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Original Article:

Burden and Coping in Informal Caregivers of Persons with Dementia: A Cross Sectional Study

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Abstract:
Caring for persons affected with dementia is associated with substantial psychological strain as evidenced by high rates of psychiatric morbidity and high levels of caregiver strain. Dementia care in developing countries will continue to be provided by immediate family members at home and is unlikely to be taken over by institutions due to socio-cultural reasons. This study aims to examine the relationship of selected factors of patients affected with dementia and their caregivers that were associated with the burden and coping of family caregivers. This is a cross sectional study of a long term project by the author (RJ), involves face-to-face interview with questionnaires with family caregivers of patients with dementia. Burden was related to patient's behavioral problems, gender, family type and the years of care giving. Principal component analysis of Brief Cope revealed 6 major dimensions: acceptance, humor, religion, substance use, behavioral disengagement and self blame as significant coping skills. Care giving was associated with more psychological complaints and a poor quality of life both physical and psychological. Self blame, behavioral disengagement, venting & emotional support emerged as an important variable as the care giver relation differ in the kind of care giving and care giving burden. Results highlight the importance of improving the mixed coping skills in burdened caregivers. Interventions need to designed and tailored to the specific needs of caregivers.

Key Words: Dementia; Informal caregivers; Burden; Coping strategies

Introduction:

Dementia was estimated to be the 10th leading cause of non-fatal burden in the world in 1990, accounting for 2.6% of total YLD, around the same percentage as congenital malformations.(1) Even with the difficulties of determining prevalence and incidence, it is clear that dementia causes a substantial burden globally.

India is currently in the second phase and is moving towards the third phase of demographic transition. The changes in the population growth rates in India have been relatively slow, but the change has been steady and sustained. As a result the country was able to achieve a relatively gradual change in the population numbers and age structure.(2) In context of the rapid demographic transition in many parts of the country, there is a rich epidemiological evidence base on dementia in India which shows this neurodegenerative condition is an important public health problem. Due to shortage of health care resources and low levels of awareness about dementia, interventions are addressing the needs of the people and directed at improving quality of life of the person dementia and the caregiver.

In the Indian Society, the cultural values and the traditional practices emphasize that the elderly members of the family to be treated with honor and respect. The families of the aged persons are expected to ensure the needed care and support for the aged. However, recent changes in the size and structure of families have caused the re-arrangement of the roles and functions of the members in the families. In the absence of formal services in most developing countries there is a heavy reliance on informal and, in particular, family care for people with dementia.(3) The lack of research evidence from developing countries of the practical, emotional, and economic impact of caring for a family member with dementia allows the myth to be perpetuated.(4) The current study aims to examine the relationship of selected factors of patients affected with dementia and their caregivers that were associated with the burden and coping of family caregivers.

Coping is most often conceptualized as a response to the demands of specific, stressful situations. In fact, providing care for a family member with dementia is associated with personal strain in number of stressful situations.(5)

The concept of burden in the caregiver situation may contain many dimensions contributing to a caregiver's feeling of distress, such as feelings of overburden, hopelessness and inability to cope.(6) Whether the demented person is at home or in an institution, it is nevertheless stressful for caregivers because care giving is an ongoing process, continuing after institutionalization.(7,8)

Coping strategies: The literature on stress and coping has grown enormously over the past two decades. Studies have examined people's responses to such disparate stressors as chronic illness, diagnosis with life-threatening illness, natural disasters, and the challenge of difficult examinations. Although several clear principles have been derived from this body of research as a whole, there is near-unanimity that many questions remain to be answered. Thus research into the coping process continues.(9)

Caregivers have reported a number of different types of coping strategies. The coping processes used by care givers can be grouped into two types: problem focused strategies (i.e., to alter or manage the situation in an active and constructive way) and emotion-focused strategies (i.e., to relieve the emotional impact of the stressful situation by using thoughts and indirect actions). Individuals use a range of specific responses of both types, sometimes at the same time and to varying degrees. There is no clear consensus regarding which type of coping strategy is most effective for maintaining positive mental health because coping strategies such as systematic solving, positive outlook and social support related to demented elderly people has been associated with a better emotional adjustment.(10) While coping responses involving strategies such as wishfulness, passivity and avoidance are often connected with a poorer emotional adjustment.(10)

The physical and emotional health of the primary caregiver is critical to optimal care of the patient with Alzheimer's disease. Caregivers suffer from increased rates of depression and physical illness and are prescribed medications at a higher rate than persons not required being in a care-giving role.(11)

Materials and Methods:

This is a cross sectional study of a long term project by the author (RJ), involves face-to-face interview with family caregivers of patients with diagnosed cases of dementia. Participants willing were recruited through convenient sampling from psychiatry outpatient clinics from three hospitals, one university hospital, a district hospital and a private centre which runs a "memory clinic" once a week. Most of the clients were seen at their respective homes. The study comprised of 125 informal caregivers.

About the questionnaires

In this study reports on brief measure of coping reactions, based on the COPE inventory.(9) The Brief COPE includes only 28 items, which measure 14 conceptually differentiable coping reactions. Some of these reactions are known to be generally adaptive; others are known to be problematic. The Brief COPE thus provides researchers a way to assess potentially important coping responses quickly.

Various tools have been developed to provide information about the activities and concerns of persons who care for patients with Alzheimer's disease. One of the earliest and most widely used tool is the Caregiver Burden Scale, a self-administered 22-item questionnaire with a five-item response set ranging from "never" to "nearly always".(12) The numbers for the responses are added to obtain the total score, with higher scores indicating greater caregiver distress. (0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.)

Data analysis: For these analyses mentioned below SPSS package (version 11.5) was used.

Descriptive statistics is used for continuous variables for the demographic data. For data analysis cross tabs and paired t tests were done for correlating burden with the coping methods employed, selected patient related variables & selected care giver related variables.

Results and Discussion:

Patient related variables - Socio demographic data

One hundred and twenty five Care givers of persons diagnosed as dementia were recruited into the study.

As per Table 1, 54.4% (68) of the persons with dementia were males and 45.6% (57) were females. Most of the patients were from the age group of 71 to 80 years (35.2%) followed by age group of 61-70 years (32.8%). 16.8% (21) of the them were from the age group of 51 to 60 years and 13.6 % (17) were above 80 years of age. Only two were below the age of 50.

Table 1: Socio-demographic profile of the cases

Socio-demographic profile	Frequency	Percentage
Gender		
Male	68	54.4
Female	57	45.6
Age group		
Below 50 years	2	1.6
51 to 60 years	21	16.8
61 to 70 years	41	32.8
71 to 80 years	44	35.2
Above 80 years	17	13.6
Marital status		
Married	82	65.6
Single	3	2.4
Widow	32	25.6
Widower	6	4.8
Polygamy	2	1.6
Education qualification		
Nil	28	22.4
Medium education level (secondary education)	66	52.8
Higher education level (Pre university and above)	31	21.8

As per the findings 65.6% (82) of the patients were married, 25.6% (32) were widows, 4.8 % (6) widower. Three of them were single and 2 had polygamy.

Maximum patients had medium educational level (66) and 21.8% (31) had higher educational level and only 22.4% (28) were illiterates.

Care giver related variables

Table 2: care giver related socio demographic variables

Socio-demographic profile	Frequency	Percentage
Gender		
Male	51	40.8
Female	74	59.2
Age		
20 – 35 yrs	26	20.8
36 – 50 yrs	44	35.2
51 – 60 yrs	25	20.0
61 – 70 yrs	23	18.4
71 – 80 yrs	07	5.6
Family type		
Nuclear	106	84.8
Extended	18	14.4
Single	1	0.8
Domicile		
Rural	97	77.6
Urban	28	22.4
Marital status		
Married	103	82.4
Single	18	14.4
Widow	3	2.4
Widower	1	0.8

Most of the caregivers i.e., 59.2% (74) were females and 40.8% (51) were males. Age for our convenience was grouped into 5 categories of 20 – 35 yrs, 36 -50 yrs, 51-60 yrs, 61 – 70 yrs, and

71 – 80 yrs. Maximum care givers were from the age group of 36 to 50 years of age. 44 (35.2%) care giver s were from this age group, and least care givers were from the age group of 71 – 80 years of age, i.e., 7 (5.6%) of the care givers were from this age group.

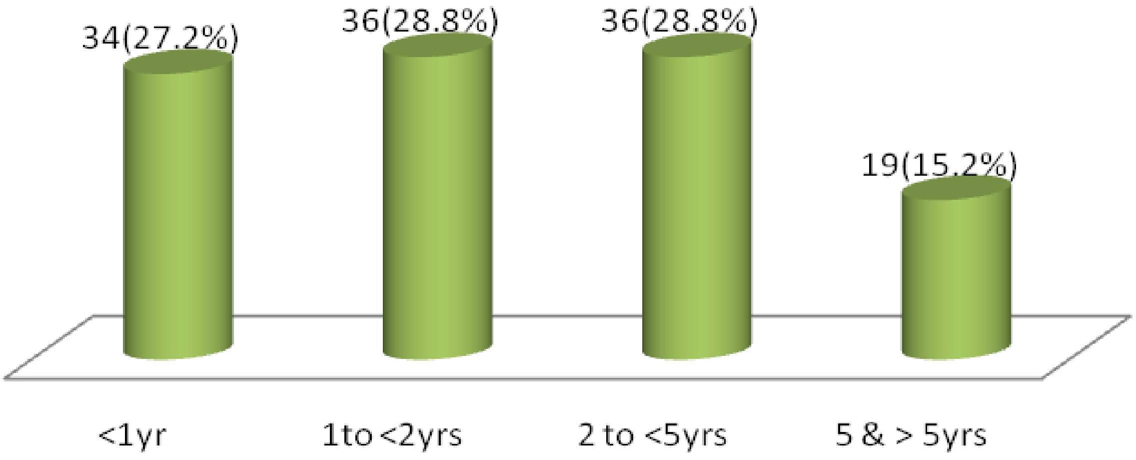
Hundred and six families of caregivers were of nuclear family type (84.8%) and 18 (14.4%) families were of extended family type and single 1 (0.8%). Maximum cases (77.6%) were from rural area and 22.4% from urban area.

Maximum number of patients i.e., 103 (82.4%) were married and had family, 16 (14.4%) unmarried, 3 (2.4%) widows and 1 (0.8%) was a widower.

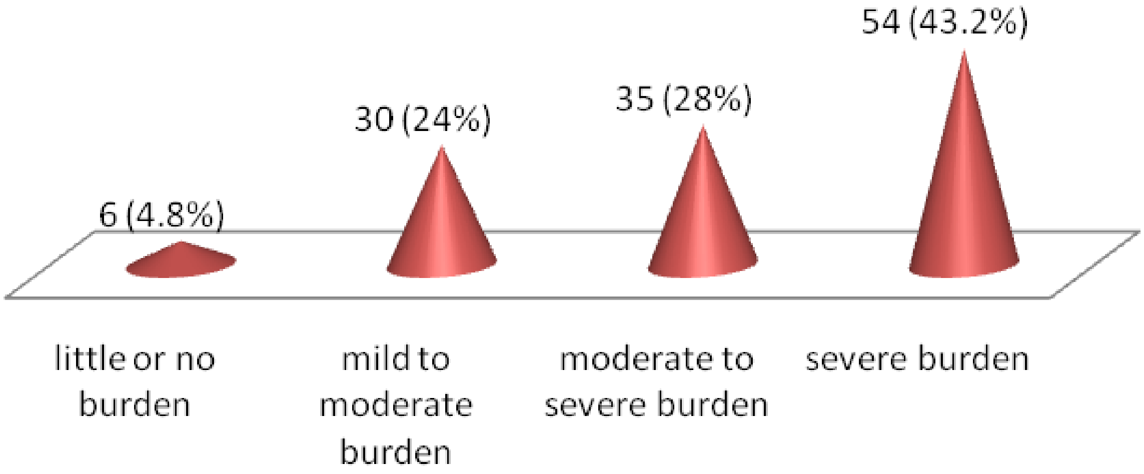
Most of the care givers had a higher educational level (59.2 %), 32% medium educational level and 8.8% of the care givers did not have formal education.

Mean age of patient and care giver

Mean age of the patients as 69.87 (SD 10.278) and Mean age of the care givers as 48.90 (SD13.787)



Graph 1: Duration of care giving



Graph 2: Frequency of Burden experienced by the care givers

Out of total sample of 125 care givers 43.3% (54) of them experienced severe burden, 28% (35) moderated to severe burden, 24% (30) mild to moderate burden and only 4.8% (6) had little or no burden.

Paired t test showing the correlation of burden with coping methods adapted

Table 3: Paired t test for coping and burden

N =125		Correlation	Sig. (p)
Pair 1	Burden & active coping	-.052	.564
Pair 2	Burden & planning	-.094	.296
Pair 3	Burden & positive reframing	-.290	.001
Pair 4	Burden & acceptance	-.148	.101
Pair 5	Burden & humor	-.090	.316
Pair 6	Burden & religion	.154	.086
Pair 7	Burden & using emotional support	-.173	.053
Pair 8	Burden & using instrumental support	-.133	.140
Pair 9	Burden & self distraction	-.108	.229
Pair 10	Burden & denial	.143	.112
Pair 11	Burden & venting	.296	.001
Pair 12	Burden & substance use	-.162	.072
Pair 13	Burden & behavioral disengagement	.176	.049
Pair 14	Burden & self blame	.418	.001

Each dimensions of coping strategies was correlated with the burden experienced by the care givers. Test of significance shows positive reframing, use of emotional support, venting, behavioral disengagement and self blame was found to be significant when correlated with burden experienced by the informal care giver.

Care givers' coping strategies

Active coping strategies

An active coping strategy tries to deal with the problem by confronting the problem. Caregivers thought about solutions to the problem or did something to try to solve it.

"I always think there is no point in waiting for situating to improve; instead I try to make the situation better by my actions" -husband

"I try to concentrate to help my husband in reading the newspaper loudly so that he is still in touch with outside world"- wife

Here frequency of coping strategy was taken into consideration. Even though the test does not show any statistical significance, the result showed out of 12 care givers who least or minimally adapted this method as coping strategy eight (66.6%) of them reported to experience severe burden when compared to care givers who adapted this method more often. That is 12 out of 32 care givers experienced severe burden (37.5%).

Planning strategies

Seeking information about the disease from the various sources including their friends and trying to plan for steps to be taken in future care

"Now a days my mother bed wets as she lost control over her toilet habits & I was so stressed about the situation my friend suggested me to stop giving liquid food after five in the evening & this plan is working for the time being" - daughter

"I am taking my wife for the evening walk so that her legs will not be weak as she wants to sleep all day"-husband

There is no significant (statistical) finding for this dimension. Frequency of planning for their activities directly affects the severity of burden experienced by the care givers. The finding shows less they adapt this strategy more severe will be the burden. Out of 19 care givers who less frequently planned for their care giving role 11 (57.89%) have experienced severe burden. And 12 out of 43 (27.9%) care givers who frequently planned for care giving role have reported to have experienced severe burden. This is less when compared to the care givers who did not plan for care giving.

Positive reframing strategies

This is trying to see the problem in different light to make to seem more positive and looking for something good in what is happening.

"I lost my young son in an accident and I am lucky to have my wife with me even though she has lost her memory. She is there for me …" husband

This method of coping is seen in very less care givers. The care givers experience of stress is enormous and they seldom see any good in future as most of them are aware of the prognosis of the disease. The result showed statistical significance. Only seven care givers reported to adapt this strategy and out of this one care giver experienced severe burden. Most of the care givers i.e., 60 care givers said that they do not have any hope and they cannot see any good in what is happening. Out of these care givers 34 (56.66%) experienced severe burden and 24 (40%) of them suffered mild to severe burden.

Acceptance of reality

Care givers effort to learn to live with the reality of fact that it has happened. Caregivers said that they have, after a long time, come to terms with the problem and can now more easily accept the situation

*"My mother is been ill for more than 2 years now and I thought of accepting the truth that she will not come back to me again. Now I feel much better even though …"*daughter

"It is very hurting to see my husband in such condition what to do? There is no escape so better accept and try to make life a little better"- wife

The results do not show statistical significance. But is it interesting note that the care givers who accepted the reality and who think that they do not have any options but to take care of their dear and near once till the end experienced severe burden than the care givers who did not accept. There were very less number of care givers who did not accept the reality. Only three of the care givers who were not ready to accept the fact & out of them 2 of the care givers were experiencing severe burden. Most of the care givers i.e., 98 care givers adapted this strategy of acceptance. In spite of their acceptance, 38 (38.77%) of them were experiencing severe burden. In this group most of them i.e., 55 (56.12%) care givers experienced mild to severe burden. This strategy of coping, we can say had the negative impact on the care givers.

Humor as coping strategy

Very few care givers shared the instances which they remembered in care giving situations and laughed heartily as they shared some of the instances

"My husband hates my mother for her toilet habits. Once it so happened that my mother urinated in the living room & it was time for my husband to return back from his work. I and my daughter saw him coming just few meters away from home. Both of us rushed to the spot cleaned it up dressed my mother in matter of seconds and lifted her and put her to bed. When my husband returned he directly went to mother to check if everything is fine. And my mother gave him a very sweet innocent smile which made us laugh heartily. Whenever we remember this incidence it makes us smile and gives us a temporary relief" daughter

Only two care givers said sometimes they recall some of the funny events in the care giving situations and enjoy those movements even though both of them were experiencing mild to severe burden. Maximum number of care givers said they have lost their sense of humor and they are not finding anything to smile at. In these 99 care givers, 46 (46.46%) experienced severe burden and 47 (47.47%) were experiencing mild to moderate burden and rest had little or no burden. The two care givers who adapted this coping method did not suffer from severe burden and if more emphasis on this is implemented in the intervention programs and new methods to develop this skill there can be a ray of hope of bringing down the experiences of burden in the informal care giving setups.

Religion

Most of the care givers tried to comfort themselves in their religion or spiritual beliefs and most of them try to cope up with praying and meditating.

"Before I rarely used to visit the place of worship but now a days I often visit these places and pray for my husband with the hope of some miracle to happen, and everything to be back to normal once again"-wife

Most of the care givers had their own religious beliefs and religious rituals at home for the benefit or recovery of the person with dementia.

Using Emotional Support strategy

Most of the female care givers, especially who had dual role of wife and mother say they feel happy if their children show some concern & sympathize for her care giving role.

"My children if they spend some time with me listening to my problems & pains I feel little relieved. Usually my daughter will take some time to visit me & listen to my problems. I hope to have some friends with whom I can share my pains"-wife

"I am very grateful to community nursing professionals who visit our house regularly and listen to me patiently and suggest some coping methods. They understand me better than my own children"-husband

The test showed significant results. Care givers who did not get any emotional support said they require someone's shoulders to cry off their burden. In 24 care givers more than 50 % carers who did not have any one to listen to their problems experienced severe burden. In 20 care givers who were using emotional coping strategy, it was observed that seven (35%) of them experienced severe burden and 11 (55%) experienced mild to severe burden. More the burden they have they will be looking for emotional support, especially women in sandwich generation.

Using instrumental support strategy

Most of the caregivers were informed and educated by the psychiatrist or by the psychiatric social work professionals about the disease & its prognoses.

"Knowing about the disease made the situations better and now I know that I have lost my dear ones and there is no escape from these care giving responsibilities. I have learnt to live with It"-son

Care givers who were educated about the disease and prognoses were able to cope up better than some of the care givers who said they are not aware of which type of disease their ward is suffering from. Seven care givers out of 13 who did not have any instrumental support reported to experience severe burden. And remaining six reported to experience mild to severe burden. Some of the care givers who were using instrument support to the maximum (21 care givers) as coping strategy, reported to experience less or no burden.

Self distraction strategy

Trying to cope by turning to work or other activities to take their mind off

"I want to watch my favorite serial in the afternoons, but it all depends on his mood. Sometimes he will be cool & tries to watch TV with me, other times he will be in agitation mood with the sound of TV itself he will be agitated and no TV serials for me"-wife

"I prefer to take part in family functions alone, leaving her with reliever"-husband

"When I am sad I try to think about good times we had together, but then I have to come back to reality which hurts"-husband

Care givers who use this method more often reported to have experienced moderate to severe burden. Six of the care givers who did not try to distract themselves away from the current responsibility, experienced very less burden.

Denial strategy

Some of the care givers refuse to believe that it has happened

"This cannot happen to my mother, they say she cannot come back to normal. How it can be? I know science have done wonders in all medical fields, and I know some day with some treatment I am going to get my mother back"-son

"I know some day we will sit together and laugh at all the events in the course of care giving. But question is when?"-husband

There is an interesting finding with the care givers using this coping method. The result showed the down ward trend in the number with respect to frequency of coping. Study showed higher they (caregivers) believe or hope that they are going to get back their loved ones, lesser is the burden experienced by them.

Venting strategy

Most of the care givers agree that venting out their feeling made them better temporarily. Care givers experienced great deal of sorrow and sadness and sharing these made them feel lighter & better.

"I have wept before my children which I never used to do before. But I think this makes me feel like I have lost some burden which was inside me"-husband

"When some persons sympathizes me for my condition I feel like bursting out weep copiously"-son

More they want to share their feelings or we can say more they share their feeling more they look forward to share their problems with others often.

Substance use as coping strategy

Some of the care givers said that they take alcohol in order to forget the reality & to get some relief from distress.

Behavioral disengagement

Care givers wished that the situation or problem would improve and go away. Some of the care givers were frustrated by many years of care giving and they want to give up trying to deal with the problem.

" *I hope my husband passes away in his sleep, I know I should not be telling this, but for you people it is easier give the advice but difficult to be on other side of the table"*-wife

Self blame

Most of the female care givers were of the opinion that this was fate and they cannot change it.

"I feel I am cursed and because of me my husband has to suffer"-wife

"If I would have taken my mother in the early stage of the disease doctors say, It could have been little better"- son

The result showed statistical significance. The care givers who thought that they are to be blamed for the current condition of their loved ones seem to cope up better than the other care givers. Self blame was seen in most of the male care givers. 67% of the care givers who adapted this strategy were males. And coping with self blame was found to be significant. Out of female care givers, four daughters and two spouses showed the highest score of self blame and moderated self blame was reported from the rest.

Care givers experiences of burden are molded by their involvement in their care giving situation. From the care givers point of view, burden in caring for a demented elderly relative emanates from a number of interrelated factors.

The shifting of women as get into the care giving process of their family process of elderly relatives, place these people into a vulnerable group for developing burden and distress. It is interesting to note that the age of the patient is not significant with care giver factors such as distress, and burden. More the years of care giving, more will be the experience of burden. One of the spouse care giver said *"I myself am weak, and need somebody to look after me, I cannot take this burden any more, I am waiting for the day of relief"*. One of the unmarried daughter said *"I feel like running away from the responsibility, it looks like never ending burden and my brothers want to escape from the responsibility of care giving"* Similar kinds of situation were experienced by many of the care givers.

From the study it was evident that the caregivers were craving for support and guidance from other family members. Characteristics of the caregivers' coping methods are directly related to caregiver burden. For example, positive reframing methods and using instrumental support strategies are associated with lower levels of caregiver burden. Active strategies include "constructing a larger sense of the illness" and being firm in directing a relative's behavior.(13) In the current study, most of the care givers showed behavioral disengagement and religion as their coping methods to divert themselves from the emotional stress. Some of the caregivers opined that they have always tried to "cope up" with the care giving burden and rest of them said that they are "giving up the attempt to cope with the situation".

Gender is important since the sexes differ in the kind of care giving and care giving burden; males displayed fewer adverse effects.

Most of the care givers had higher level of education. One of the important findings is that the burden experienced the different groups (educational level) were not significant when correlated with distress and years of care giving. The language of distress and burden is same for every individual despite of education levels. Care giving was associated with more psychological complaints and a poor quality of life both physical and mental. Although it may be tempting to classify people according to their style of coping, the current study found considerable change and overlaps between types of strategies. Categorizing caregivers according to personal orientations may be questionable. Instead, people's relationships alter both subtly and significantly alongside fluctuations in health and mobility. This indicates that classifying couples or individuals according to one or other type may not reflect their experiences over time nor the nature of changes in relationships at times of mobility change. (13) Although the circumstances of each individual were unique, instead of depicting their relationships as 'care', what mattered most was the change in their relationships with each other. While constructs such as 'care' have an important role in claims about rights and responsibilities, it seems sensible to remember that such language does not necessarily echo that of the everyday life of older people with dementia.

It was found out that the care givers emotions and feelings are wide-ranging and individualistic. They used different care giving strategies to help their situation and sometimes they used more than one strategy.

These findings are important implications for the theories about coping with burden. Results indicate that developing or experiencing burden either has a direct effect on coping strategy or influences the relationship between burden and coping strategy. In fact this study shows that mixed strategies of positive reframing, emotional support, venting, behavioral disengagement, self blame to be effective strategies.

Conclusions:

Results highlight the importance of improving the coping methods in burdened caregivers. Clinical significance to be given more importance than statistical significance. Interventions need to designed and tailored to the specific needs of caregivers. At present a memory clinic program is conducted in one of the selected caregiver setting once in a week and variety of interventions have been developed which aim to offer support for caregivers. Interventions include: training and education programmes and formal approaches to planning care which take into account the specific needs of carers and people with dementia using specially designated social workers and other members of the healthcare team.

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