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Research Paper

Correlation between Resilience and Quality of Life of Caregivers of Dementia patients

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ABSTRACT

Background & Aim: - The study was aimed to find out the correlation between Resilience and Quality of Life of (QOL) of caregivers of dementia patients. There were a total 50 participants which included the male and female caregivers of KITES Dementia Care Centre, HRBR layout, Bangalore. **Methods: -** The Connor-Davidson Resilience Scale (CD-RISC) was used to measure the dementia caretaker's level of resiliency and the WHOQOL-BREF was used to measure the Quality of Life of the caregivers. To assess the effect of resilience on quality of life, Pearson rank difference method was used. **Results: -** The results reflect that all the four domains, i.e. Physical health, social relationship, psychological health and environment is correlated to the resilience of the subjects. **Conclusion: -** Overall, each domain assessed by the WHOQOL-BREF showed a positive relationship with resilience. These outcomes underline the multidimensional impact of resilience across various aspects of caregivers' lives.

Keywords: *Dementia, Caregiving, Caregivers' burden, Quality of Life, Resilience*

Everyone experiences changes as they age. Few of them experience these changes sooner than others. Ageing is affected by several factors such as genes, life-style, nutrition, stress, exercise, mental wellbeing, behavioral health, physical environment, etc. Most older adults live with one or the other health conditions. Along with this ageing in adults, several issues arise i.e. increased healthcare demands, economic challenges, social concerns, etc. Difficulty with everyday tasks, slower reaction times and reduced problem-solving abilities and mobility lead to dependence on others. With increasing life expectancy, ageing-related cognitive disorders like dementia and Alzheimer's disease are on the rise, significantly impacting families and healthcare systems.

Memory loss is different from forgetfulness. It can be temporary and caused by dehydration, illnesses, reactions to medications and stress. But sometimes it is linked to Alzheimer's disease (AD) and dementia. Dementia leads to progressive decline in memory, reasoning, and the ability to perform daily activities, often necessitating constant supervision. They want to stay close to their families and friends. As a result, the role of caregivers has become increasingly crucial. Most dementia patients prefer to live and grow old in their own

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homes and communities. Some clients who are believed to have no more than six months to live may choose and be eligible for hospice care. The goal of hospice care is no longer on curing disease but to make sure the person's last days are spent comfortably, with dignity and quality, surrounded by the people they love. Such facilities can be given in the client's home, a hospital, adult family home, assisted living facility, nursing home, or anywhere of patient's choice.

A dementia caregiver provides ongoing, quality care for a senior suffering from dementia. **Caregiver can be** a family member, friend or a professional who provides care and support for a child or a dependent adult. **Caregiving** comes from love and forms the basis of healthy adult relationships. General responsibilities include discreet assistance with the activities of daily living, such as bathing, dressing and incontinence. Dementia caregivers also provide various types of additional in-home support. Becoming a caregiver is about looking after someone without expecting anything in return. Caregiving involves setting boundaries and limits with the person being cared for as well as yourself. A caregiver may feel satisfied overall with their life and also experience chronic stress from their caregiving responsibilities. Caregivers also have other life pressures and responsibilities similar to other professions. Caregivers face many challenges in order to balance caregiving with other demands, including child rearing, career, and relationships. They might suffer from stress, depression, etc. Not all stress is bad as it is a part of everyday life. Usual amounts of stress keep us alert and motivate us to take actions. But too much stress for long periods of time is hard on the overall well-being and it can have a negative impact on the quality of life of the caregivers.

Sherwood P. R. (February 2006) concluded that interventions to reduce distress for caregivers of older persons with cancer have the potential to lower patients' hospital re-admissions to improve patients' and caregivers' emotional health. He also suggested that oncology practitioners must consider the needs of family caregivers when planning and implementing interventions to improve or maintain caregiver health. Comprehensive management of the patient with dementia includes building a partnership between health professionals and family caregivers, says Henry Brodaty & Marika Donkin (April 2022). This will help us to identify the causes of caregivers susceptible to negative effects can be identified and thus they could be targeted for interventions.

Caregivers often neglect their own emotional, mental, physical, and spiritual health. While caregiving can be rooted in affection and a sense of duty, it often brings substantial emotional, physical, and financial challenges, collectively referred to as caregiver burden. Hoenig and Hamilton (1966) first proposed the concept of burden and believed that burden could be divided into subjective and objective burden. Subjective burden involves the personal feelings of caregivers which are generated while performing the daily caring routine, while objective burden is defined as events related to negative caring experiences. The three attributes of caregiver burden identified from the literature are self-perception, multifaceted strain, and over time.

Caregivers who are burned out feel like they are left with nothing. Burnout is not limited to physical exhaustion, but also there is a loss of hope, purpose, and meaning. Caregiving is hard and seems like a thankless job and it can lead to feelings of stress, guilt, anger, sadness, isolation and depression. Feelings of grief, sadness, and a range of other emotions can impair resilience. Several studies have explored these burdens in depth. Sherwood (2006) found that interventions targeting caregivers of older adults with cancer can improve emotional well-being and reduce hospital readmissions. An in-depth qualitative study by Guberman et al. (1992) focused on the caregiving relation rather than on the specificities of aging and mental illness. The study highlighted how societal expectations and gender roles shape women's caregiving experiences, revealing deeper socio-cultural dimensions of caregiver stress. Data indicates that analyses attempting to understand women's caregiving must take into account the sexual division of labour, its reinforcement through social policy, and how women internalize ideas and norms regarding appropriate gender-role behaviour. During the COVID-19 pandemic, significant differences were noted in the resilience and coping oh Healthcare Workers, especially the nurses, says Ivana, Sherry and Jyanth (April 2021). Cutrino A. & Santamaria J. (June 2013) study was focused on issues and research related to informal caregivers. They found that the level of caregiver burden was related more to caregiver perception and attitude than to patient disease. Amanda Elliott and colleagues provide evidence of an intervention that was successful in improving caregiver health.

Elif Koca et. al. (March 2017) mentioned the Caregiver Burden in Different Stages of Alzheimer's Disease (AD) as it leads to emotional burdens and psychological distress in family members and caregivers alongside the patient. They concluded that emotional burdens of caregivers from these responsibilities lead to a decreased quality of life and disturbed body physiology. Incapacity, despair, weariness, and loneliness are the hidden emotions of this iceberg. Glajchen M (March 2004) suggests that the diagnosis of cancer presents a major crisis not only to the patient but also to the patient's primary caregiver. His study provided an understanding of the multifaceted role of caregivers in cancer care and imparting an understanding of the caregiver's burden and unmet needs. Bass D. M. and Noelker L. S. (June 1987) worked on the "Influence of Family Caregivers on Elder's Use of In-Home Services: An Expanded Conceptual Framework". This research focused on whether characteristics of the primary and secondary family caregivers influence the elder's use of in-home nursing. Findings of this study indicated that caregiver need characteristics account for significant variation in whether or not services are used, while family enabling factors are the most important predictors of the number of services used.

A number of researchers have used quantitative approaches to explore the experiences of family caregivers of relatives with severe and persistent mental illness. Chang K. H. & Horrocks S. (January 2006) conducted a study to explore the meanings of the lived experiences that Chinese family caregivers in Malaysia. They also studied the impact of the stigma of the relatives' mental illness on family caregivers. Findings suggest that family caregivers tried to avoid talking about their relative's mental illness with extended family or friends. Researchers suggest to educate the public about mental health and ill health through health promotion and education. Lane P., McKenna H., Ryan A., Fleming P. (Jun 2003) studied the experience of the family caregivers' role: A Qualitative Study. The data yielded a rich and meaningful picture of the caregiving experience, profiling the complex nature of this diverse and multifaceted role. Researchers emphasized on the importance of the need to develop an understanding of the effectiveness of specific health and social care interventions.

Caregivers may also experience grief from both their own losses and those of the people they care for. Grief is a natural reaction to loss which has strong emotional and physical symptoms. They should also practice good self-care to manage their own grief. Managing the emotions and physical symptoms of grief is an important part of the caregiver's self-care. It is also important to be aware of the losses which someone may experience as a caregiver. Self-care takes time, motivation and effort to understand the signs and symptoms of stress so they can take care of themselves and avoid burnout.

Aging and Long-Term Support Administration published a book titled, "Fundamentals of Caregiving (3rd Edition)" which states that self-care helps the caregivers to cope with stress and avoid burnout. Similar to filling a car with gas before it is empty and stops working, self-care can refuel the body, mind, and spirit. It also suggests that all the caregivers should focus on self-care and well-being are essential to their role as a caregivers. They should be proud of what they are doing and accomplishing. The demands and challenges of caregiving may be overlooked by others, so it is important for them to take pride in their own work. Caregiving is an essential and very difficult job. They deserve recognition for what they do. If the recognition is not available from family and society, one should acknowledge and reward themselves.

An increasingly recognized factor that can mitigate these negative outcomes is resilience. Defined as the ability to adapt and recover from adversity, resilience enables caregivers to manage stress and maintain functioning even under chronic strain. Certain individuals are better able to withstand the experiences of hardship, stress, and adversity. Being resilient means having the ability to "bounce back" from negative situations. Shame resilience theory was introduced in 2006 by Brené Brown. It is the ability to recognize this negative emotion when we feel it and overcome it constructively in such a way that we can "retain our authenticity and grow from our experiences (Brené Brown). Another type of resilience is community resilience. Magis defined community resilience as the "existence, development and engagement of community resources by community members to thrive in an environment characterized by change, uncertainty, unpredictability, and surprise." According to Boston Consulting Group, organizational resilience can be thought of as "a 'culture of resilience,' which manifests itself as a form of 'psychological immunity'" to incremental and transformational changes. Fullerton D. J., Zhang L.M., Kleitman S. (February 2021) suggest that resilience research has moved from conceptualising resilience as a *trait* towards studying resilience as a *process* by which resources protect against the negative impact of stressors to produce positive outcomes.

Ahern N. R., Ark P. and Byers J. **(December 2008) conducted a study on, "**Resilience and coping strategies in adolescents – additional content" and concluded that resilience is dynamic, developmental in nature, and interactive with one's environment, irrespective of age and gender. The findings suggests that there is a need of useful resources for application to nursing education, practice, and research. The resources are very helpful to minimize risky behaviours and promote positive lifestyle practices. According to Seligman's (1990) 3Ps model—Personalization, Pervasiveness, and Permanence—resilience involves recognizing and re-framing negative thoughts that impede recovery. Croghan et al. (2021) and Kinser et al. (2021) demonstrated that resilience predicted better emotional regulation and lower stress in both healthcare workers and mothers during the COVID-19 pandemic. This aligns with Norman Garmezy's findings that resilience is a dynamic trait shaped by personal, social, and environmental protective factors.

In the context of dementia caregiving, resilience may determine how caregivers perceive and manage their role, influencing their overall quality of life. Quality of Life (QOL) is a multidimensional concept encompassing physical, material, psychological, social, and environmental well-being, as defined by the World Health Organization. a theory of Quality of Life (QOL) was first suggested by Cummins. Cummins (1992) conceptualized Quality of

Life (QOL) as an objective evaluation of a person's life circumstances and their subjective evaluation of satisfaction, determined by the significance they place on each sphere. The term *quality of life* is ambiguous, as well as highly subjective.

Fallowfield L. (1990) in her book "*The Quality of Life: The Missing Measurement in Health Care"* aimed at all those in the caring professions as well as the general public. The author discusses some of the measures that have been developed for specific diseases including cancer, heart disease, arthritis, AIDS and the universal problems of ageing and dying. She suggests that emotional well-being plays a large part in a person's ability to cope with illness, and response to treatment will depend on a number of factors, including temperament, lifestyle and physical condition. Within the healthcare context, QOL is used to evaluate the broader impacts of disease and caregiving on daily functioning and satisfaction.

Kinser P. A. et al. (May 2021) conducted a study to evaluate the experiences of pregnant and postpartum women in the United States in the early phase of the COVID-19 pandemic. This study focused to identify risk for anxiety, depression, and PTSD symptoms in perinatal women during acute public health situations. The found that the most common predictors were job insecurity, family concerns, eating comfort foods, resilience/adaptability score, sleep, and use of social and news media. Findings indicated that women with family and job concerns and low resilience scores seem to be at high risk of psychological stress. Research by Glajchen (2004) and Hudson & Payne (2011) has shown that unaddressed caregiver stress can reduce quality of life, especially in palliative care settings. Caregivers often experience sleep disturbances, anxiety, loneliness, and physical health decline—factors that lower QOL and caregiving effectiveness. In context with caregiving, Quality of Life (QOL) is affected in four main domains i.e. physical capacity, psychological state, environment and social relationship.

Given the pandemic's added stress and isolation, understanding this relationship is especially essential. This study therefore aims to examine the correlation between resilience and Quality of Life (QOL) among caregivers of dementia patients, providing insight into psychological factors that sustain caregiver health and performance and acknowledging the unique and often intense demands of caregiving.

METHODS

Rationale of the study

Worries and anxiety about COVID-19 and its impact was overwhelming. Social distancing made it even more challenging. The COVID-19 pandemic has brought many changes to the life of every individual, and with it, at times, uncertainty, altered daily routines, financial pressures and social isolation. During the COVID-19 pandemic, people experienced stress, anxiety, fear, sadness and loneliness. And mental health disorders, including anxiety and depression, worsened.

Surveys show a major increase in the number of adults who reported symptoms of stress, anxiety, depression and insomnia during the pandemic, compared with surveys before the pandemic. At some point, almost everyone experiences hardship, sadness, or frustration. Not everyone deals with these emotions in the same way. Although some individuals face more severe and life-impacting instances than others. Some of these instances are tragic events such as the death of a loved one, a natural disaster, or a debilitating illness.

The present study is focused to find out the effect of resilience during pandemic on the quality of life (QOL) of caregivers of dementia. This study will help to overcome the problems during caregiving sessions.

Gap in the knowledge

A numerous studies have explored the individual constructs of resilience and quality of life among caregivers of dementia patients, but there are limited research in understanding the direct correlation between these two variables, particularly within diverse cultural, socioeconomic, and caregiving contexts. Most studies tend to focus on the burden of care or psychological distress without examining how resilience may act as a protective factor that influences overall well-being. Addressing this gap could inform targeted interventions aimed at enhancing caregiver resilience and, consequently, improving their quality of life.

Research Problem

- What is the effect of resilience on the quality of life of caregiver of dementia.

Objectives

The objective of the study was: -

- To find a correlation between resilience and quality of life of the Caregivers of Dementia

Hypothesis

Based on the available literature and expert advice, it is hypothesized that, “there will be a positive correlation between resilience and the quality of life of caregivers of dementia”.

Variables:

- Quality of Life (QOL): WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

Quality of life (QOL) is a concept that aims to capture the well-being of a population or individual regarding both positive and negative elements within the entirety of their existence at a specific point in time.

- Resilience: According to APA, resilience is the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioural flexibility and adjustment to external and internal demands.

When we face adversity, misfortune, or frustration, resilience helps us bounce back. It helps us survive, recover, and even thrive in the face and wake of misfortune, but that’s not all there is to it.

- Caregiver: A caregiver can be a family member, friend or a professional, who provides care and support for a child or a dependent adult**.** **Caregiving** comes from love. It forms the basis of healthy adult relationships. Caregiving involves setting limits with the person being cared for as well as yourself. A dementia caregiver provides ongoing, quality care for a senior suffering from dementia. General responsibilities include discreet assistance with the activities of daily living, such as bathing, dressing and incontinence. Dementia caregivers also provide various types of additional in-home support. These caregivers are either health professionals or family members. Depending on their responsibilities, caregivers are categorised as primary caregivers or secondary caregivers.

- Dementia: - Dementia may be defined as a wide range of medical ailments, including Alzheimer's disease. It is termed as a loss of several cognitive functions, such as memory, problem-solving, thinking and language The five most common forms of dementia are:
  a) Alzheimer's disease, the most common dementia diagnosis among older adults. It is caused by changes in the brain, including abnormal build-ups of proteins, known as amyloid plaques.
  b) Frontotemporal dementia, a rare form of dementia that tends to occur in people younger than 60. It is associated with abnormal amounts or forms of the protein's tau and TDP-43.
  c) Lewy body dementia, a form of dementia caused by abnormal deposits of the protein alpha-synuclein, called Lewy bodies.
  d) Vascular dementia, a form of dementia caused by conditions that damage blood vessels in the brain or interrupt the flow of blood and oxygen to the brain.
  e) Mixed dementia, a combination of two or more types of dementia.

- Caregiving Burden: - Hoenig and Hamilton first proposed the concept of burden and believed that burden could be divided into subjective and objective burden. Subjective burden primarily involves the personal feelings of carers generated while performing the caring function, while objective burden is defined as events or activities related to negative caring experiences.

Among these variables, resilience decides the Quality of Life (QOL) of the dementia caregivers. And the correlation between resilience and quality of life was supposed to be studied. So, Resilience is the independent variable and Quality of Life (QOL) is the dependent variable in the study.

Sample:

For the study fifty (50) subjects were selected for data collection on two scales; i.e. resilience scale and Quality of Life (QOL) scale. Male and female both were included for data collection. The sample selected were the caregivers of KITES, Residential Dementia Centre, HRBR Layout, Bangalore. For the selection simple random sampling technique was used.

Tools:

a. Connor-Davidson Resilience Scale 10 (CD-RISC 10)

The Connor-Davidson Resilience Scale (CD-RISC; Connor, K.M., & Davidson, J.R., 2003) measured college student's level of resiliency. The CDRISC is comprised of 10 questions, to which the respondents answer in terms of how they have felt within the last month. Each question is rated on a five-point Likert-style scale, ranging from not true at all (0) to true nearly all the time (4). Scores on the CD-RISC 10 can range from 0 to 40. Cronbach's Alpha of 0.89 indicating a high level of reliability for CD-RISC-10. The CD-RISC-10 has been shown to correlate significantly with other measures of resilience and related concepts, such as well-being, optimism, and self-esteem, supporting its validity.

b. WHOQOL BREF

It is an abbreviated version of the WHOQOL-100. The WHOQOL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the

24 facets contained in the WHOQOL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included. The WHOQOL-BREF should be self-administered if respondents have sufficient ability: otherwise, interviewer-assisted or interview-administered forms should be used.

For domains of WHOQOL-BREF, Cronbach's alpha ranged from 0.62 for social relationship domain to 0.76 for psychological well-being, indicating a good internal consistency. The WHOQOL-BREF had good internal consistency as Cronbach's alpha coefficient for the overall scale was 0.91. The convergent validity results indicated that the correlation coefficients values for all scale domains are significantly correlated at $\alpha < 0.01$.

Statistical Technique:
In the present study, an attempt is made to find out the relationship between resilience and quality of life of caregivers of Dementia patients, following a correlational research design. To assess the effect of resilience on quality of life, Pearson rank difference method was used.

RESULTS

In the present study, data were collected from 50 caregivers (N=50) from KITES Dementia Centre of Bangalore. After data collection, necessary statistical calculations were done for verification of the hypothesis.

Descriptive Statistics of data

Table 1: Demographic details of caretakers of Dementia

	N	50	%
Gender	Male	20	40%
	Female	30	60%
Educational Qualification	High School	10	20%
	Intermediate	20	40%
	Graduate	5	10%
	Postgraduate	15	30%
Residential Status	Residential	20	40%
	Day care	20	40%
	Family	10	20%
Marital Status	Unmarried	15	30%
	Married	30	60%
	Widow	5	10%

Table 1 shows the ratio of gender, educational qualification, residential status and marital status of the Dementia caregivers.

Table 2: Total sum, Mean and Standard Deviation of the scores of QOL domains

	Domain 1 (Physical Health)	**Domain 2 (Psychological Health)**	**Domain 3 (Social Relationship)**	**Domain 4 (Environment)**
Total	3527	3520	3719	3600
Mean	70.54	70.4	74.38	72
St. Dev.	12.2993	15.7894	22.5704	18.1609

Table 2 shows the mean and standard deviation of of the Dementia caregivers.

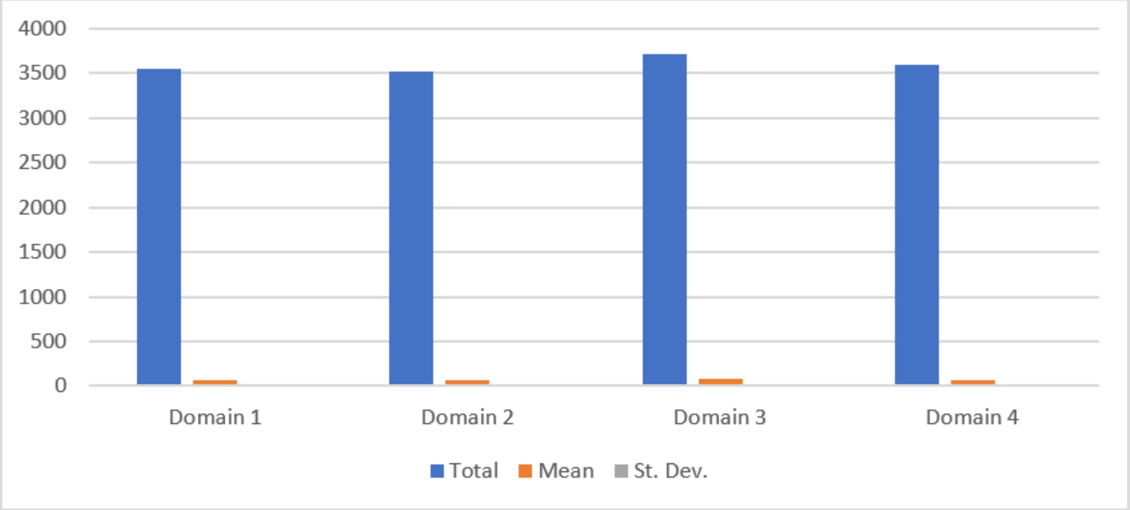

Fig 1: Represents the total sum, mean and standard deviation of all the four domains of Quality of Life

Table 3: Descriptive data of Quality of Life and Resilience

QOL		Resilience
Domain 1 (Physical Health)	3527	1515
Domain 2 (Psychological Health)	3520	1515
Domain 3 (Social Relationship)	3719	1515
Domain 4 (Environment)	3600	1515

DISCUSSION

The purpose of this study was to find the correlation between resilience and QOL of caregivers of dementia.
Analysis of the obtained results support the hypothesis –

Table 4: Correlation between Physical Health and Resilience

Variables	Physical Health	Resilience
Total Sum	3527	1515
Correlation	**0.200746536**	

Table 4 shows the correlation value of 0.200746536, which ranges between 0-1, indicating a positive correlation between Physical Health and Resilience.

The findings show a correlation coefficient of 0.20 between physical health and resilience, suggesting a moderate positive association. Physical health—comprising mobility, energy, pain management, sleep, and the ability to perform daily tasks—appears to benefit from higher resilience levels. Caregivers who are more resilient likely manage physical demands more effectively, sustaining their health despite the demands of caregiving.

Table 5: Correlation between Psychological Health and Resilience

Variables	Psychological	Resilience
Total Sum	3520	1515
Correlation	**0.307656396**	

Table 5 shows the correlation value of 0.307656396, which ranges between 0-1, indicating a positive correlation between Psychological Health and Resilience.

A correlation value of 0.31 was recorded between psychological well-being and resilience, reflecting a stronger connection. Psychological health encompasses aspects such as emotional regulation, bodily image and appearance, cognitive processes (thinking, learning, memory and concentration), self-esteem, and spiritual beliefs. Caregivers with greater resilience might experience fewer negative emotions and a stronger capacity to maintain a positive mental state under stress, enhancing their psychological stability.

Table 6: Correlation between Social Relationship and Resilience

Variables	**Social Relationship**	**Resilience**
Total Sum	3719	1515
Correlation	**0.43289843**	

Table 6 shows the correlation value of 0.43289843, which ranges between 0-1, indicating a positive correlation between Social Relationship and Resilience

The correlation between resilience and social relationships stood at 0.43, pointing to a meaningful association. Social well-being—defined by the quality of personal relationships, emotional support, and intimacy—is likely preserved or even enhanced when caregivers possess robust coping mechanisms. This emphasizes the importance of community and social connectivity in maintaining caregivers' morale.

Table 7: Correlation between Environment and Resilience

Variables	**Environment**	**Resilience**
Total Sum	3600	1515
Correlation	**0.590430485**	

Table 7 shows the correlation value of 0.590430485, which ranges between 0-1, indicating a positive correlation between Environment and Resilience.

With the highest correlation of 0.59, the relationship between environmental quality and resilience is particularly noteworthy. This includes home environment, participation in recreation / leisure activities, physical environment (pollution / noise / traffic / climate), financial security, access to healthcare, safety, transportation, and educational or recreational opportunities. The findings suggest that resilient individuals are more adept at navigating and adapting to their environments, even in challenging caregiving roles.

CONCLUSION

This study aimed to assess the relationship between resilience and Quality of Life (QOL) of caregivers of Dementia. Each domain of Quality of Life, i.e. physical health, psychological health, social relationship and environment had different scores in relation to the scores of resilience. But overall, each domain assessed by the WHOQOL - BREF showed a positive relationship with resilience. These outcomes underline the multidimensional impact of resilience across various aspects of caregivers' lives. Individuals with a higher capacity to adapt and bounce back from adversity can sustain better physical and mental health. Also, they are able to maintain stronger relationships and navigate their environment more effectively.

So, it can be concluded that **"There is a positive correlation between Resilience and Quality of Life of the caretakers of Dementia".** Thus the **'hypothesis is accepted'.**

Implications

There are certain strategies that can lessen the burden of caregivers-

- As a caregiver, first of all one should be patient and educate themselves about the disease.
- One should talk about feelings in an open, constructive manner during informal conversations.
- To make oneself adjusted and consistent with caregiving process, one should never go for isolation. Instead, one must meet everyone regularly to boost their social life.
- One should consider counselling for themselves.
- Ask other family members to help and ask them to share the responsibilities.
- One should engage the person with dementia in conversation even when his/her ability to participate becomes limited.
- One should engage family members in activities such as a walk or other indoor games.

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Conflict of Interest

The author(s) declared no conflict of interest.

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