

An Evaluative Study of Elderly Patients of Neurocognitive Disorders Carers' Quality of Life

Dr. Tripti Singh^{1*}, Dr. Kamayani Mathur²

ABSTRACT

Neurocognitive disorders (Dementia and Alzheimer's) belong to the category of conditions that commonly cause mental impairment. They are a type of biological brain illness that makes it harder for individuals to retrieve stimuli, believe in themselves, interact with others, and take care of themselves. Families and carers are presented with several challenges while caring for these relatives who suffer from this illness. This eventually makes a huge impact on their own quality of life, as they are required to make several transitions in their lifestyle and routine. **Objective:** This research was designed to assess the quality of life of carers and its impact on their functioning as a caregiver during the task of caregiving to patients with neurocognitive disorders. **Method:** A collective sample of 100, wherein 50 males and 50 female caregivers, of elderly patients with neurocognitive disorders (Dementia and Alzheimer's), were selected, using a purposive sampling method from various cities of Gujarat. **Tool:** **Adult Carer Quality of Life Questionnaire (AC-QoL; 2010)** published by the Princess Royal Trust for Carers in association with Nottingham University, was used. The collected data was statistically analyzed employing the Mann – Whitney U test. **Results and Conclusion:** The findings demonstrated the important distinction between the genders of caregivers, regarding their quality of life (QoL). The difference was indicative from the mean scores of QoL, which were found to be higher among the male caregivers as compared to the female caregivers. The mean scores were high among female caregivers with respect to two dimensions (sense of value and carer satisfaction) with an exception in rest of the six dimensions (support for caring, caring choice, caring stress, money matters, personal growth, and ability to care) where males showing a slight increase in the mean scores with regards to the females. It is conclusive of the study that the overall quality of life does not differ significantly for both the groups; for this reason, chiefly being a carer to an elderly patient with neurocognitive disorder is a very strenuous task. The higher mean scores among males for (support for caring, caring choice, caring stress, money matters, personal growth, and ability to care) reflect that males are more resourceful with respect to the dimensions stated and therefore have a superior quality of life as compared to females. The other two dimensions (sense of value and carer satisfaction) where mean scores of females are higher due to their nurturing nature.

¹Assistant Professor, GITAM (deemed to be University), Hyderabad, Telangana.

²Supervisor, Professor & Head, Department of Psychology; Director, School of Psychology, Philosophy & Education, Gujarat University, Ahmedabad, Gujarat.

*Corresponding Author

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Neurocognitive disorders involve a group of conditions that often results in impaired mental functioning. Neurocognitive disorders commonly occur among older adults but may affect younger individuals, as well. A reduced mental function may include:

- struggle with memory
- changes in behavior
- difficulty comprehending language
- inconvenience in performing daily activities

These symptoms may be caused by a neurodegenerative condition, such as Alzheimer's disease or Dementia. Neurodegenerative disorders, resulting in a progressive loss of neurological function, causes the brain and its nerves to deteriorate over time. As a consequence of brain damage or drug abuse, neurocognitive disorders may also develop. Based on the reported symptoms and the outcomes of medical testing, healthcare providers may usually assess the root cause of neurocognitive disorders. The causality and severity of neurocognitive disorders may help identify the desired treatment plan for various healthcare providers.

Neurocognitive problems may also be more likely to occur if the person is:

- above 60 years of age
- possess a cardiovascular disorder
- have diabetes
- abuse of alcohol or drugs
- participate in sports activities that involve a high risk of head trauma, such as soccer and rugby.

Neurocognitive disorders such as *Dementia* or *Alzheimer's* on which the present study focuses, present a challenging outlook. This is primarily because such diseases have no treatment and brain capacity progressively gets worse over time.

Dementia is caused as a result of damage to the brain cells. This impairment is detrimental to the capability of brain cells to connect. In brain cells, as they are ordinarily unable to communicate with one another, thinking, actions and emotion are altered. Specific forms of damage to brain cells are associated with various types of dementia in specified areas of the brain. Many dementias are incremental, meaning the symptoms, especially with memory problems or other variations in thinking skill, begins gradually. The most prominent form of dementia is Alzheimer's. While the symptoms of dementia can vary significantly, at least two of the following primary functions of the mind, are found to be considerably impacted.

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception

Alzheimer's is a type of dementia that affects memory, thought processes and behavior. Eventually, the symptoms become severe enough to conflict with day-to-day activities. The most prevalent form of dementia is Alzheimer's, a generic term for memory loss and other cognitive skills, severe enough to interfere with everyday life. Alzheimer's disease accounts for 60-80 percent of cases of dementia. It is not a common part of aging to develop

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Alzheimer's. Rising age is the largest recognized risk factor, and the majority of individuals with Alzheimer's are 65 years or above. Over time, Alzheimer's exacerbates. Alzheimer's is a progressive disease where, over a period, signs of dementia steadily intensify. Memory loss is moderate in the early stages, but in late-stage Alzheimer's, individuals lose the capacity to initiate a conversation and relate to their surroundings. Difficulty recalling recently acquired information is the most common early symptom of Alzheimer's since Alzheimer's effects usually transpire in the area of the brain that involves learning. As Alzheimer's progresses through the brain, it leads to more serious symptoms, including disorientation, shifts in attitude and behavior; deepening uncertainty about activities, time and place; irrational doubts about relatives, friends and skilled caregivers; more radical changes in memory and behavior; and difficulty in communicating, eating, and walking.

A **caregiver** is anyone who offers fundamental support and treatment for someone who is either elderly, disabled, or unwell and requires assistance. In order to support everyone else with their everyday lives, caregivers perform a wide range of activities, such as managing a chequebook, buying groceries, assisting with medical visits, giving prescribed medicines, or helping someone to feed, bathe, or wear clothes. Many family members and friends do not regard such assistance and care as “*caregiving*”— they are just doing what comes to them naturally: caring for those they love. But for months or years, such treatment and care will be required, which may take a psychological, physical, and financial toll on caregiving families.

Caregiving is especially cumbersome for someone with Neurocognitive disorders, such as Dementia and Alzheimer's as they deteriorate in many aspects. Care, in general, lasts for many years, and in order to provide care, caregivers must change their own lifestyles often. Even though being a family caregiver is always beneficial, with strain and mental morbidity, combined with social alienation, physical discomfort and economic hardships, the consequences of being a family caregiver are ordinarily detrimental. Care becomes a strenuous task when individuals with neurocognitive disorders, become aggressive or restless. Psychological distress and stress levels in caregivers are considerably higher and levels of empathy, subjective well-being and physical health are extensively lower.

Quality of life (QoL) has become a key goal of contemporary health care. It is often misinterpreted with standard-of-living. However, the standard of living refers to the possession of wealth or material goods. A consensus about how to define and measure QoL is still debated. In the 1970s, its definitions contained terminological similarities with definitions of stress. At a time when stress was often seen as a phenomenon that exceeds an individual's resources, in order to provide a good QoL, these resources needed to be adequate in terms of gratifying people's wants, needs, and capacities. Since then, definitions have placed greater emphasis on people's subjective perceptions of the important features of their life and, in particular, explored the varied meanings ascribed to these experiences. The ways in which people interpret life's events (e.g., as stressful or pleasant) affect how they see their QoL. Wenger et al. (1984) defined QoL as “an individual's perceptions of his or her functioning and well-being in different domains of life.”

Objective of the present study

The present research was designed to understand the quality of life, and assess its impact on the role of caregivers during the task of caregiving to the patients with Neurocognitive disorders.

Hypotheses

The main hypotheses for the present research are as follows:

- **Null Hypothesis:** There will be no significant mean difference between the quality of life scores explained through its eight dimensions (sense of value, carer satisfaction, support for caring, caring choice, caring stress, money matters, personal growth, and ability to care) between carers' gender (male and female) among elderly patients of neurocognitive disorders.
- **Alternate Hypothesis:** The male group of carers of neurocognitive disorder patients will have a better quality of life elaborated in its dimensions as compared to the female carers.

METHODOLOGY

Sample: The total sample consisted of 100 caregivers of elderly patients with neurocognitive disorders from various hospitals and clinics across the city of Ahmedabad, Gujarat, who were approached and became part of this study as to give the required details. Since the study was on elderly patients therefore the patients' age, whose caregivers were considered were above 65 years. To constitute the sample, a purposive sampling technique was employed. Efforts were made to select the sample as representative as possible, in terms of the gender of caregivers for the elderly patient with Dementia and Alzheimer's. Proper rapport was established with the caregivers and was informed about the confidentiality of their details.

Variables

Independent Variable:

- Gender: Male and Female

Dependent Variable:

- The scores of Quality of Life scale

Research Measures

Inclusion Criteria:

- Only clinically diagnosed patients of Dementia and Alzheimer's by the Neurologists were considered.
- Gender of Caregivers of Dementia and Alzheimer's patients.
- Elderly patients with Dementia and Alzheimer's are between 65 years to 75 years.

Exclusion Criteria:

- Younger patients with Dementia and Alzheimer's who were below 60 years.
- Effect of the death of the spouse on caregiving of the elderly patient with Dementia and Alzheimer's.
- Any other complications involved in Dementia and Alzheimer's patients were not taken.

Tools

1. For data on demographic features of participants, a personal information sheet has been used.
2. **Adult Carer Quality of Life Questionnaire (AC-QoL; 2010)** - The Adult Carer Quality of Life Questionnaire (AC-QoL), published by the Princess Royal Trust for Carers in association with Nottingham University was employed. The scale consists of eight dimensions:
 - support for caring

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- caring choice
- caring stress
- money matters
- personal growth
- sense of value
- ability to care
- carer satisfaction

Data Collection and Procedure

The samples of elderly neurocognitive disorder patients' caregivers were identified in specific areas of Ahmedabad. Written permission was sought from the incharge officers / Superintendents of the hospitals from where the data were to be collected. Rapport was established by the researcher and explained the purpose and objectives of the current study to them. Before initiating the data collection, rapport was established and informed consent was taken with the assurance that the data and names shall not be disclosed and shall be used for the purpose of the said study. All those who have shown a willingness to participate in the research study were given proper instructions for the test and accordingly, it was administered. The collected raw data were scored as per the scoring key given in the test manual. The raw data was statistically analyzed using Mann-Whitney.

RESULTS AND INTERPRETATION

The results of the present study of the research study are presented below:

Table: 1(a) Mean, z-score and p-value for Gender on Measure of first dimension of Quality of Life – Support for Caring:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	6.52	-2.41	.015	0.05
Female	50	6.06			

*** Significant at 0.01 level, * significant at 0.05 level and NS Not significant*

As can be seen from the above table the two groups under study differ significantly in relation to support for caring with regard to the quality of life. According to the scoring pattern, a higher score indicated better-perceived support for caring in terms of emotional or practical or professional support. Thus, from the result, it could be said that male caregivers group show very slightly higher mean scores for support for caring as compared to female caregivers of elderly patients of Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(b) Mean, z-score and p-value for Gender on Measure of second dimension of Quality of Life – Caring Choice:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	7.48	-2.38	.0168	0.05
Female	50	6.98			

*** Significant at 0.01 level, * significant at 0.05 level and NS Not significant*

As can be seen from the above table the two groups under study differ significantly in relation to caring choices with regard to quality of life. According to the scoring pattern, a higher score indicated better control over their own life; they pursue other things besides caring. Thus, from the result, it could be said that male caregivers group shows slightly

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higher mean scores for caring choice as compared to female caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(c) Mean, z-score and p-value for Gender on Measure of third dimension of Quality of Life – Caring Stress:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	7.68	2.419	.0155	0.05
Female	50	7.16			

** Significant at 0.01 level, * significant at 0.05 level and NS Not significant

As can be seen from the above table the two groups under study differ significantly in relation to caring stress with regard to quality of life. According to the scoring pattern, a higher score indicated higher stress resulting from caregiving tasks, leading to exhaustion and depression. Thus, from the result, it could be said that male caregivers group shows slightly higher mean scores for caring stress as compared to female caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(d) Mean, z-score and p-value for Gender on Measure of fourth dimension of Quality of Life – Money Matters:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	8.34	-1.30	.190	NS
Female	50	7.94			

** Significant at 0.01 level, * significant at 0.05 level and NS Not significant

As can be seen from the above table the two groups under study do not differ significantly in relation to money matters with regard to quality of life. According to the scoring pattern, a higher score indicated higher financial satisfaction or security. Thus, from the result, it could be said that male caregivers group shows very slightly higher mean scores for money matters as compared to female caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(e) Mean, z-score and p-value for Gender on Measure of fifth dimension of Quality of Life – Personal Growth:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	8.08	-2.97	.0029	0.01
Female	50	7.44			

** Significant at 0.01 level, * significant at 0.05 level and NS Not significant

As can be seen from the above table the two groups under study differ significantly in relation to personal growth with regard to quality of life. According to the scoring pattern, a higher score indicated a higher growth perspective in terms of self-scaling or development. Thus, from the result, it could be said that male caregivers group shows slightly higher mean scores for personal growth as compared to female caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

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Table: 1(f) Mean, z-score and p-value for Gender on Measure of sixth dimension of Quality of Life – Sense of Value:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	8.16	-0.358	.718	NS
Female	50	8.24			

*** Significant at 0.01 level, * significant at 0.05 level and NS Not significant*

As can be seen from the above table the two groups under study do not differ significantly in relation to sense of value with regards to quality of life. According to the scoring pattern, a higher score indicated a higher sense of value and respect received, this shows a positive relationship between the carer and the person they are caring for. Thus, from the result, it could be said that female caregivers group shows higher mean scores for sense of value as compared to male caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(g) Mean, z-score and p-value for Gender on Measure of seventh dimension of Quality of Life – Ability to Care:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	8.44	-0.137	.888	NS
Female	50	8.4			

*** Significant at 0.01 level, * significant at 0.05 level and NS Not significant*

As can be seen from the above table the two groups under study do not differ significantly in relation to ability to care with regard to quality of life. According to the scoring pattern, a higher score indicated a higher sense of competency in their caregiver's role. Thus, from the result, it could be said that male caregivers group shows very slightly higher mean scores for ability to care as compared to female caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(h) Mean, z-score and p-value for Gender on Measure of eighth dimension of Quality of Life – Carer Satisfaction:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	8.7	2.264	.238	0.05
Female	50	9.16			

*** Significant at 0.01 level, * significant at 0.05 level and NS Not significant*

As can be seen from the above table the two groups under study differ significantly in relation to carer satisfaction with regard to quality of life. According to the scoring pattern, a higher score indicated higher satisfaction in their role as caregivers. Thus, from the result, it could be said that female caregivers group shows higher mean scores for carer satisfaction as compared to male caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

Table: 1(i) Mean, z-score and p-value for Gender on Measure of Quality of Life:

Group	N	Mean	z-score	p-value	Level of Significance
Male	50	63.4	-1.868	.061	NS
Female	50	61.38			

*** Significant at 0.01 level, * significant at 0.05 level and NS Not significant*

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As can be seen from the above table the two groups under study do not differ significantly with regard to quality of life. According to the scoring pattern, a higher score indicated better quality of life in their role as caregivers. Thus, from the result, it could be said that male caregivers group shows higher mean scores for carer satisfaction as compared to female caregivers of elderly patients with Neurocognitive disorders that include Dementia and Alzheimer's.

DISCUSSION

Caregivers manage the physical, emotional, spiritual, and practical needs of another individual, all while managing their own lives, needs, family, and career. Caregiving could become exhausting, frustrating, anxiety-provoking, stressful, and nerve-wracking. It can test an individual's body, spirit, emotions, and patience. It may present economic challenges. The needs of the loved ones may outweigh their capacity as caregivers and often surpass their own needs. The present study is viewed in the light of the quality of life as further elaborated across eight dimensions while providing care to elderly neurocognitive disorder patients. They require a lot of support and acceptance from their caregivers. Caregiving requires a great deal of commitment, flexibility, respect, and empathy from the caregiver.

Quality of life of the carer is at stake and is conceptualized in many aspects as their life undergoes lots of transitions and compromises thus making the task of caregiving more overwhelming. It is the perception of an individual toward their competency as a carer.

The results showed that male caregivers group had higher mean scores as compared to female caregivers with regards to the overall quality of life and six of its dimensions (support for caring, caring choice, caring stress, money matters, personal growth and ability to care) which clearly indicates they are able to manage and be resourceful with regards to the support easily availed or venture in other things besides caregiving; they manage finances better and do focus on the personal growth along with having a better perception about their ability to care; they easily accept their limitations as a carer but they also get stressed out easily with the task of caregiving. The other two dimensions (sense of value and carer satisfaction) receive higher mean scores among female group as they are usually the homemakers and stay at home for longer hours and the responsibility of the entire family is on their shoulders. As nurturers by nature, they believe in the concept of caregiving can be a rewarding, rich, meaningful experience because they easily adapt. It provides individuals with the opportunity to love, support, bond, share and be together. The caregiving relationship is a gift given to each other. The overall result of the quality of life of both the groups was found to be non-significant due to the tediousness of the task which surely has an impact on the carer and their mental, emotional, or physical health.

A similar study was found where the task of caregiving was involved with depressive symptoms among family caregivers with respect to their quality of life.

Morrison, B., Predicting Quality of Life in Caregivers of Persons with Mild and Major Neurocognitive Disorder (2017): Empirical Investigation of a Psychosocial Adjustment Model. University of Wisconsin-Madison.

Neurocognitive disorders (NCDs) are progressive, life-altering disorders that causes significant cognitive, psychological, and behavioral changes in individuals. NCD symptoms often lead individuals toward a life of increased dependence on others, limited engagement in social activities, and increased difficulties with self-care and other activities of daily living.

NCD symptoms presents a multitude of challenges for not just the care recipients, but their caregivers as well. The emotional, social, and financial burden that accompanies caregiving for individuals with NCDs often negatively affects the caregiver's psychological well-being, physical health, and social life. Given the expected increase in the prevalence of NCDs over the next 30 years, greater focus on improving caregiver outcomes is needed. Improving caregiver outcomes will likely help improve care recipient outcomes, as well as help decrease the increasing burden of NCDs on our healthcare system. The present study sought to identify whether specific care recipient and caregiver risk and resistance factors significantly predicted caregiver quality of life (QOL). The current study also aimed to identify whether caregiver demographics moderate the relationship between care recipient risk variables and caregiver QOL. An adapted version of Mercurio-Riley and colleague's (2013) psychosocial adaptation framework was used as the basis for choosing specific risk and resistance variables. One-hundred and three caregiver/care recipient duos participated in the current study. Hierarchical regression analysis (HRA) was used to investigate the influence of risk and resistance factors on caregiver QOL. HRA was also used to address whether caregiver demographics moderated the relationship between care recipient risk factors and caregiver QOL. Results of the study showed that risk and resistance factors each uniquely accounted for a significant proportion of variance in caregiver QOL, with the final model accounting for 40.6% of the variance in caregiver QOL. Specifically, there were a total of four variables that significantly predicted caregiver QOL in the final model: caregiver age, care recipient functional dependence, caregiver social problem-solving, and caregiver perceived social support. Results of the moderation analysis did not support caregiver demographics as moderators of the relationship between care recipient risk variables and caregiver QOL. The findings in this study add to the caregiver QOL literature, providing more evidence for the important role of care recipient functional dependence, caregiver age, and caregiver resistance factors in determining caregiver QOL outcomes.

Overall, a family is a rudimentary unit having a single-minded, unconditional desire to provide a loving, caring home. Thus, caregiving happens as a natural phenomenon. Thus, making caregiving an utmost important task and providing a better understanding of caregivers' issues. Caregivers who ignore their own needs can be at a higher risk for caregiver burnout as well as physical and mental health problems.

CONCLUSIONS

Caring for a patient with cognitive deficits is associated with greater loneliness, strain, and burden for caregivers, and increased depression. Caregivers may benefit from interventions designed to compensate for the stress and interpersonal loss associated with patients' declining empathic accuracy. There is a need for social acceptance and understanding of elderly dementia patients. They go through a lot of emotional turmoil and stress. That makes caregiving very crucial as the caregivers also have a lot of issues which has an adverse effect on their mental and physical health. The caregivers especially females are restricted to the house and have more responsibilities to shoulder, which makes their role and responsibilities very extensive. They are natural nurturers; therefore, for them, others' emotions are more important than their own. Females in countries like India always keep their families ahead of their own health, choices, issues and concerns. Therefore, it is important for all family members to contribute and help the primary caregivers balance their life as well as the life of elderly patients with Dementia and Alzheimer's.

Limitations and Suggestions

As with the other studies, the present study too has its own limitations. Due to time constraints, the data has been collected from various cities in Gujarat only. Further studies could be employed and conducted in other cities and states. Here sample selection was limited to only up to 100 carers of elderly patients with neurocognitive disorders; therefore, the results cannot be generalized to a larger sample using varied psychological dimensions. Also, other variables could be included as to see its impact on the carer's quality of life and work toward its intervention.

Implications of the present research

The present research could be implemented to generate a better understanding of caregivers for the caregiving aspect of elderly Dementia and Alzheimer's. It can be useful to clinical and health psychologists, especially gerontologists. It can be useful to Neurology and Neuropsychology professionals, medical professionals and nursing staff who are dealing with these patients and their caregivers on a daily basis. The study highlights the importance of this field of study in helping patients and caregivers to cope with diseases and for the development of ad-hoc psychological strategies. Also, it can be helpful for society and the community.

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Conflict of Interest

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