

## Religion and Coping with Caregiving Stress

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### Abstract

*Objectives: Religious beliefs and practices constitute one of the most frequently used methods of coping in times of crisis. Family caregivers of persons with serious mental illness often turn to spirituality for support, and religiosity may be an important contributor to caregiver adjustment. The purpose of the current study was to present insights in how caregiving is experienced by family caregivers, and the religious coping strategies utilised by them. Design: The qualitative descriptive method was used. Methods: 75 caregivers belonging to both urban and rural areas were interviewed. The age of the participants ranged from 18-75 years and the mean age was 44.44 years. Interviews were done and qualitative inquiry was used to enable the caregiver to narrate his/her story. Data was qualitatively analyzed and several themes were identified. Results: From the narratives of the caregivers, it is clear that faith healing and medical modes of treatment coexist. Almost all the caregivers had tried faith healing at one time or the other. Caregivers admitted having faith in traditional healing. Caregivers said that they have performed sacred ceremonies, prayers, and visited religious places. Conclusions: It can be concluded that religion may serve as a potentially effective method of coping for and so the need is to integrate it into psychiatric and psychological practice. Moreover, collaborative partnerships between mental health professionals and religious communities represent a powerful resource for meeting the support needs of caregivers of persons with serious mental illness.*

**Keywords:** Caregiving; Burden; Coping; Religious coping strategies

### Introduction

The caregiving experience has been extensively investigated in some chronic/severe mental illnesses. It is evident that relatives of patients with mental illness are likely to experience considerable stress as a result of the caregiving role. The coping strategies adopted by them may influence their response to the complex set of demands placed upon them when a close member of the family suffers from severe mental illness. Coping influences adjustment and the use of effective coping strategies have consistently been linked with higher levels of well-being (McCrae & Costa, 1986).

Caring for a family member with mental illness is a challenging task. It requires time, patience and energy and may cause frustration among caregivers. To minimize disruptions within the family and individual suffering, caregivers must adapt to their new role by learning successful coping strategies. This study deals with the coping strategies used by caregivers of the mentally ill. Coping is defined as a set of concrete response to a stressful situation or event that is intended to resolve the problem or reduce distress. In this study coping was operationalized in terms of what individuals did when facing a specific stressful situation like caregiving. Coping

was not assessed as a threat, loss or challenge. Coping was not assessed as a characteristic style that describe how individuals usually or typically respond to stress but as a discrete response to a particular stress (Lazarus & Folkman, 1984). This approach allows the individual to report unusual and uncharacteristic ways of responding that may be a function of a particular stressful situation i.e. caring for mentally ill family member. Religious coping was defined as a means of dealing with stress (which may be a consequence of illness) that are religious. These include prayer, congregational support, pastoral care, and religious faith.

Religious beliefs and practices constitute one of the most frequently used methods of coping in times of crisis. This is particularly so in case of chronic stress and adjustment to changed life circumstances such as prolonged illness (Ellison 1991; Stanton Staton, Danoff-Burg, Cameron, Bishops, Collins, Kirk, Sworowski & Twillman, 2001). According to Pargament (1996) religion acts as an orienting system, a general way of perceiving and dealing with the world. It acts as a frame of reference for interpreting and evaluating events, as well as a resource to fall back upon in times of crisis. It also helps in providing a sense of comfort and closeness with God

(Pargament & Park, 1995). Prayer is often thought of as the most distinctive characteristic or behaviour associated with religion and is the most frequently mentioned religious coping (Cinnirella & Loewenthal, 1999).

Though some researchers have viewed religious coping as an emotion focused strategy, others like Pargament (1996) view it as being both problem focused as well as emotion focused. Pargament, Smith, Koenig and Perez (1998) identified three forms of religious coping with stress: the self-directing, collaborative and the deferring style. The self-directing style lays emphasis on the individual's own responsibility and active role in solving the problem. The deferring style places the responsibility of solving problems on God, with the individual playing a passive role. The collaborative style involves a sharing of responsibility for solving the problem on God as well as the individual. The self-directing and collaborative styles have been linked with higher levels of psychological competence, while the reverse is true for the deferring style.

Not all forms of religious coping, however, are beneficial to the individual. Some of them can be harmful and lead to negative outcomes. Some of the negative forms of religious coping include spiritual discomfort, appraisal of events as a punishment from God, and interpersonal religious discontent (Pargament, Koenig & Perez, 2000). Individuals who express dissatisfaction with the God, or feelings of abandonment or anger at God experience poorer mental health status, negative mood state, poor conflict resolution and also feelings of despair, hopelessness and resentment (Pargament et. al., 1998). Religious coping thus takes diverse forms and method and can have both positive as well as negative outcome for the individual.

In a study Pargament, Ensing, Falgout, Olsen, Reilly, van Haitisma & Warren (1990) found that the most strongly endorsed approaches to negative events was that the individual had to accept the situation and that the event represented God's will. Belief in a just world, the experience of God as a supportive partner in the coping process, search for spiritual support through religion and involvement in religious rituals were related to positive outcome.

The caregiving wives used belief in God, prayer and forgiveness as coping mechanisms. Caregivers also engaged in private prayer, and sought spiritual guidance in making daily life decisions more frequently than non-caregivers (Kaye & Robinson, 1994).

The prevalence of religious coping and its relationship with symptom severity and over all functioning was examined by Tepper, Rogers, Coleman and Maloney (2001). Overall, 325 (80%) of the participants reported using some type of religious activity or had some type of religious belief that helped them cope with symptoms. Specific strategies like prayer or reading the Bible were more likely to be used by patients with greater symptoms

and poorer level of functioning. It was concluded that religious beliefs and activities serve as important coping strategies, warranting their integrations to interventions for these patients.

Loewenthal, Cinnirella, Evoixa and Murphy (2001) in a study reported that religious coping activities were seen as relatively ineffective in comparison with social and cognitive forms of coping, such as community support and having goals to aim for. For individuals who used religious coping, religious faith and the use of prayer were found to be most effective strategy.

The role of religion and spirituality in dealing with the caregiving situation was evaluated by Chang, Noonan and Tenenstedt (1998). Results indicated that caregivers who made greater use of religious coping were more likely to have a good quality relationship with the elderly care recipient, and this in turn was associated with lower levels of psychological distress as well as role distress.

The studies reviewed indicate that religious beliefs and practices are an important part of the coping process for an individual facing a wide variety of stressful situations. Some studies on care givers also highlight the fact that the religious or spiritual dimension facilitates adjustment to the caregiving role. Not all religious coping is positive, and some forms of religious coping which are maladaptive have also been identified. Religious beliefs and practices have been found to be useful in providing a sense of control, hope and better adjustment, and common practices like prayer and seeking support and reassurance from God have emerged as the most frequently used religious coping strategies.

Caregivers used belief in God and prayer as a coping mechanism. Moreover, belief in a just world, and the experience of God as a supportive partner in coping process was related to positive outcome (Kaye, & Robinson, 1994; Pargament, et. al., 1990; Loewenthal, et. al., 2001).

## Method

### Sample

The sample of this study comprised of 75 caregivers of chronically mentally ill family member. In this study the term caregiver was used to refer to any person 18 years of age, male or female actively involved in the care of the patient and being with the care recipient in the same house for at least two years prior to the study. Caregivers with chronic physical illness or with a history of past or current psychiatric consultation were excluded.

Most of the respondents were female i.e. 52% and males were 48.0%. 81% of the respondents were from urban background and only 18.7 % were from rural background. The mean age of the participant was 44.44 years. Majority of the respondents were the parents of the patients (49.35%), followed by spouses (13.3%). 33.33% of the caregivers were mothers, followed by husbands (24.0%), father (6%) and wife (13.3%). Most of

the caregivers belonged to middle level economic group. 38.7% of the caregivers had no income and 29.3% had an income between Rs. 3000-10000.

Mean income of the caregivers was Rs. 3263.72. 42% of the sample had studied upto intermediate level and 34.7% of the sample was graduates and 17.3% were post graduate.

In the case of patients, 64% of the patients were schizophrenic and 36% of the patients were diagnosed as having other psychoses including mood disorders. 46.66% of the patient had a history of multiple previous hospitalizations while 54% of the patients were never hospitalized. 37.3 % of the patients were suffering from illness since last 3 years, 35% between 3-8 years, and 12% for more than 8 years.

### Measure

Data for this study was drawn from a larger study completed by the authors that included both qualitative and quantitative methods. Data was collected through semi-structured interviews. The interview schedule consisted of scales on objective and subjective burden, coping and family functioning.

Religious coping was measured by an open ended question. The question was "In addition to going to doctor, what else you have done to cope with ..... Illness"?

### Procedure of Data Collection

Data was collected through semi structured interviews in Psychiatric Out Patient Departments of Hospitals in Lucknow, India. Data was collected through semi structured interviews. This was necessary as this gave caregivers an opportunity to describe their own experiences without any preconceived notions, about types of problems they encounter while dealing with a mentally ill family member. A flexible approach was adopted in conducting the interviews and the questions were not asked in the same order with all the participants and many times some of the questions were not asked as participants had already given their views on them while narrating their problems. The questions were often reframed at the time of the interview to suit the respondent's language, style and educational level. The participants were not interrupted in their narratives and minimum interjections were made. This approach allowed participants to discuss their experience in their own language and in their own way, according to their level of comfort in disclosure.

The interviews were initiated with a brief account of the purpose of this study and whenever it was required, an introduction of the interviewer was also given. The interviews generally lasted about 50 minutes to 1 hour. Most participants were open and frank about their feelings and behaviours and they themselves volunteered

information about sensitive issues. They often expressed genuine emotion, and the rapport between the investigator and respondents was excellent. The participants at the end of the interview were also given an opportunity to ask interviewer any question or clarifications.

### Plan of Analysis

Qualitative data contains human responses in their full richness. This feature is both strength and a difficulty. The main part of data analysis consists of identifying categories, recurrent themes, ideas or language and belief system that are shared across participants and settings (Marshall & Rossman, 1995). Before analysis, data was systematically organised. In this study, as recommended by Glesen and Peshkin (1992). Codes were used, when generating themes and as emphasized by them the progressive process of coding, clumping data into major categories, categorizing the data, within each group of data into a meaningful sequence or interrelated pattern. The major purpose of each code was to identify a central concept or idea, with enough major codes generated to subsume all of the data. A code was assigned to any amount of text (from a phrase to a paragraph). Deciding how codes fit into categories and how they are interrelated was exciting and tedious and required analytical stamina, creativity and persistence. For this purpose content analysis was used. Content analysis, a common type of category generation, involved finding patterns in the data and placing each pattern into a category (Patten, 1990, p. 381).

In defining themes, van Manen, (1998) states that themes touch at the core of the notion we are trying to understand, helping us to make sense. Since they may not always completely unlock the mysterious aspects of the experience, related sub-themes capturing details and nuances may be required to provide a comprehensive picture. The notion of themes implies making something of a lived experience by interpreting its meaning through a process of insightful invention, discovery or disclosure. Thematic analysis refers to the process of recovering the themes that are embodied or dramatised in the evolving meanings and imagery of the text.

In the present study, transcripts and field notes were read several times in order to gain a sense of the overall experience of the participant. Through the holistic approach, the researcher tried to develop an idea of what it meant for a person to live the experience. Following the identification of the essential theme, selective reading was undertaken, where significant statements, related to and illustrating the various dimensions of the essential theme, were identified in the process. As the themes emerged, the components of each participant's statements that were relevant for each meaning unit were highlighted. Redundancies in the units were eliminated and relevant statements were clustered.

Finally, for each groups of participants, the core theme and their constituent themes were joined into a text that captured the lived experience in its constituent.

The position of the text was examined, and given a label. These labels or codes that make up the data index were then applied to the corresponding passage within the data. Before generating categories, themes and pattern data was transcribed. Transcription was a tedious process. However, selective transcription was not done and interviews were transcribed as they were with no editing.

After transcriptions, as a next step, the narratives obtained under each of the domain were compiled from each respondent category at one place so as to make them more manageable and intelligible. Also this facilitated a comparison of the narratives obtained from each groups in each of the domains. Subsequently, efforts were made to demarcate the narrative that was amenable to it, into categories. This was done as an instrument for the descriptive presentation of the data.

Data was also analysed and reviewed for themes, which the investigator expected to find but were missing, or absent. This guided the investigator to a new perspective. Sometimes, people fail to say what they treat as common knowledge or as being very obvious. Many of the most central understandings in a community are unspoken because they are taken for granted, and driven by a simplistic approach to content analysis researcher will misinterpret apparent absence (Breakwell, 1995). The researcher tried to keep analysis open to verification as far as possible as maintained by Breakwell (1995). For this purpose description of the data on which conclusions were based were provided, so that someone else can repeat what has been done and check conclusion.

For the purpose of presenting the data in the written form, some amount of translation of certain aspects of interviews in the English language was required since all the interviews were in Hindi language. When this was done, care was taken to approximate the sense of the language as nearly as possible. For this back translation was also done. Two research scholars back translated items, to ensure equivalence of meaning and content.

In some places, the English translation of the participants accounts have been quoted where in care has been taken to retain the essence of their actual words when verbatim translation was not possible.

### Religious Coping: Major Themes

Religious beliefs and practices influence both appraisals as well as coping with stress as is evident from Western as well as Indian studies. Caregivers sought consolation and solace in their religion and spirituality. In fact, it was consistently found that some aspects of spirituality allowed these caregivers to survive the severe stress experienced as a result of their caregiving responsibilities.

This section deals with religious coping as adopted by caregivers to deal with their caregiving stresses.

One form of coping most frequently used by caregivers was religious coping. Almost all of the participants had relied on religion in their attempts to cope with caregiving stress. It is clear from the narratives that almost all caregivers had opted for some kind of faith healing at some point of time. It was observed that religious help seeking formed an important part of psychiatric help seeking, with traditional healers often given preference over medical or psychological treatment' as observed by a number of researchers (Chaddha, Agarwal, Singh, & Raheja, 2001; Chandrashekhar, 1981; Kakar, 1982).

One of the important ways of dealing with stressors of caregiving was reliance on 'Karma theory'. Caregivers used it to explain their problems.

*"It is the result of my karma.... how else I can explain it,"* said a mother.

*"At times I think that I am being punished for some bad karma,"* said a husband.

Thus, it is clear that the doctrine of 'karma' deserves special attention. It is roughly translated as 'destiny' or fate, against which all human efforts are seen to be of no avail (Rao, 2001). The theory of karma enables the acceptance of present suffering as unavoidable, and gives hope that one can avoid suffering in future, through performance of righteous deeds (Dalal & Misra, 1999). However, an interesting idea gleaned from the narratives of the caregivers was that they differentiated between karma and destiny. Karma was seen as a consequence of their own deeds, either of previous birth or present life but 'Bhagya' was seen as their destiny or fate which was beyond their control. So in some way caregivers felt responsible for their difficulties, when they used karma as an explanation, but not in the latter case when their present problems were seen as fated to occur. Many of the caregivers saw the illness as an affliction given by God and they felt that only God could provide a solution. This belief helped caregivers to cope with their problems especially when the illness had been continuing for years and no mode of treatment either medical or traditional worked. As narrated by caregivers,

*"Malik (supreme being) had written this in my destiny ... so I have to suffer,"* said a husband.

*"Illness is given by God .....There is always happiness and sadness in life."* said a father.

*"God has given this illness ... God will make him well ..,"* said a mother.

As one father said, *"God does everything. God does everything for good" ..*

Or as one wife said, *"I have left everything on God"*.

From these excerpts of the caregivers it is clear that when nothing worked, then caregivers surrendered to a

supreme power i.e. God. Moreover, when attribution to an external cause was made it absolved the individual of personal responsibility resulting in better coping and emotional well being. Lam and Palsane (1997) also observed that in Indian settings low stress is associated with external control such as God or fate as this reduces the individual sense of personal responsibility. When caregivers accept the illness and disability resulting from the illness, as a result of karma, it help in reducing emotional distress, and act as a mechanism of rationalization and coping with the stress of caregiving. A deferring style of coping where the caregiver placed the responsibility on God, with the individual playing a passive role was identified by Pargament (1996). When caregivers saw God as the cause then they also believed that one day God will provide the solution, as one mother said, "God has given this problem, only he will find a solution to it..." This was particularly observed in cases where patients had been ill from many years and no form of treatment had worked.

Prayers and seeking assurance from God was also used as a coping mechanism. One of the most common forms of religious coping reported by the majority of caregivers was prayer. Most of the caregivers relied on prayers. When nothing worked for them and they didn't know which way to go, what to do and how to deal with it, then they prayed. In their prayers, they laid all their troubles on God and this gave them a feeling that they are not alone and their God is with them. They go to temple and seek help from God when they feel insecure. "Supreme being will deal with this..." said a mother.

"Used to pray ... one day God will listen to me ..," said a mother.

"I left everything on God .... He is supreme being ... pray to him to take away all my problems," said another mother.

Moreover, caregiver also sought assurance from God. They felt that God would look after them. They felt that may be God was testing them and that this was a passing phase and God would take care of their troubles and problems.

As one caregiver said "... my God is with me."

This feeling of God being with them helped them to deal with the stresses of caregiving. Some of the caregivers also practiced yoga and meditation. They also visited their religious Gurus and attended religious discourse (pravachan).

Few caregivers also reported attending 'satsang' – a religious gathering, where people sing devotional and religious hymns together. They said that once they attended such satsangs they felt relief as this was a way of connecting with God, and for that period of time they forgot all about their problems.

"I attend satsang regularly ... at times also take her along.... Forget about my problems, just me and my God," said a husband.

Or as one mother remarked, "I visit temple everyday ... satsang, over there everybody ask me about him (son) ... help me with whatever possible...."

At such congregations, the caregivers were also able to share their problems with others. In addition to enabling them to forget about their problems, others empathize with them and share their problems which in itself led to some measure of relief. They felt lighter after sharing their trouble and problems with their fellow satsangis.

Many times caregivers offered supernatural explanations such as black magic or possession by a spirit. In such cases, they often visited faith healers or adopted other forms of religious coping. It appears as if there is a parallel system run by faith healers to the medical system. This is because folk traditions often emphasize supernatural causes, as well as astrology and karma (Ng, 1997). When they consider cause of illness beyond their control then they feel solution is also beyond them. This feeling helped in reducing their stress.

Moreover traditional folk healing pluralistic and religious affiliation of the patient, caregiver, and healer are unimportant with Hindus visiting Muslim healers and Muslims visiting Hindu healers.

However, not all forms of religious coping were beneficial. Some of these can lead to negative outcomes, like spiritual discomfort or appraisal of events as punishment from God. In some case, caregivers did accept the illness and resulting stress from it as punishment from God. Sometimes they felt that they were being punished for some misdeed done.

As one caregiver said, "I feel that may be in previous birth I must have done something wrong."

"God is punishing me for something ... doesn't know what," said a wife.

Or as one wife said, "what can I say ... maybe I have done something wrong, otherwise why would I be suffering like this."

As is apparent from the above statements caregiver often adopted a fatalistic attitude. However, there were very few caregivers who reported dissatisfaction with the religious mode of coping or expressed negative views. The majority of the caregivers reported satisfaction with religious coping.

## To Conclude

The stress buffering effect of religious coping was evident. Acceptance was an often used strategy. This helped them to deal with the distress associated with caregiving. Moreover, it provided caregivers a frame work

with the help of which they were able to make sense of what was happening to them. Religion acted as an orienting system, a general way of perceiving and dealing with the world. It is a frame of reference for interpreting and evaluating events as well as a resource to fall back upon, in time of crisis. It also helped them, in providing a sense of comfort and closeness with God (Pargament & Park, 1995). Calling upon their spirituality proved to be comforting for many caregivers as they sought to deal with essential issues related to their relative's illness.

Religious help seeking is an important part of psychiatric help seeking with traditional healers often forming the first line of treatment in the pathways to treatment. Some of the caregivers also felt that what had happened was inevitable and they were unable to reverse the cause of the illness. Moreover, they also believed that everything happens for good.

Caregivers thus, expressed the belief that out of this difficulty something good will emerge for them. This feeling also helped them to bear with the stressors of caregiving.

In research literature also religious beliefs were found to facilitate coping with the stressors of caregiving (RamMohan, et. al., 2002a), and it has also been recommended that they may be incorporated in therapeutic programs (Sharma et. al., 1995).

People take comfort in the concept of karmaphala. This finding is similar to the ones obtained in earlier studies (Agarwal & Dalal, 1993; Dalal & Pande, 1998; Dalal & Singh, 1992; Joshi, 1995). Karma is a deep seated and enduring belief. But things that are deep seated sometimes have to be brought to the fore. In the Indian worldview, causality extends beyond the natural world to the moral domain. A conscious effort on the part of the researcher was required to bring the discussion of Karma back to the everyday world. In addition to Karmaphala, caregivers also attributed their problems to God's will and fate. Attributing disease to metaphysical belief make sense in a culture where religion pervades in all life domains, as Joshi (1995), found that caregivers refers to these beliefs to explain suffering.

Family intervention programs, for chronic mentally ill need to be culturally sensitive and flexible as observed by Kapur (1992). Moreover, as observed in this study, certain themes need to be incorporated when designing interventions for families. These include providing information that is compatible with the educational and religious background of the caregivers.

Thus, it could be concluded that the religious and spiritual dimension facilitated caregiver adjustment. Religious belief and practices have been found to be useful in providing a sense of control, hope and better adjustment. Common practices such as prayer and

reposing trust in God have emerged as the most frequently used religious coping strategy.

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