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Personal Growth and Psychological Well-Being of Dementia Caregivers

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Abstract

Dementia is a neurological condition that impacts mental processes such as reasoning or the ability to think. Caregiving for such individuals is a strenuous process that leads to both positive and negative changes in the caregiver's life. Thus, the purpose of this research was to investigate the correlation between the personal growth and psychological well-being of caregivers. With the aid of pre-existing literature, two hypotheses were formed: (i) there is a positive correlation between personal growth and psychological well-being of a dementia caregiver, (ii) having significant social support positively correlates with improved personal growth and psychological well-being of the caregiver. Using convenient sampling, a sample of 102 participants from Pakistan above the age of 18 was selected, and two scales were administered to the participants. The first scale was 'the role of caregivers' skills in caregivers' syndrome and caregivers' burden', which assessed the extent of changes in psychological well-being and personal growth that the severity of dementia within patients had on the patient's caregiver. The second was the 'Caregiver Appraisal Scale' which measured the caregiver's burden, satisfaction, mastery, demands and the impact experienced by them. No deception was involved, and confidentiality of participants was maintained. Their participation was completely voluntary and their rights as research participants were protected at all times. Results were analyzed using the correlation coefficient. No significant correlation was found for either of the hypotheses. This research aimed to create awareness regarding the significance of being a caregiver and what it entails.

Key Words: Caregiver, Dementia, Personal Growth, Psychological Well-being, Support

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Introduction

The occurrence of diseases on a global scale continues to escalate, with an apparently boundless array of ailments affecting numerous individuals annually. Within this assortment of ailments, neurological diseases present a significant obstacle, with dementia serving as a prominent illustration. Dementia is an incapacitating malady that arises from brain injury, often resulting from trauma or infection, leading to a spectrum of cognitive impairments encompassing deficits in reasoning, alterations in personality, and disorders of memory (CDC, 2019). Alzheimer's disease, a subtype of dementia, stands as the most widespread manifestation, distinguished by the destruction of the patient's memory region, compromised cognitive capabilities, and a loss of autonomy in everyday tasks. Irrespective of the specific form of dementia, patients become heavily dependent on caregivers to address their psychological, physical, financial, and social requirements. In numerous societies, such as Pakistan, caregiving responsibilities typically fall upon family members or loved ones, as the act of placing the patient in hospice care is regarded as insensitive and disrespectful. The function of a caregiver entails a complex and indispensable procedure that necessitates immense vigor, resolve, concentration, and resilience. The caregiver's unwavering commitment to this role holds utmost significance for the patient's welfare, as it encompasses a myriad of obligations such as routine examinations, transportation, financial assistance, medication administration, and ensuring the patient's security by refraining from leaving them unaccompanied (Jpanayotov, 2020). Nevertheless, the caregiving process profoundly affects the caregiver themselves, fostering personal development and inducing psychological transformations. The primary objective of this scholarly article is to examine the consequences of providing care for dementia patients on the caregiver's individual growth and psychological well-being. Despite the extensive examination of patients and their medical conditions, caregivers frequently remain insufficiently researched, and the profound emotional and psychological repercussions they encounter while witnessing their loved ones' agony are frequently disregarded. In Pakistani society, the act of taking care of an elderly or sick family member is not only anticipated but also perceived as a commendable and virtuous deed. This viewpoint often results in the disregard and repression of the emotional and experiential aspects of caregivers. The duration of the caregiving process allows for personal transformation and advancement. Some caregivers emerge from this process with favorable personal growth, while others encounter unfavorable experiences that reshape their outlook on life. The caregiving process is unquestionably arduous and demanding, prompting us to investigate both the positive and negative consequences it has on caregivers.

Method

Research Design

The research conducted is correlational in nature, as it is a non-experimental study aimed at investigating the potential relationship between two variables. A cross-sectional design was used, to collect data at a single point in time through the survey method. This approach was chosen to avoid manipulating variables and enable the examination of multiple variables simultaneously.

Participants and Sampling

The sample consisted of 102 participants, both male and female, all above the age of 18 years, recruited through the process of convenience sampling. The participants were the family members of the dementia patient(s) and they were either currently taking care of or have looked after in the past. All the participants belonged to Pakistan, with most of them being from Lahore. The exclusion criteria included anyone not belonging from or residing in Pakistan, being below the age of 18, and not a dementia caregiver.

To recruit the participants, the use of social media was employed, specifically the applications of Facebook, Whatsapp, and Instagram. The questionnaire was sent in the form of a google forms document; the link was posted in multiple caregiver support groups that were available on these applications.

Instruments

The instrument administered to the participants had 3 sections preceded by an information sheet and informed consent form, and following instruments were used. To measure the variable social support, the demographics were used which made up the third section. The participants were to report if they were a primary caregiver (to see whether they had help or not), how many members they had in their family, and the family system they resided in.

Informal Dementia Caregivers in Pakistan Scale

The first section had the first tool, which was used to measure the variable personal growth, called the ‘Informal Dementia caregivers in Pakistan: The role of caregivers' skills in caregivers' syndrome and caregivers' burden’, is the scale developed by Dr. Christian Beyle, modified by Dr. Saima Eman in the context of Pakistan (Aftab et al., 2021). The scale is currently under review. The scale consists of 87-items rated on a 5-point Likert scale, with 1 representing never to 5 representing always, will assess the extent of impact that the severity of dementia within patients has on the burden of the patient’s caregiver by assessing the skills regarding the well-being of the caregiver (alpha value: 0.84, mean: 3.01, and standard deviation: 0.71), skills related to self-efficacy of caring of the caregiver (alpha value: 0.86, mean: 3.45, and standard deviation: 0.60), instrumental skills (alpha value: 0.81, mean: 4.14, and standard deviation: 0.59), knowledge related skills (alpha value: 0.80, mean: 4.53, and standard deviation: 0.48). Each subscale has scores ranging from 10 to 50 points, with lower scores indicating lower compliance with desirable behaviors or attitudes for a caregiver. A cumulative score of the four subscales can be obtained between 40 and 200 points.

Neuropsychiatric Inventory (NPI) and the Zarit Burden Scale Inventory

The Neuropsychiatric Inventory, NPI measures the presence and severity of neuropsychiatric symptoms in dementia patients along with informant distress (Musa et al., 2017). It has good content reliability and validity as well and is suitable to use for psychological assessment. The scores vary from 0-144 with a high score showing the severity of symptoms in dementia patients according to the caregiver (Lai, 2014). The Zarit Burden Scale Inventory measures caregiving burden among caregivers. It has an alpha value of 0.91 and research conducted showed that it is a reliable and valid scale. The scores are between 0-88 and a high value indicates greater burden which causes stress (Al-Rawashdeh et al., 2016).

Caregiving Appraisal Scale, CAS (Lawton et al., 2000)

To measure the variable of psychological well-being, the Caregiving Appraisal Scale, CAS (Lawton et al., 2000) was used in the second section of the questionnaire. This is a 37-item instrument, scored on a 5-point Likert scale, regarding the point to which a statement is true (1= disagree a lot to 5= agree a lot) and to the extent to which the statement is agreeable by the caregiver (1= never to 5= nearly always). The items of this scale measure the caregiver’s burden, satisfaction, mastery, demands and the impact experienced by them. Questions such as “How often do you feel isolated and alone as a result of caring for your elder?” will help the researcher determine the impact that caregiving has had on the psychological wellness of the caregiver. The Cronbach alpha value for this scale is 0.68, which suggests it is reliable.

Statistical Analyses

SPSS version 25 was used to run all the tests in this study. First the Cronbach alpha value was calculated for both the scales after which the descriptive statistics were obtained. A normality test was also run which showed that the distribution was not normal. Spearman’s rho, a non-parametric test was then used to find out the correlation between the two scores of the scales. The point Biserial correlation coefficient was also used to find out the correlation of social support with personal growth and psychological well-being.

Ethical Considerations

This research was conducted in accordance with the APA guidelines, after getting approval from the IRB. All the participants recruited were over the age of 18. This was made sure prior to administering the measurement tools. The informed consent form, detailed out the purpose of the research, which was to get information regarding the caregiver’s psychological well-being and personal growth. They were requested to take part in the study and no form of coercion was used to influence the participant’s decisions. They were provided with the contact details of the principal researcher in case they felt the need to seek any help at any point of time. They were also informed about their rights as a research participant, including the right that they can withdraw from the study at any time they wish to, without providing an explanation. Their confidentiality was maintained at all times and the data collected was only accessible to the researchers involved.

No personal identifiers were taken such as their names, email addresses or phone numbers to avoid any conflicts of interest and maintain anonymity. Although the research did not intend to cause any mental harm to the participants, they were informed that if they experienced any sort of mental distress after filling out the questionnaire, they can contact the principal researcher and request for psychological help, which was provided to them through the licensed clinical psychologists who volunteered for this purpose. There was no deception involved hence, no debriefing will be needed now that the study has been completed. However, if the participants wish to know about the results of the study, they will be briefed.

Results

A sample of 102 people was collected from all over Pakistan, with majority of the participants belonging to the city of Lahore, Punjab. Out of the sample collected, 77.3% of the participants were women, whereas the rest of the 26.7% participants were men. Out of these 102 individuals, 55.4% were employed, and the remaining 44.6% were unemployed. 60.4% of the sample lived in a nuclear family system, whereas the rest of the 39.6% lived in a joint family system. 66.7% of participants were primary caregivers for patients with dementia. The age of these participants ranged from 18 to 68 years (*M*=34.48, *SD*=11.84).

Table 1

Tests of Normality (N=102)

	Kolmogorov-Smirnov		**Shapiro-Wilk**	
	Statistic	***p***	**Statistic**	***p***
TotalIDCP	.06	.002	.97	.000
TotalCAS	.06	.006	.98	.001

*Lilliefors Significance Correction

The test of normality for both the scales was also conducted by employing the use of the Kolmogorov-Smirnov and Shapiro-Wilk tests. Since the significance value for both the scales was less than the p-value of 0.05, it indicated that the distribution is not normal, and a non-parametric test was to be used for inferential statistics (Table 1).

Table 2

Correlation of IDCP Scores with CAS Scores (N=102)

	Correlation Coefficient	***p***
Personal Growth and Psychological Well-being	.11	.26

$p<0.05$

To find out the correlation between the two scales, IDCP (Informal Dementia Caregivers in Pakistan) and CAS (Caregiver Appraisal Scale), which represent personal growth and psychological well-being respectively, the statistical test Spearman's rho was used. The results show that the variables personal growth and psychological well-being have a very weak positive correlation, *r* (102) = 0.11, *p* = .26. The *p*-value is also above the alpha value of 0.05, which suggests that the results are not statistically significant, as seen in Table 2.

Table 3

Correlation of Demographical Aspects of Social Support with Personal Growth and Psychological Well-being (N= 102)

Variables	Correlation Coefficient	p
Family System and Personal Growth	-0.08	0.37
Primary Caregiver and Personal Growth	-0.03	0.73
No. of Family Members and Personal Growth	-0.14	0.14
Family System and Psychological Well-being	-0.01	0.91
Primary Caregiver and Psychological Well being	-0.12	0.19
No. of Family Members and Psychological Well-being	-0.11	0.23

p<.05

To find out if social support correlated with personal growth and psychological well-being of the caregiver, three demographical aspects were correlated with the scores of the scales: family system, status of caregiver (primary or not), and members of the family. The Biserial correlation coefficient was used for each of the three aspects. The composition of the variable social supports depicts that from the data collected, there is no significant relationship of social support with improved personal growth and psychological well-being of the caregiver. Since the correlation coefficients are less than 0.00 and all the *p*-values more than the alpha value of 0.05, the results are statistically insignificant as shown in Table 3.

Discussion

The primary objective of this research was to examine the correlation between personal growth and psychological well-being in dementia caregivers. Dementia caregivers fulfill various roles, including caregiver, sibling, child, grandchild, spouse, and friend, which contribute to their elevated stress levels (Campbell et al., 2008). The study's hypotheses were based on existing literature primarily from Western contexts. The first hypothesis proposed a positive association between personal growth and psychological well-being in dementia caregivers. However, the findings revealed no significant correlation between these variables, contradicting previous research that demonstrated a positive link between psychological well-being and personal growth and negative with psychological distress (Ayub & Iqbal, 2012). It was discovered that caregivers who were content with their caregiving abilities were more inclined to experience personal growth (Lloyd et al., 2016). The progressive nature and severity of dementia had a detrimental impact on the well-being and personal growth of caregivers (Frias et al., 2020), and psychological well-being emerged as a strong predictor of personal growth (Sharma & Rani, 2014). Emotional distress, feelings of burden, and declining physical health in caregivers were associated with factors related to the behavior and cognitive decline of dementia patients (Kim et al., 2021).

The second hypothesis proposed that significant social support was positively associated with enhanced personal growth and psychological well-being in caregivers. However, the results obtained by running the Biserial correlation coefficient, disapprove of the hypothesis; there is no relationship between social support and the two variables. The personal growth and psychological well-being of dementia caregivers were not affected by the type of family system, primary caregiving status, or the number of family members. This finding contradicted previous research that suggested social support positively influenced caregivers' psychological well-being by providing them with an opportunity to confide in loved ones for emotional relief (Ruisoto et al., 2020). Notably, family support was found to have a particularly positive impact on psychological wellness (Thomas, 2009). Established models, such as the Poulshock and Deimling model and the Pearlin and Colleagues model, indicated that social support played a crucial role in caregiver well-being (Pearlin et al., 1990; Poulshock & Deimling, 1984). Low social support was associated with a lower quality of life and decreased emotional well-being, while high social support reduced the likelihood of experiencing depressive symptoms (Frias et al., 2020; Sun et al., 2019). According to the stress-buffering model, social support acted as a protective factor against the negative effects of stress on mental well-being (Rodriguez et al., 2019). Caregiver stress was found to be positively correlated with informal social support and had a stress-alleviating effect, especially when it came from family or friends (Choo et al., 2003). Similarly, high social support was linked to lower depressive symptoms and improved psychological well-being (Zhong et al., 2020).

This research had several limitations; reliance on non-local literature, a small sample size (102 participants) reducing the generalizability, accessibility issues due to the online survey being in English, and constraints on caregivers' time. Access to dementia patients and their caregivers was also challenging, as many cases in Pakistan go undiagnosed. To improve future research, it is recommended to adapt measurement scales to the Pakistani context, translate them into Urdu, and administer surveys in person to provide assistance to participants. Developing shorter, more focused scales can enhance data reliability and validity.

The implications of this research can be fruitful to the field of research and to the caregivers of dementia. While the results of this study do not support the hypotheses and the pre-existing literature, they do open the conversation regarding the mental well-being and personal growth of individuals caregiving for the people with dementia. In Pakistan, there is an obvious lack of awareness among the general public about dementia and what its implications are, not only to the patient themselves, but to the people caretaking for them as well. Most people do not bother getting symptoms of dementia checked, attributing it to old-age and refusing treatment for it. This proves to be detrimental to both the caregiver and the patient with dementia (Balouch et al., 2021). Since dementia can bring about physical symptoms along with psychological ones, the caregiver often finds themselves distressed and unaware as to what to do to manage the patient (Jpanayotov, 2020). Moreover, most people are unable to get the dementia patients proper treatment due to a lack of finances. Treatment for dementia is expensive and, in a country, where inflation is through the roof, the residents of Pakistan find it difficult to administer the proper treatment. This also serves as the reason why most caregivers in Pakistan are family members themselves, and not professional nurses.

Another reason why people are hesitant in admitting the patients into hospitals or facilities is the cultural tradition of living with your parents and grandparents. People in the West move out of their parent's homes at the age of 18, and admit their parents into hospice or nursing homes but this concept is unknown to the Pakistani population. It is considered a huge disrespect if the child admits their parent into a facility which is helpful for them. Furthermore, the conditions of the nursing homes in Pakistan are so poor that it is not considered appropriate by most people.

The dementia patients living in old-age homes are in a horrible condition, which further discourages the people for sending their loved ones there (Balouch, et al., 2021). Hence, this study can help in raising the question about the awareness of the dementia patients and their caregivers. Moreover, this study can also prove to be basis for further research on dementia patients and their well-being, because the caregivers not only answer questions pertaining to themselves, but to the patients as well. The caregiver knows the patient inside and out, with minute details that can often go overlooked by others. This research can also contribute in the formation of research in the future upon dementia caregivers; further research can be conducted to assess the state of dementia caregivers in Pakistan and provide solutions to their problems so that future caregivers have awareness and can take steps to protect their psychological well-being.

Dementia is a neurological disease that impacts not only the patient but the caregiver as well. It was interesting to observe how culture influenced the results of this research as there is an ample amount of awareness regarding dementia caregiving in the West, from where much of the literature is collected. Further research needs to be carried out to corroborate the results of this study or to reject them by using a larger sample size and more literature from Pakistan. This is crucial for the prosperity of future caregivers so that they may be educated about the lives they are about to live, and that they can make things better for themselves and the person with dementia. With the right tools and resources, the implications of this study can prove to be quite fruitful to the field of neurology and psychology.

Contribution of Authors

Aisha Ateeq: Conceptualization, Methodology, Writing - Reviewing & Editing, Supervision

Zainab Attique: Methodology, Investigation, Data Curation, Formal Analysis, Writing – Original Draft

Noor ul Huda: Methodology, Writing - Reviewing & Editing

Conflict of Interest

There is no conflict of interest declared by the authors.

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Data Availability Statement

The datasets of the current study are not available publicly due to ethical reasons but are available from the corresponding author [N.U.H.] upon the reasonable request.

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