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ORIGINAL ARTICLE

ASSESSMENT OF CARE-ARRANGEMENT OF PEOPLE WITH DEMENTIA IN KARACHI BY 10/66 PROTOCOL

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ABSTRACT

Background and objective:

Pakistan is a low middle-income country (LMIC) in South Asia with a rising aging population. This study aimed to understand care-arrangement and resources of people with dementia (PWD) in Karachi, Pakistan.

Methods:
This cross-sectional mixed-method (qualitative and quantitative) study was carried out using 10/66 protocol for dementia patients. Data collection for the study was done from September 2016 till August 2017.This assessed characteristics of patients and caregivers, the economic impact of caregiving, and resources available to care for people with dementia (PWD).

Results:
One-hundred-nineteen PWD and their caregivers were included in the study. The average gross national product (GNP) per PWD per capita was $140. Majority of the caregivers were married women, family members, and full-time housewives. Three quarters of the caregivers were patients' children or spouse residing with the patient, in a 2-to-3-bedroom house. Majority of the time of the caregivers' day was spent with the PWD.

Conclusion:
In Pakistan majority of PWD are dependent on female family members for care. Caregiver roles are full-time responsibilities with little to no burden shared by others. There is low monthly GNP per PWD with a high cost of medical needs of PWD.

Keywords: Dementia, care, Pakistan, cost of illness, 10/66

INTRODUCTION

The 10/66 dementia research group (DRG) is focused on promoting dementia research in low- and middle-income countries (LMICs) and remarkable research has been done by the group in the last two decades. However, Pakistan was not a research site for the group studies.[1] The first dementia study using 10/66 DRG protocol was completed in Pakistan in 2017 by our group which included translation and validation of dementia diagnostic battery as well as of other 10/66 tools including those for care-arrangement and caregiver burden.[2-4] Some studies reporting caregiver characteristics, burden, and distress have been done in Pakistan however care-arrangement of people with dementia (PWD) using 10/66 protocol has not been studied in Pakistan before.[2,4]

Pakistan is a low middle-income country in Southeast Asia with a population of 220 million in 2020 according to the World Bank data. It is currently the fifth most populous country of the world and is expected to become the third most populous country by 2050.[5] About 97 % of the country's population is Muslim. Peoples' religious beliefs and culture affect their lifestyle and family dynamics greatly. Families often live together in multi-generational setting however this trend is changing in urban areas due to immigration of younger members to western countries. This arrangement and resources available to PWD are important to study for clinicians and policy makers in order to improve and organize care. This study aimed to understand care-arrangement and resources of people with dementia (PWD) in Karachi, Pakistan.

METHODS

This was a cross-sectional mixed-method (qualitative and quantitative) study that was carried in Karachi for one year from September 2016 to August 2017. One-hundred-nineteen patients with mild and moderate dementia were recruited from the urban community in the Aga Khan University Hospital Outpatient Neuropsychiatry clinic and subspecialty clinics, and from the nursing homes in the community. The 10/66 protocol for care assessment was translated and back translated by two different qualified language experts fluent in Urdu and English and was tested for acceptability and conceptual validity by a team of psychologists, nurses and community elderly with intact cognition and pilot tested in 10 caregivers.

This study is a part of a 10/66 study that was done to translate and validate 10/66 dementia diagnostic battery in Urdu in Karachi, Pakistan. The data for this study is extracted from the original study data. The original study sample size was calculated by taking the first 10/66 pilot study as a reference, in which 200 people, equally divided into participants with normal cognition and dementia, were studied by using estimation of a proportion of 92%—midway between the sensitivity of 94% and specificity of 90% to achieve a maximal error of ± 5. One-hundred-nineteen patients with mild and moderate dementia were recruited. Patients were diagnosed by clinicians using DSM-IV TR criteria and severity was rated using Clinical Dementia Rating scale (CDR).[6] Patients with severe dementia, intellectual disability, those who were not able to understand Urdu, and those without a caregiver were excluded. A preliminary, open-ended interview was conducted to determine that the caregiver being interviewed was the primary caregiver. Data was entered twice to avoid errors. All procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by the institutional review board (IRB) of Aga Khan University (3868-Psy-REC 15).

Written informed consent was taken from PWD and their caregivers after explaining the study to them in detail and a copy of consent form and information sheet (both in English and Urdu) were provided. Family members/caregivers provided consent on behalf of PWD if they were not able to understand completely, although this was not the case in majority of the cases as severe dementia was an exclusion criterion for this study. No direct compensation was provided to the participants for taking part in the study however transportation cost of Pakistani rupee (PKR) 500 was provided to those who travelled to AKU hospital for the study. Patients from the community were interviewed in their homes or community centers. The study was funded by the the Aga Khan University, University Research Council (URC) grant. Pilot testing sample included 10 people and data collection for the study was done from September 2016 until August 2017.

Besides collecting demographic information, two instruments that were used are reported here: i) Client Service Receipt Inventory (CSRI) and ii) Time spent in week before the interview.[7] CSRI consists of six parts. The first part consisted of information about the PWD including monthly income. The second part consisted of information about the household such as identification of head of the household, accommodation, and inhabitants. The third part consisted of basic information about the caregiver. The fourth part was about caregiver's employment and income, the fifth part was about informal caregivers, and the sixth part was about the use of health care services. Economic impact was assessed using the CSRI. The second instrument asked about the number of contact hours caregivers spent with the PWD in the last two days before the interview regardless of the fact that caregiving was provided or not.

Monthly health care cost, averaged over three months, was calculated by adding the amounts spent as payment for services, travel to access services, and medicines. Data was entered using EPIDATA and was re-entered to avoid errors. Statistical Package for Social Sciences (version 21) was used to analyze the data. Descriptive statistics were used to analyze demographic data.

RESULTS

The number of PWD in the study was 119. Table 1 shows the characteristics of people with dementia and comorbidities. Mean age of PWD in the community was 71.8 years with an almost equal distribution of males and females. About half of the population reported one or more comorbid conditions with dementia. The most common medical conditions

reported were hypertension and diabetes.

Table 1: Characteristics and comorbidities of people with dementia

Patient Demographics	
Mean Age	71.8 years
Gender	
Male	58 (49%)
Female	61 (51%)
Marital Status	
Married	68 (57%)
Divorced/ Separated	1 (0.001%)
Widowed	46 (39%)
Never married	3 (0.025%)
Missing	1
Level of Education	
Low (≤ 8 grades)	73 (61%)
High (>8 grades)	46 (39%)
Comorbid conditions	
Yes	50%
No	50%
Comorbid Diseases	
Hypertension	38 (32%)
Diabetes	27 (22.7%)
Stroke / TIA	4 (3.4%)
Ischemic Heart Disease	7 (6%)
Thyroid Disease	4 (3.4%)
Benign Prostatic Hyperplasia	3 (2.5%)
Asthma	2 (1.7%)
Parkinson’s Disease	3 (2.5%)
Impaired Hearing	3 (2.5%)
Difficulty Ambulating	1 (1.2%)
Depression	6 (5%)
Alcohol Abuse	1 (1.2%)

Table 2 shows characteristics of caregivers of PWD.

Table 2: Caregiver characteristics

Caregiver Characteristics	
Age groups	
11-20 years	1
21-30	10 (8%)
31-40	34 (29%)
41-50	21 (18%)
51-60	17 (14%)
61-70	22 (19%)
71-80	11 (9%)
81-90	1
Not specified	1
Mean Age of Caregiver	43 years
Gender	
Male	41 (35.5%)
Female	78 (65.5%)
Relationship to the Patient	
Children	54 (46%)
Daughter	28 (24%)
Son	26 (22%)
Daughter-in-law	15 (12.6%)
Spouse	37 (31%)
Wife	26 (22%)
Husband	11 (9%)
Siblings	2 (1.7%)
Sister-in-law	1 (0.8%)
Friends/ neighbors	4 (3%)
Paid help	3 (2.5%)
Caregiver Marital Status	
Married	99 (83%)
Single	17 (14%)

Separated/ Divorced	1
Widowed	2
Caregiver's education	
Minimal or no education	15 (13%)
Primary education	18 (15%)
High school education	22 (19%)
College or further studies	64 (54%)
Head of household	
Patient	37 (31%) 7 females 30 males
Other:	81 (68%)
Caregiver's son/daughter	55 (46%)
Caregiver's spouse	19 (16%)
Son/Daughter -in-law	4 (3%)
Sibling	1
Friend	1
Other relative	1

Table 3 shows care-arrangement for PWD. Most of the PWD owned the house they occupied, with majority having a 2–3-bedroom house and had other family members in the house. One third of the caregivers were employed and most of the caregivers did not have paid or unpaid help available to care for the patient.

Table 3: Care-arrangement of people with dementia

Care-arrangement	
Accommodation	
Owner occupied	91 (76.5%)
Rented Missing	25 (21%) 3
Rent in PKR/month	
Less than 5000	4 (16%)
5000-15000	16 (64%)
15000-30000	4 (16%)
30000-40000	1 (4%)
Number of bedrooms in the house	
1	6 (5%)
2	47 (40%)
3	39 (32%)
4	18 (15%)
More than 5	7 (5.9%)
Median Household size	4 Interquartile range 3-5
Adults sharing the house	
Alone	9 (7.6%)
2-4	80 (67%)
5-6	20 (17%)
7-10	10 (8%)
Children under 16 years of age in the house	
None	56 (47%)
1-2	47 (40%)
3-4	10 (8%)

5-6	6 (5%)
Caregiver living with patient	101 (85%)
Caregiver Employment Status	
Full time housewives/husbands	63 (53%) 54 females 9 males
Full time employment	21 (17.6%) 9 females 12 males
Part time employment	16 (13%) 8 females 8 males
Retired	11 (9%) 3 females 8 males
Unemployed	6 (5%) 4 females 2 males
Student	2 (1.7%) 0 females 2 males
Skill subset of Employed caregivers	
Professionals (e.g. health teaching, legal, financial)	14
Associate professionals (e.g. technical, nursing, artist)	5
Managers/administrators	4
Skilled labor (e.g. builder, electrician)	1
Semi-skilled labors (e.g. helper)	5
Unskilled labor	2
Effect of caregiving responsibilities on work	
Had to give up	3 (8%)

Had to cut down	4 (11%)
Caregiver Allowance	
Income from employment	35 (30%)
Other (such as business, family, saving certificates)	73 (61%)
Income from rented land or assets	5 (4%)
Occupational pension	4
Government pension	2
Caregiver’s benefit	0
Income per month	
5000-15000	24 (19%)
>15,000-20,000	21 (17.6%)
>20,000-40,000	14 (12%)
>40,000-50,000	12 (10%)
>50,000-100,000	14 (12%)
>100,000	2 (1.7%)
Help in caring for patient	
None	113 (95%)
Friends or relatives	6 (5%)
Hours of help per week	
3-4	1
5-6	5
Paid help during the day	
None	116 (98%)
Occasional	2
Constant	1
Paid help at night	1

Table 4 shows economic impact of caring for PWD.

Table 4: Economic impact of caring for people with dementia in Pakistan

Monthly income per patient per month (per capita GNP/month)	PKR 22075 $140
Effect of Caregiving on work	
Principal caregiver had given up work due to caregiving	2.5%
Principal caregiver had to cut back on work	3%
Additional caregiver has given up due to caregiving	0%
Additional caregiver had to cut back on work	5%
Paid daytime carer	2%
Use of health services by patients with dementia in the three months prior to interview	
Government doctor	
Patient saw doctor in last 3 months	1 (0.8%)
Average time spent travelling	15-20 minutes
Average time spent with doctor	10 minutes
Average money spent on traveling	150 PKR
Average money spent on consultation	1000 PKR
Average visits in the last 3 months	2-3
Private doctor	
Patient saw doctor in last 3 months	15 (12.6%)
Average time spent travelling	30 minutes
Average time spent with doctor	20 minutes
Average money spent on traveling	203 PKR
Average money spent on consultation	1313 PKR
Average visits in the last 3 months	2-3
Hospital admissions	
In the last 3 months	1 (0.8%)
Traditional healer consulted	2 (1.7%)
No services	80%

Taking medications in the last 3 months	97 (82%)
Average cost of medications per month per person	9945 PKR (63 USD)
Average monthly healthcare costs of patients with dementia	8306 PKR 52 USD
Comparative index of healthcare costs (as % of per capita GNP)	
0% (no costs)	22 (18%)
1-10%	30 (25%)
>10%	67 (57%)
Use of healthcare by patients with normal cognition (controls)	
Visited a government doctor in last 3 months	0
Visited a private doctor in last 3 months	16
Average cost of travelling	359 PKR
Average cost of consultation	2597 PKR
Hospital admissions	1
Traditional healer consulted	3
Medication use	88 (68%)
Average cost of medications per month per person	11803 PKR
Caregiver's time spent with the patient in the 2 days prior to interview	
Morning hours	73%
Afternoon	72%
Evening	83%
Night	84%

DISCUSSION

This is the first study that assesses care-arrangement for people with dementia in Pakistan using 10/66 protocol. Mean age of people with dementia in the community reported in this study is older than the mean age reported in the hospital-based dementia population in a prior study (66 years).[8] This also points towards low awareness and high treatment gap in the community as 90- 95 % of the people were undiagnosed. A significant number of these hospital-based cases were of Lewy body dementia and thus had more behavioral problems than seen in Alzheimers dementia and could be the reason for early hospital presentation. Memory loss or forgetfulness is also considered part of normal aging by many in Pakistani culture and is an important factor in delaying diagnosis.

There was an almost equal distribution of males and females with dementia in the community in this study. Although some studies in the literature suggest increased prevalence of dementia in women, other studies have suggested equal incidence of dementia in men and women up to high age.[9] There was a 60:40 ratio of married and widowed people among those with dementia in this study. The world literature shows increased predilection for dementia among single, divorced, and widowed people as compared to married or co habiting couples.[10] In Pakistani culture, especially in older population marriage is considered very important, number of single people is probably very low, and divorces are rare. As expected, there was only one divorced individual with dementia in our sample. There was a 60:40 ratio of people with low education and high education in our sample. World literature has reported association of lower education with increased risk of dementia especially in developed regions.[11]

In our study about one third of dementia population reported hypertension as a co-morbid condition and less than a quarter reported diabetes. Association of midlife hypertension and diabetes with increased risk of AD has been reported in the literature and these are identified as having higher population attributable risk in LMICs than the world estimates, and thus are important modifiable risk factors in the developing world.[12,13] It is interesting to note that in our study only 5 % of the people with dementia reported depression, however when the same cohort was tested for depression by using standardized scales in 10/66 protocol (Geriatric mental state exam) 50 % were positive for depression. This points towards people possibly being less aware of depression or possible stigma related with reporting depression which increases the rate of undiagnosed and untreated depression, which is identified as a modifiable risk factor for dementia.[14] Around 2.5 % of the people in our study reported hearing loss. We speculate that these figures may be lower than the actual figure as hearing loss is identified as a sign of old age by many and also has stigma associated with it due to which people may have under-reported it. Hearing loss has been associated with higher risk of dementia in older adults.[15]

Among the caregivers, two trends were observed. There was a younger group between 31-50 years of age who were mostly children of patients with dementia with an almost equal distribution of sons and daughters, and an older group between 51-70 years of age who were mostly spouses of patients with a predilection for females/wives. Overall, two thirds of all caregivers were females. In the 10/66 cross cultural study for care assessment, 75 % of caregivers in India were reported to be females similar to our figures.[16] In our study the most frequent caregivers were children of patients with an almost equal distribution of sons and daughters, followed by spouses, majority being females/wives. The Indian cohort in the 10/66 study showed similar patterns however daughters in law were more frequent care providers than in our population.[16] Our study was conducted in an urban community where nuclear family arrangement also exists; we speculate that the same trend of daughters in law being more common caregivers also exists in rural parts of Pakistan where extended family arrangement is the most common style of living. The patriarchal norms of the society expect females to be primary caregivers for unwell family members. In our study most of the caregivers were married. About two thirds of caregivers had 10 or more years of education and about one-quarter had primary or less education. About two-thirds of the patients were not reported to be heads of families majority being females, and one-third were reported to be heads of household majority being males. In most instances primary caregiver was reported to be the head of household. In Indian cohort about half patients were reported to be heads of household.[16] This suggests change in family dynamics with dementia diagnosis.

In our study three quarters of people with dementia lived in their own houses in a 2–3-bedroom house, and the rest rented the house and for most of them the rent was up to Rs 15000 per month (USD 93). Most of the people with dementia shared home with other adults and about half shared home with children, and most of the caregivers lived with the person with dementia in the same house as was the trend seen in Indian cohort. About one third of the caregivers were employed, similar to the figure in Indian cohort, and the rest were either stay- at- home spouses, retired, or unemployed and depended on their savings or support from children for living due to lack of retirement benefits, pension, or social welfare services.[16] Of the employed caregivers one-fifth had given up/cut down work due to caregiving responsibilities. No caregiver received any caregivers' benefit. About half of the caregivers made ≤ PKR 20,000 (126 USD) per month. This reflects towards the lack of financial resources for this set of population. Most of the primary caregivers lived in the same house with the person with dementia and did not receive any formal or informal help for caregiving unlike in other developing countries.[17] This fact is important as it increases caregiver burden and has important implications for policy makers and other stakeholders.

The per capita monthly gross national product (GNP) for people with dementia was USD 140 and a greater number of people were on medication than those with normal cognition (82% vs. 68%). Due to lack of public and private health insurance, most of the health care expense in Pakistan is out of pocket. A significant amount of monthly GNP/person of those with dementia was spent on health care most of which was spent on medication. People with normal cognition had higher per capita monthly GNP and spent more money on medication as well. Thus, people with dementia had lower income than those with normal cognition and are more frequently on medication and this may add to the financial burden of those with dementia and their families. People with dementia who needed medical care mostly sought help in private clinics and hospitals which is the trend seen in upper, middle, and low middle income urban population in Karachi, due to long wait times and relatively low-quality care in government hospitals. Majority of the caregivers reported spending time with the patient throughout the day and at night which is also seen in other LMICs. Studies have shown that the amount of caregiver time spent with the patient is an objective indicator and directly proportional to stress and depression among caregivers.[18] Majority of dementia patients in Pakistan are cared for at home by the family members. There is stigma attached to moving the parents out of the house and is considered as abandonment. Also, there are very few long term care institutions in Karachi which do not operate at the government level; some of them are run by charitable organizations and some are private and only support out of pocket payments.

CONCLUSION

In Pakistan majority of PWD are dependent on female family members for care. Caregiver roles are full time responsibilities with little to no burden shared by others. There is low monthly GNP per PWD with a high cost of medical needs of PWD.

REFERENCES

1. Krishnamoorthy ES, Prince MJ, Cummings JL, editors. Dementia: A global approach. Cambridge University Press; 2010 Oct 7.
2. Khan QA, Khan YH, Khan MZ, Najam S. Dementia Survey amongst Attendees of a Dementia Awareness Event in Karachi. Pakistan. J Alzheimers Neurodegener. 2017;3:014.
3. Prince MJ, Khalid W, Zulfiqar M. Translation and Validation of 10/66 Dementia Diagnostic Battery in Urdu in Karachi, Pakistan. Alzheimer Dis Assoc Disord. 2020 Apr 16;34(2):163-9.
4. ul ain Khan Q. Assessment of Dementia Caregiver Burden in Karachi, Pakistan using 10/66 Protocol. Pak J Neurol Sci. 2020;15(4):41-5.
5. Qadir F, Gulzar W, Haqqani S, Khalid A. A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. Care Manag J. 2013 Dec 1;14(4):230-40.
6. Morris JC. The Clinical Dementia Rating (CDR): current version and scoring rules. Neurology. 1993 Nov.
7. Chisholm D, Knapp MR, Knudsen HC, Amaddeo F, Gaite LU, Van Wijngaarden BO, et al. Client socio-demographic and service receipt inventory–European version: development of an instrument for international research: EPSILON Study 5. Br J Psychiatry. 2000 Jul;177(S39):s28-33.
8. Siddiqui S, Zaman M, Waqar A, Aziz Ali S. Profile of dementia patients from a tertiary care center in Karachi, Pakistan. Pak J Neurol Sci. 2018;13(2):11-6.
9. Ruitenberg A, Ott A, van Swieten JC, Hofman A, Breteler MM. Incidence of dementia: does gender make a difference?. Neurobiol Aging. 2001 Jul 1;22(4):575-80.
10. Sundström A, Westerlund O, Kotyrlo E. Marital status and risk of dementia: a nationwide population-based prospective study from Sweden. BMJ open. 2016 Jan 1;6(1):e008565.
11. Sharp ES, Gatz M. The relationship between education and dementia an updated systematic review. Alzheimer Dis Assoc Disord. 2011 Oct;25(4):289.
12. de Bruijn RF, Ikram MA. Cardiovascular risk factors and future risk of Alzheimer's disease. BMC Med. 2014 Dec;12:1-9.
13. Mukadam N, Sommerlad A, Huntley J, Livingston G. Population attributable fractions for risk factors for dementia in low-income and middle-income countries: an analysis using cross-sectional survey data. Lancet Glob Health. 2019 May 1;7(5):e596-603.
14. Muliyala KP, Varghese M. The complex relationship between depression and dementia. Ann Indian Acad Neurol. 2010 Dec;13(Suppl2):S69.
15. Thomson RS, Auduong P, Miller AT, Gurgel RK. Hearing loss as a risk factor for dementia: a systematic review. Laryngoscope Investig Otolaryngol. 2017 Apr;2(2):69-79.
16. Prince M. Care-arrangements for people with dementia in developing countries. Int J Geriatr Psychiatry. 2004 Feb.
17. Brinda EM, Rajkumar AP, Attermann J, Gerdtham UG, Enemark U, Jacob KS. Health, social, and economic variables associated with depression among older people in low and middle income countries: World Health Organization study on global AGEing and adult health. Am J Geriatr Psychiatry. 2016 Dec 1;24(12):1196-208.
18. Dias A, Patel V. Closing the treatment gap for dementia in India. Ind J Psychiatry. 2009 Jan;51 (Suppl1):S93.

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Quratulain Khan; Concept, data collection, data analysis, data interpretation, manuscript writing, manuscript revision

The author has approved the final version of the article, and agrees to be accountable for all aspects of the work.