' spiritual well-being and strain. The analysis indicated that the scores of caregivers' strain ranged from 1 to 13 with a mean of 6.36 and SD of 2.89. The mean score of Ideal spiritual well-being of caregivers were found to be 88.19 with SD of 7.76 and ranged from 63 to 100. The score for Lived Spiritual Well-being was ranged from 24 to 93 with mean score of 66.75 and SD of 14.38. Also, Pearson Product Moment Correlation results showed negative correlation between spiritual well-being and caregivers' strain ($r = -.567$, $p < .01$). The study suggests that caregivers of persons with dementia would benefit from culturally relevant and spirituality based interventions to enhance their SWB for helping them to cope with care giving strain so that caregivers can admire the positive experiences in caring for a demented relative.

Keywords: Dementia, Family Caregivers, Spiritual Well-being, Strain.

INTRODUCTION

Because of its increased incidence, dementia becomes a global public health challenge. World Health Organisation estimates that more than 47.5 million people are living with dementia worldwide and this number is expected to triple by 2050 impelled by population ageing. In India, many families are living with dementia. It is estimated that 4.1 million people above 60 years old have dementia which constitutes 3.7% of India's elderly population (Dementia care notes, 2015).

This advancing tidal wave in the incidence of the disease creates another hidden population, the caregivers. Persons with dementia require high levels of assistance to perform daily living routines. Without caregivers, people with dementia would have a poorer quality of life. Unlike the Western countries where countries invest for paid dementia caregivers, in India most of which is provided by informal or family caregivers because responsibility of providing care to the frail elders often rests entirely on family members in Asian Indian families (Gupta, Rowe, & Pillai, 2009). Caregivers are critical resources not only for the families but also for the public health care system.

Caring for a person with dementia perhaps is more challenging and exhausting than caring for persons living with other terminal illness. Mostly family caregivers experience strain and poorer quality of life. Even its early stages, dementia may have a greater impact on family caregivers because of its chronic progressive and depersonalizing nature. Caregivers of persons with dementia live in a state of continuous change and disruption of routine life (Prorok, Horgan, & Seitz, 2013). They are more prone to experience severe burden, depression, and physical health deficits throughout the years of caregiving (Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012). The burden associated with caregiving is likely to increase as the desease progresses to later stages (Kim, Chang, Rose, & Kim, 2012; Liu et al., 2012; Turro-Garriga et al., 2013). These hurdles in caregiving process impact their overall state of well-being and in turn the quality of care they provide for the patient. Caregivers of persons living with dementia frequently use a variety of coping strategies to deal with caregiving burden and stress (Pearlin et al., 1990; Quayhagen & Quayhagen, 1988). According to Pearlin et.al

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(1990) these strategies help them to minimize the caregiver burden, to perceive the meaning of the situation and to manage the symptoms of distress that arise in themselves.

In recent years spirituality became an integral determinant of health and well-being of each individual which may or may not be related with religion. People develop their own spiritual ways to cope with the life challenges and experience a state of well-being and it will be reflected in all domains of their life. More recently, caregiving research literature has examined role of religiosity/spirituality in both positive (Roff et al., 2004) and negative caregiving experience including caregiver burden (Herrera et al., 2009), depression (Lopez et al., (2012) stress, perceived rewards, satisfaction, hope (Borneman & Ferrel, 2002) etc. Choi, Tirrito, and Mills (2008) stated caregivers are likely to give better care when religious beliefs are strengthened by spiritual support, which may be provided by the caregivers' religious institutions. Hodge & Sun (2012) further added that spirituality partially mediate the effect of subjective stress on Positive Aspects of Caregiving.

Spiritual well-being "pertains to the wellness or 'health' of the totality of the inner resources of people, the ultimate concerns around which all other values are focused, the central philosophy of life that guides conduct, and the meaning-giving centre of human life which influences all individual and social behavior" (Moberg, 1979, p. 11). It is an outcome of the spiritual experience. Fisher (1998) proposes four major domains of spiritual well-being; personal, communal, transcendental, and environmental well-being. Gomez and Fisher (2003) state that; the personal domain reflects how one intra relates with oneself with regard to meaning, purpose, and values in life. The communal domain expresses in the quality and depth of inter-personal relationships, between self and others, and includes love, justice, hope, and faith in humanity. The environmental domain deals with the care and nurture for the physical and biological world, also includes a sense of awe, wonder, and unity with the environment. The transcendental domain deals with the relationship of self with some-thing or some-one beyond the human level, such as a cosmic force, transcendental reality, or God, and involves faith towards, adoration, and worship of, the source of mystery of the universe. (p. 1976). These four domains integrate to form overall spiritual well-being for an individual.

In a study, conducted by Shah et al. (2001), of dementia caregivers, 96% considered themselves as religious or spiritual and reported high levels of religious coping. Religious Discontent Religious coping (one among the six subscales that measure the extent to which a person turns to religion, in both positive and negative ways, in response to stressful life circumstances) was positively associated with depression and burden. No significant correlation could find between Organizational, non-organizational or intrinsic religiousness and depression or burden.

The external spiritual/religious support is also significant in the lives of caregivers. Schillings (2012) suggested that spiritual support is an important coping mechanism among dementia caregivers. In his study of Caucasian and African American dementia caregivers, it was reported that the global score of the burden measure is negatively correlated with the global score of the Spiritual Support Scale. An increase in spiritual support is correlated with a decrease in perceived burden. Of special note, the researcher added that spiritual support actually provides a positive outlook on burden. That is if a caregiver has a positive attitude towards caregiving because of spiritual support, burden may be perceived as lower.

In an exploratory study conducted among 128 dementia caregivers, Márquez-González et al. (2012) found that spiritual beliefs help dementia caregivers to find meaning in caregiving experiences and thus appraise care recipients' behavioural problems as less stressful.

Research findings have consistently confirmed that caring for a family member with Dementia is associated with stress and often results in tremendous burden among caregivers. Also, the effect of spirituality/religiosity on caregiver's perceived stress and burden has confirmed previously. However only a few studies have assessed the caregiver's subjective strain and how spiritual well-being regulates this feeling especially in Indian socio cultural context. It is relatively new construct in the scientific studies of Indian caregiver population. Any attempt to conceptualize the relationship between spiritual well-being and caregivers strain from the perspective of Indian informal caregivers will add to the existing literature and will inform the spirituality based interventions for enhancing their quality of life.

The current study expanded on the previous literature by investigating the relationship of spiritual well-being with strain experienced by the dementia caregivers in South India.

MATERIALS AND METHODS

The Study Population and Sample

The present study was conducted in Kunnathunadu Taluk of Ernakulam district in Kerala, India. All the family caregivers who have been caring for their demented relative at their home reside in the geographic territory of Kunnathunad Taluk of Ernakulam district in Kerala State, India, and enrolled in either of the sixteen government hospitals of this Taluk constituted the population for the study.

Prior to participating in this study, it was verified that their care-recipients had received a probable diagnosis of dementia from their physician. They should be registered in either of the sixteen government hospitals and often being visited by the palliative health workers. In this study, a family caregiver was defined as a relative of a person with dementia who assisted the care-recipient at their own home with the majority of activities of daily living (e.g., bathing, feeding, dressing, toileting), instrumental activities of daily living (e.g., managing finances, transportation), and service provisions required by that individual. Individuals participating in this study were required to be in the role of primary caregiver. In addition to the primary caregiver being a relative of the care-recipient, they were also required to be only caring for one older adult at the time of the study. Maintaining the specific caregiver criteria was critical in order to reduce caregiver variability, and to ensure that all participants within the study are indeed providing the majority of care for the care-recipients.

Firstly, the researcher prepared a sample frame of all the possible respondents who met the eligibility criteria as per the recommendation of community palliative health workers of Government hospitals. The final sample frame consisted of 364 subjects. A random sample of 182 caregivers was selected in-order to ensure 50% representation of the total population.

Data Collection Procedures

The process of data collection consisted of each participant completing the research instruments (described below). The researcher visited the respondents at their home and each participant was provided with a packet containing an explanation of the study; consent forms and study instruments. Caregivers were allowed to complete the questionnaires. Completed materials were collected by the researcher directly.

Measures

Socio-Demographic Profile: A socio-demographic schedule was developed by the researcher. It includes the caregivers' as well as care recipients' details such as age, gender, religion, education, occupation, marital status, family type and size, income, place of residence, relationship with the care recipient, duration of caregiving, and time spending for caregiving per day.

Spiritual Well-Being Questionnaire (SWBQ) (Gomez, R. & Fisher, J.W., 2003)*:* The SWBQ is half of an instrument called the Spiritual Health And Life-Orientation Measure (SHALOM) developed by Gomez, R. & Fisher, J.W., 2003, which asks for two responses from people for each of 20- items - 5 in each of four domains of spiritual well-being such as personal, communal, environmental and transcendental. The instrument involves double-response method (comparing lived experience with ideals) that gives a better measure of quality of relationships in the four domains. Each item is answered on a 5-point Likert scale ranging from 'very low' to 'very high'. SHALOM has undergone rigorous statistical testing in several languages. For the present study, the Cronbach's coefficient alpha reliability of Spiritual Well-being Scale was 0.934.

Caregiver Strain Index (CSI) (Robinson, 1983): It is a 13-items measurement that measures strain related to care provision. There is at least one item for each of the following major areas of concerns such as employment, financial, physical, social and time. Positive responses to seven or more items on the index indicate a greater level of strain. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. Internal consistency reliability was high with an established alpha of 0.86. The construct validity was supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation. For the present study, the Cronbach's coefficient alpha reliability of the Caregivers' Strain Index was 0.726.

All the instruments were first translated to Malayalam, regional language of the respondents by two bilingual experts and then back translated by another two bilingual experts of medical and social work arena. Discrepancies between the back translated and the original versions were examined and suggestions made to modify the wordings slightly to develop the final version. Then they were subjected to face validation by a panel of three experts who were working in Dementia field for at least

five years. Then pre-test was conducted among eight family caregivers whose care recipients were enrolled in Vengola Community Health Centre. Based on the reviews at different level and interviews with the respondents, the researcher prepared the final version of the instruments for data collection.

Data Entry and Analysis

Descriptive statistics was conducted using the Statistical Package for Social Sciences (SPSS), version 20.0. Data analysis was progressed from descriptive analysis (such as frequency distribution, measures of central tendency) to correlation analysis using Pearson product moment correlation.

RESULTS

Table 1 shows the socio-demographic characteristics of caregivers of persons living with dementia. Most caregivers were from the age groups of 41 to 50 years (31.9%), followed by 31-40 (22.5%), and 51-60 years (17%). About 83% of the caregivers were women, 90% were living in rural area, 33.5% completed high school education and 17.6% completed upper primary education (5-7 grades). Nearly 87% were married, and 61.5% were unemployed.

Table1. *Socio-demographic characteristics of caregivers of persons with dementia*

Age group	**N**	**%**	**Education**	**N**	**%**
20-30	11	6.0	Primary	23	12.6
31-40	41	22.5	Upper primary	32	17.6
41-50	58	31.9	High school	61	33.5
51-60	31	17.0	+ 2	26	14.3
61-70	23	12.6	UG	31	17.0
71&more	18	9.9	Uneducated	09	4.9
Gender	**N**	**%**	**Marital status**	**N**	**%**
Male	31	17	Married	158	86.8
Female	151	83	Unmarried/separated	24	13.2
Living space	**N**	**%**	**Occupation**	**N**	**%**
Semi-urban	18	9.9	Full time job	14	7.7
Rural	164	90.1	Part time job	33	18.1
---	---	---	Unemployed	112	61.5
---	---	---	Unemployed	09	4.9
---	---	---	Left job for care	14	7.7

As showed in Table 2, nearly half of the persons with dementia belong to the age group of 71-80 year of age (46.7%), 29.1 belonged to the age group of 81-90 years of age. About 64% were women and nearly 60% of the persons with dementia's spouses died or separated. Nearly 30% of the older persons with dementia were under mediation at the time of the study and nearly 30% reported complete dependence upon caregivers.

Table2. *Socio--demographic characteristics of persons with dementia*

Age group	**N**	**%**	**Education**	**N**	**%**
60-70	44	24.2	Primary	72	**39.6**
71-80	85	46.7	UP	**45**	**24.7**
81-90	53	29.1	HS	**10**	**5.5**
Gender	**N**	**%**	+2	**06**	**3.3**
Male	**66**	36.3	UG	**18**	**9.9**
Female	**116**	63.7	No education	**30**	**17**
Marital status	**N**	**%**	**Severity of dependence**	**N**	**%**
Married	**73**	40.1	Dependent	**52**	**28.6**
Separated/unmarried	**109**	**59.9**	Non-dependent	**130**	**71.4**
Medication status	**N**	**%**			
Yes	54	29.7	-----	-----	-----
No	128	70.3	-----	-----	-----

Table3. *Strain experienced by the caregivers*

Variable	**N**	**Min-Max**	**Mean**	**SD**
Caregivers' Strain Index	182	1-13	6.36	2.89

Table 3 shows the descriptive analysis of the extent of strain experienced by the family caregivers of persons living with dementia. The analysis reveals that the scores on caregivers' strain ranged from 1 to 13 with a mean of 6.36 and SD of 2.89.

Table4. *Descriptive Analysis of Ideal and lived Spiritual Well-being across Sub-domains Experienced by the Family Caregivers*

Sl. No	Key Concepts	Ideal Spiritual Well-being				Lived Spiritual Well-being			
		N	Min-Max	Mean	SD	N	Min-Max	Mean	SD
1	Personal Well-being	182	19-25	23.93	1.30	182	5-25	16.42	4.03
2	Communal Well-being	182	14-25	23.40	1.79	182	5-25	18.31	4.16
3	Environmental Well-being	182	5-25	16.89	5.85	182	5-25	12.34	5.58
4	Transcendental Well-being	182	9-25	23.97	2.55	182	9-25	19.68	4.61
5	Spiritual Well-being	182	63-100	88.19	7.76	182	24-93	66.75	14.38

The caregivers' responses on their stated ideals and lived experiences in each of the four domains of spiritual well-being were reported in Table 4. The results show that there is consistently high ideals (caregivers' expected variables what make them feel good) for all the four domains because of the reported values of each domains were above the middle value in the range of possible scores and hence it suggests a higher level of Ideal Spiritual Health. With regard to their lived experience, the mean score for personal domain was 16.42 which ranged from 5 to 25 with SD of 4.03. The communal well-being was ranged from 5 to 25 with mean of 18.31 and SD of 4.1. For Environmental domain mean was found to be 12.34 ranged from 5 to 25 with SD of 5.58 and the mean value of transcendental well-being was 19.68, ranged from 9 to 25 with SD of 4.61. This indicates that the caregivers have substantially higher level of Spiritual wellbeing in Personal, Communal and Transcendental domains. Whereas a low score in environmental domain suggests substantially poor spiritual well-being in that particular domain. Overall, Lived Spiritual Well-being was ranged from 24 to 93 with mean score of 66.75 and SD of 14.38.

Table5. *Correlation between Lived Spiritual Well-being and Caregiver Strain*

Sl.No.	Key Variables	Strain (r)
1	Lived Personal Well-being	-.464**
2	Lived Communal Well-being	-.559**
3	Lived Environmental Well-being	-.416**
4	Lived Transcendental Well-being	-.354**
5	Lived Spiritual Well-being	-.567**

***Correlation is significant at .01 level (2-tailed)*

Table 5 shows the correlation between the sub-domains of spiritual well-being and total spiritual well-being with strain experienced by the caregivers. It is interesting to note that all the sub-domains of spiritual well-being were negatively correlated with the caregiver strain. Increased personal well-being, communal well-being, environmental well-being and transcendental well-being are likely to result in reduced caregiver strain. The strongest correlation was found between the lived communal well-being and strain ($r = -.559$, $p < .01$) followed by correlation between lived personal well-being and strain ($r = -.464$, $p < .01$). This was stronger than correlation between lived environmental well-being and strain ($r = -.416$, $p < .01$). The lowest correlation was found between the lived transcendental domain and strain ($r = -.354$, $p < .01$).

DISCUSSION

The purpose of this study was to examine the relationship between the caregivers' spiritual well-being across personal, communal, environmental and transcendental domains and their strain related to caregiving for a demented relative. Caregivers' reported substantially high scores in all the domains of ideal spiritual well-being. Whereas they had high lived personal, communal and transcendental well-being but consistently low level of lived environmental well-being. It confirms that the dementia caregivers perceive better meaning purpose and values in life as their reported personal well-being was high. Studies state that caregiving for a terminally relative often distrupts the caregivers' relationships (Gwyther, 1998; Fisher & Lieberman, 1994;Spruyette, Van Audenhove, Lammertyn,& Storms, 2002) and they experience lack of social connections and feel loneliness. In contrast to these previous literatures, the present study reveals that the caregivers keep better inter-personal relationships in the community which provides feeling of love, justice, hope and faith in humanity. The possible explanation might be that the majority of the participants live in rural community where strong inter-personal relationships do exist. Lee & Robbins (1998) stated that individuals who feel connected with others are better able to cope, are less prone to anxiety and depression, and have better overall physical health. What lacks for the caregiver was the care and nurture for the physical and biological world around them. They were not able to experience the wonders of nature. Caregivers may prefer to be

connected with the neighbourhood than observing and relating with their biological world. Further it is evident that, they were connected with the divine force through practicing religious rituals and prayers.

This study explored the relationship between spiritual well-being and strain among a relatively understudied population, dementia caregivers. In-fact, various studied have demonstrated the role of spirituality in alleviating strain associated with caregiving, few studies have examined the relationship between spiritual well-being and subjective and objective burden. The findings of the present study support the results reported by Spurlock (2005). He studied the relationship between spiritual well-being and caregiver burden in family caregivers of persons with Alzheimers' Disease and reported a significant inverse relationship between the variables. Further, it is found that all the sub-domains of spiritual well-being are negatively correlated with the caregiver strain. Among these relationships, the strongest correlation was found between the lived communal well-being and strain. As suggested by Yatchmenoff et al. (1998) meaningful relationships, such as support from friends and family, have been associated with lower reported caregiver stress. The findings from the present study also provide evidence that the effective social relationships can reduce caregiver strain.

The findings highlight the importance of addressing the continuous need for spiritual well-being among caregivers because it is highly correlates with the strain experienced by them. Literature suggests that people who are more strainful experience more burden in caregiving process which influences their overall well-being. Practitioners may pay more attention on enhancing the self of caregivers and develop intervention plans helping them to develop positive affirmation to life by enriching a positive relationship with their own self, others, environment and a divine force. Practitioners can help the caregivers to explore the sources of spiritual well-being in their life and utilize them. It may help them to experience the caregiving process more positive one and finding meaning in life. Integrating spiritual beliefs, values and connectedness in strain management interventions for family caregivers may have a better impact on their total well-being.

CONCLUSION

The researcher adopted a quantitative, descriptive correlational research design in order to study the relationship between caregivers' spiritual well-being and strain. This study indicated that caregivers who have better and meaningful relationships with self, community, environment and a divine force are likely to experience reduced strain. It suggests the spirituality based interventions for family caregivers based on the firm belief that individuals can be empowered with spirituality. Discovering and appreciating positive outlook towards life within personal, communal, environmental and transcendental contexts will help the caregivers to cope with the caregiving challenges.

The study is limited by its cross-sectional nature. Future longitudinal studies may help to better understand the results found in the study. The geographic area selected for the study was comparatively smaller one. The study can be replicated among caregivers of people with other terminal illness.

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