The Adaptive Coping by Caregivers of Individuals with Mental Illness

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ABSTRACT

Present research is an exploratory study carried out to understand the coping resources used by caregivers of individuals with psychological disorders and to know the impact it has on their mental health. Caregivers adapt to a number of coping strategies to overcome the difficulties they face due to the responsibility of caring for a loved one. The sample comprises 50 caregivers (25 males and 25 females) of individuals being treated at a psychiatric clinic for various disorders. The Mean age of the sampled persons was 47.42 years. The tools administered were Coping Resources Inventory (Hammer and Marting, 1988) and the Mental Health Inventory (Veit and Ware, 1983). A semi-structured interview was also conducted to find out the coping strategies used by the caregivers. Religious and spirituality was found as the best coping strategy (50%) by caregivers and the frequency of mental agony was minimum. The present study has implications for Intervention based programs for the caregiver as it can help to enhance and develop healthy coping strategies and reduce their stress and burden due to caregiver role.

Key Words : Caregiver, Care recipient, Coping resources

INTRODUCTION

Coping has become one of the central concepts in the discipline of psychology. Coping is the management of external and internal demands that are considered to be exceeding an individual's resources (Lazarus and Folkman, 1984). The individuals try to modify or eliminate the issue they are facing, try to decrease its intensity by changing their own views and relieve the effects by diverting themselves in various means such as consumption of tranquilizers, alcohol or to do something physical.

Coping includes thoughts, emotions and actions. It involves purposeful and conscious actions of an individual. These actions occur as a response to events that shakes the senses of stability.

Billings and Moos (1981) views coping as a set of psychological mechanisms that protects an individual from psychological and external threats. It is considered as an attempt to eliminate feelings of discomfort.

Coping resources are inherent in individuals that help them to cope with stress, experience fewer intense symptoms when exposed to the stressor and to recover faster from a stressful situation (Hammer and Marting, 1998). Several studies have highlighted the role of effective coping resources in caregivers which improves relationships in the family and reinforces cohesion where as other studies have expressed the negative impact of caregiving on the general health and psychological conditions of the caregivers.

A Caregiver can be a friend, relative or a neighbor who gives day-to-day unpaid and practical support to an individual who is not able to complete daily living tasks. The individual who receives care is the care recipient who is suffering from some chronic condition that causes difficulties in completion of daily living tasks. Researchers have focused upon the mental health of caregivers. For instance, Victorian Carers Program conducted a

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population-based study that focused upon the differences in well being between caregivers and non-caregivers. It was found that there is less life satisfaction, less positive affect and more negative affect among caregivers. (Schofield *et al.*, 1998). Approximately 30% of caregiver reported that their well-being had been affect and they often feel depressed and worried (Australian Bureau of Statistics, 1998)

Another study conducted in 2018 by Brian, Kymes, DiBenedetti, Brevig and Velligan focused on the experiences, attitudes and perceptions of caregivers of individuals suffering from treatment-resistant schizophrenia (TRS). 27 caregivers reported that they provide direct care for 37 hours a week where as 21 caregivers reported that they are on call 24/7. Caregivers also reported that persecution is the most challenging symptom of the disorder as it makes their job difficult. Caring for an individual with TSR affects the sense of freedom, career, social relationships and finances of the caregiver.

The family members are unprepared and untrained for the role of caregivers. Providing care for an individual suffering from a mental disorder can be stressful. It has a major impact on the physical as well as psychological health of the caregiver. It can be a tasking job depending on the type of disorder their loved one is suffering from. The quality of life (QOL) of the caregivers is also hampered. According to WHO, Quality of Life is a perception of an individual about their position in life in the context of the value systems and culture they live in and the goals, expectations, standards and concerns the individual have. Providing care to a normal individual is itself taxing at times. Therefore, giving care to individuals suffering from disorders can be strenuous which may affect the QOL of caregivers.

The individual who is receiving care and is unable to complete daily living tasks due to some chronic illness is a care recipient.

The relation between a care recipient and a caregiver is an influential factor that impacts the process of caregiving. It has been seen that parents reported more satisfaction as caregivers than spouses and spouses reported more satisfaction than offspring. Love and intimacy between caregivers and the care recipient resulted in lower levels of psychiatric symptoms and burden. There are a number of moderating factors that impacts the mental health of the caregivers such as financial situation, social support caregivers have, coping strategies they employ and their own self-esteem. These factors can be categorized as coping resources. Dunn *et al.* (2001) conducted a research stating that the stressors faced by parents of autistic children were influenced by moderating factors such as coping style and social support and is not a direct predictor of negative outcomes. A financial resource such as money is another mediator that would increase the coping options available to any person. Schofield *et al.* (1998) concluded that poor wellbeing in caregivers was associated with financial difficulties. It was found in a study that social support from 18 sources, both formal and informal was related to emotional well being of parents of children with disabilities.

Young *et al.* (2018) explored the experiences of parent caregivers of adult children with schizophrenia. The findings suggested that parent caregivers required greater support for protection of their mental and physical health.

The psychological status and coping styles of caregivers of individuals with intellectual disability and psychiatric illness was assessed. Caregivers experienced depression, anxiety and stress symptoms. Religious coping emerged as the most common coping style used by caregivers (Panicker and Ramesh, 2018).

METHODOLOGY

Sample:

About 50 (25 Male and 25 Female) caregivers as respondents took part in the study conducted at a private clinic in southwest Delhi under the guidance of qualified psychiatrist. The purposive sampling design was followed throughout the study.

Measures:

Coping resource inventory:

The Coping Resource Inventory developed by Hammer and Marting (1987) to measure the coping resources used by individuals was used. The scale consisted of 60 items and five domains. For each item, the respondent used a 4-point scale to indicate how they were engaged in the behavior described in the items in the past six months. In addition to five scores, a total resource score was also computed by summing the five scale scores. The higher the score the higher will be the resource. The five domains measured are:

Cognitive: the degree to which individuals maintain a positive outlook toward other people, maintain a positive

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sense of self-worth and optimism in life.

Social: the extent to which individuals are embedded in social networks that provides them support in times of stress.

Emotional: the degree to which people express and accept a range of effect, based on the premise that a range of emotional response aids in ameliorating long-term negative consequences.

Spiritual/philosophical: the extent to which the actions of people are guided by values derived from their religion, family tradition, culture, and personal philosophy.

Physical: the extent to which individuals enact health promoting behaviors to contribute to their wellbeing.

Mental Health Inventory- 38 (MHI-38):

It is a self-report tool designed to measure general psychological distress and wellbeing by Veil and Ware, 1983. It includes positive aspects of wellbeing (such as cheerfulness, interest in and enjoyment of life) as well as negative aspects of mental health (e.g. anxiety and depression). The MHI can be completed either as a selfreport measure or as part of an interview.

Interview schedule:

A semi-structured interview schedule consisted of 12 semi-structured questions. The interview was carried out in Hindi. Few of the questions were:

"आपको अपने लिए समय मिल जाता है?" "आप दिन के कितने घंटे इनकी देखभाल में बिताते है?"

Data collection procedure:

The present research was an exploratory study to assess the mental health status of the caregivers and the coping resources they adapt when stumbling upon stressors. MHI and CRI were translated into Hindi. The t test, Mean and Standard Deviation were used for comparison purposes. Written consent was obtained from the respondents. They were briefed about the purpose of the study. The participants were ensured of confidentiality. Post quantitative data collection; a semistructured interview was conducted with the caregivers to have a deeper understanding of the coping strategies and thematic analysis was done.

RESULTS AND DISCUSSION

The present research was an attempt to understand

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the coping resources used by caregivers and their mental health status. They use different strategies and resources for coping to adapt to their surroundings that affects their mental health.

For quantitative analysis, two inventories (Coping Resources Inventory and Mental Health Inventory) were administered which helped to examine the mental health of the caregivers and the coping resources they resort to. t test was used for comparison purposes. The differences between the scores of male caregivers and female caregivers were not significant (Table 1). It was found that caregivers use spirituality more as an adaptive coping resource. Spirituality in this context refers to the extent to which actions of people are guided by values derived from their religion, family tradition, culture and from personal philosophy. According to the Global Spirituality Index conducted in 2018 in 115 countries, India stands at the third place with a spirituality index score of 34. India is known for its religious diversity, freedom, and spirituality. This might be the reason due to which the caregivers resort more to spirituality as a coping strategy.

Table 1 : t test values of coping resources and mental health index between male and female caregivers		
Variables	Independent sample t test	
	t test value	df
Cognitive	.92	48
Social	4.8	
Emotional	.02	
Spiritual	1.24	
Physical	.23	
MHI	.46	

Physical and Cognitive are the next set of coping resources which are frequently adopted by the caregivers. Physical refers to the extent to which individuals enact health-promoting behaviors to contribute to their wellbeing whereas, cognitive is defined as the degree to which

Table 2 : Mean and resources of	Standard Deviation of the total population	of the coping
Variable	Mean	SD
Cognitive	42.02	11.67
Social	39.24	12.9
Emotional	40.14	10.63
Spiritual	50.04	10.77
Physical	43.08	11.04
Total Resource score	214.94	57.01

individuals maintain a positive outlook towards other people. Emotional and social are the least coping resources used by the caregivers (Table 2).

There is a negligible difference between the coping of male caregivers and female caregivers. Male caregivers score higher on cognitive, social and physical coping resources whereas female caregivers scored higher on spiritual and emotional coping resources (Table 3). According to the gender built of women they were supposed to be emotional and social towards patient, spiritually more inclined in comparison to men, work inside home, care provider and health promoting persona in any family. Female caregivers scored higher on total resource score than males depicting that they are more resilient and resort to more coping strategies when they experience caregiver burden and stress. Hammer and Marting (1988) reported that women score higher on the emotional, spiritual and total resource score whereas they score lower on the physical scale.

The overall mental health index score of the sample is moderate stating there is a less frequent occurrence of negative mental health symptoms among caregivers of individuals suffering from mental disorders. There are no significant differences in the mental index score of female and male caregivers (Table 4). Perlick et al examined the gender differences among caregivers of patients with bipolar disorder. They found that there were no gender differences based on depression or caregiverstrain.

The responses from a semi-structured interview conducted with caregivers helped to gain a deeper understanding of the burden of the role and the strategies they use to cope with it (Table 5). The first theme extracted were the coping strategies used by caregivers. The most prominent coping strategy used by caregivers was 'Spiritual/Religious coping'. Most of the caregivers expressed their belief in god and how they hope the circumstances will be better due to the omnipresence of God. As a result, they resort to praying, reading sacred texts and visiting a temple and religious places daily. However, female caregivers adapt to spiritual coping strategies more than male caregivers. Panicker and Ramesh (2018) conducted a study suggesting that religious coping was the most common style of coping used by caregivers.

The second theme extracted was 'Cognitive coping'. The caregivers tried to have a positive outlook on the whole situation. They were hopeful and optimistic regarding the future of their loved one. It was also found that male caregivers resort to physical and social coping. They exercised daily and discussed their issues and feelings with others. Other ways of coping used by caregivers were by watching television and performing

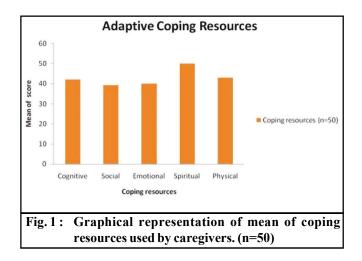


Table 3 : Mean and Standard deviation of coping resources used by male and female caregiver				
Variables	Male Car	regivers	Female Car	egivers
	Mean	SD	Mean	SD
Cognitive	44.32	12.28	39.7	10.79
Social	47.28	11.81	31.2	8.09
Emotional	36.36	9.58	43.92	10.83
Spiritual	47.64	9.92	52.44	11.25
Physical	45.84	10.93	40.32	10.64
Total resource score	221.44	54.52	207.58	51.6

Table 4 : Mean	and Standard Deviation of	the Mental Health In	dex of the caregivers		
MHI T	otal population	MHI Male ca	aregiver	MHI Female	caregiver
Mean	SD	Mean	SD	Mean	SD
144.54	33.79	142.40	31.85	146.68	36.17

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Coping Strategies	Caregiver duties/responsibilities
Spirituality/religious coping	– Full day care
– Trust on god	- Look after their meals and medicines
– Praying	 Encouraging to share and talk
 Visiting religious places daily 	– Taking them out
– Better because of god	– Planning their future
– Will look after everything	 Regular doctor's appointments
 Reading and remembering holy texts 	Caregiver's Burden
Cognitive coping	- Tensed all the time
– Positive outlook	- Maintain a track of their medicine
– Hopeful and optimistic	- Care recipients are destructive, violent, stubborn and aggressive
– Self-regulation	 Taking care recipient along everywhere
– Better than others	 Dealing with the abusive language
Physical coping	 – Financial burden
– Daily exercise	– No time for oneself
Other ways of coping	 Change in daily routine
- Watching TV	 Frequent visits to hospital
– Household work	 Sudden episodes of abnormal behavior
– Hitting	 Disturbed family dynamics
– Aggression	 Physical issues like high Blood Pressure
- Stop paying attention	 Disturbed sleeping pattern
Emotions felt	 Worry about the future
– Crying	Views on Mental disorders/ mental health
– Upset	- There is treatment for all the illnesses
– Sad	 It destroys the person
– Tensed	– Behavioral issues
- Worried	– Person is unaware
– Anxious	 There is no such thing as a disorder
Mental State of the caregiver	– Just one's thinking
– Not happy	- Chemical imbalance
– I'm fine	 Taboo in India no acceptance
- Tensed	– Not given importance like physical health
– Нарру	- Can be treated with medicine and counseling

household chores. They also resort to negative and unhealthy coping by expressing their anger, hitting the care recipient at times and not paying attention. However, they felt guilty after behaving in such manner.

The caregivers constantly felt like crying. They were upset, tensed, worried and anxious regarding the condition of the care recipient; second theme 'emotions felt'. Most of them were not happy and were disturbed and stressed out with the role of caregiving; third theme 'mental state of the caregiver'. Schofield *et al.*, (1998) stated that there is less life satisfaction, less positive affect and more negative effect among caregivers. Therefore, coping strategies helped caregivers to regulate their emotions and be resilient for the betterment of the care recipient that helps in improving their mental health level.

Under the fourth theme 'caregiver responsibilities/

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duties', they reported various duties and responsibilities they performed. They provide care, meals, medicines, encouragement and motivation to the patient. They even take them out of the house, plan their future and make sure to have regular checkups with the doctor. Therefore, it can be inferred that caregiving is a strenuous task performed by the family members of the individual suffering from a mental illness.

The fifth theme was 'Caregiver's Burden'. When asked about the difficulties they faced as caregiver they repeatedly used the term 'tensed'. They had to deal with the verbal abuse and stubbornness of the patient. There is a change in their daily routine, they have to cooperate with the care recipient and are unable to leave the individual alone for a longer period of time. There is a financial burden on the caregivers.. Some of them stated they have a disturbed sleeping pattern and suffered from high blood pressure. Therefore, the continuous stress of caregiving has a deteriorating effect on the physical and mental health of the caregiver.

The fifth theme emerged is 'views on mental disorders/mental health'. Majority of the caregivers reported the changes and issues an individual faces when suffering from a disorder. However, they stated it is treatable and should be considered equally important as physical illness. However, some of the caregivers reported that it is a hoax and an individual's perception.

Venkatesh *et al.* (2015) conducted a study to assess the extent of the stigma associated with mental illness and knowledge of mental illness among the community, the prevalence of stigma toward mentally ill people was found to be 74.61% of the total sample.

Another study conducted in New Delhi observed lack of awareness regarding the biomedical concept of mental illness with socially restrictive, stereotyping, pessimistic, and non-stigmatizing attitude toward mental illness in the capital city (Salve *et al.*, 2013).

From the interview responses, it can be seen that caregivers bear with disturbances caused by the ill family members. They are so invested in the role of caregiving that they have to curtail their own social and leisure activities. They feel stressed, anxious and tensed. They carry the role without complete knowledge of the illness. Therefore, they develop different kinds of coping strategies to deal with the burden. These coping strategies help the caregiver to improve their mental health. Religious coping has been one of the most significant strategies voiced by a majority of the caregivers.

Conclusion :

The caregivers provide key support to individuals with mental illnesses and suffer considerable burden resulting from the caregiving role. It is important to identify the needs of the caregivers and look after their wellbeing. Very low frequency of negative mental health symptoms were found among caregivers. Religious and Spiritual strategy was found as the most important coping strategy while social as the least. The present research work has implications in terms of taking preventive actions through seminars, workshops and awareness programs for the target population *i.e.* the caregivers who are prone to developing a serious mental condition themselves. Future researches can design intervention based studies for reducing the burden of caregivers and develop healthy coping strategies.

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