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Report

Dementia Survey amongst Attendees of a Dementia Awareness Event in Karachi, Pakistan

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Abstract

Due to the differences present between dementia patients and caregivers in Low and Middle Income Countries (LMICs) and in high income western societies, contextualized dementia research has been widely done in the last decade. Pakistan is also an LMIC with very limited research related to dementia. This study was a pilot survey among the attendees of a dementia awareness session held at the Aga Khan University Hospital in Karachi, Pakistan. A self-reported questionnaire was used to find out about the most distressful and frequent symptoms of dementia, care arrangement, and knowledge about the diagnosis. Out of the 38 participants who returned filled questionnaires, about half identified the type of dementia as "Alzheimer's" and the other half was not aware of the type. Memory loss was reported as the most prominent and most distressing symptom by all patients and caregivers followed by anger/aggression and low mood/anxiety. Two thirds of patients/caregivers reported that patients engaged in hobbies or activities and "watching TV" was reported as the most common activity while "exercise" and "listening to music" were reported by the least number of people. Almost all caregivers identified themselves as primary caregivers, reported living in the same house with the patient and bearing the financial cost of care. Half of them were children of patients with dementia. One third of all participants reported having paid help. About 50% of all participants reported the activity as helpful and showed willingness to participate in such activities in future. The results from this study provide important insight into patient's symptoms and knowledge about dementia as well care arrangement in Pakistan and has important implications for health care providers in managing patients and their families as well as in designing customized programs and policies.

Keywords: Dementia; Karachi; Lower and middle income countries; Pakistan; Survey

Introduction

According to Alzheimer's Disease International World Report 2016, over 47 million people worldwide have dementia and this number is expected to rise to more than 131 million by 2050 [1]. In 2015 58% of the total dementia population is estimated to reside in Low and Middle Income Countries (LMICs) which is expected to rise to 63% by 2030 and 68% by 2050 [2]. Dementia and related issues in LMICs are different than in the West including assessment, diagnosis, awareness, caregiver characteristics, resources, and policy and strategies. Therefore research done in the West may not be applicable to LMICs in all aspects and contextualized research is needed for tailored solutions in such settings [3].

Pakistan is a low middle income country in South East Asia with a rapidly aging population. It is currently the sixth most populous country in the world and is expected to become the third most populous by 2050 [4,5] and 10% of the country's total population is estimated to be over 60 years of age [6]. Islam is the religion of the state with 97 % of the population being Muslim [7], with a very low literacy rate of 56% and low GDP per capita [8]. Among several factors identified as contributors to people's understanding of different medical conditions, religious and cultural beliefs, level of education and living arrangements are also important ones that play a role in explanatory models of disease symptomatology [9] and outcomes [10]. In Pakistan, joint family system prevails and people with dementia are mostly cared for at home by family members and informal caregivers. A qualitative study conducted in Lahore, Pakistan interviewed 8 dementia caregivers to explore thinking patterns, physical health; identified maladaptive cognitive patterns fatigue and sleep disturbances as causes of caregiver distress [11]. Caregiver distress is also often associated with type, severity, and frequency of dementia symptoms [12]. Caregiver characteristics and relationship with patient may also differ in different geographical regions, affecting the dynamics, quality of care and care burden [11]. In Pakistan, caregiver role is usually assigned to women [13] who may be spouses, daughters or daughter in laws of the affected person. Due to the unique characteristics of this society and dearth of dementia related research, it is important to study people's knowledge about dementia, cultural beliefs, most common and difficult to manage symptoms and resources available.

We designed a 15 item questionnaire survey to be filled out by the participants of a dementia awareness program in Karachi to study patients' knowledge, care arrangement and caregiver characteristics.

Methods

Aga Khan University Hospital (AKUH) is a private teaching hospital located in a densely populated area of Karachi. The hospital is considered to be one of the most sophisticated in the country and regularly organizes CME sessions, awareness events and capacity building exercises for trainees, physicians and general public in the city and the country. The hospital has the only trained neuropsychiatrist (Khan Q) in the country. As a part of the hospital's many events, a dementia public awareness event was organized on International Alzheimer's Dementia Day in October 2015. The event was advertised in two most widely circulated newspapers in English and Urdu languages and was open and free for public with no prior registration required. It was 2 hours long and included 4 sessions 20-25 minutes in duration conducted by a neuropsychiatrist, a neurologist, a psychiatrist

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and a neurology nurse followed by questions and answers. The first session was about symptoms and course of dementia, the second session addressed risk factors and prevention of dementia, the third session included neurological complications and the fourth caregiver responsibilities and burden.

Each attendee was handed a paper questionnaire at the entrance of the auditorium which were collected by the volunteers after 10-15 minutes. Participants had to sign their names with area of residence and contact phone number or email at the registration table in the auditorium lobby. Patients were also asked to write name, age and contact number/email on the questionnaire. The questionnaire included 15 questions, written in English and each question was followed by multiple choices to choose from; some questions were required to be answered as "yes" or "no". 5 out of 15 items were about dementia patients. The first question was if the person filling the questionnaire was someone with dementia or the caregiver and the following 3 questions asked about the type of dementia, most prominent and most distressing symptoms. 2 questions were about the hobbies or activities that the patient engaged in. The next 7 questions were about the care arrangement such as identifying the primary caregiver, if the caregiver lived with the patient, time spent with the patient, person bearing the financial needs of the patient, any other relatives involved in patient care and if any paid help was available to care for the patient. 2 questions were about the participant's opinion if the session was helpful or not and willingness to participate in future in any such activities. We did not include any open ended or descriptive answer choices in the survey as the questionnaires were filled by the participants themselves during the session. In our experience these kinds of questions are answered better in interviews conducted by a researcher or interviewer and in focus group discussions.

The study was approved by the Aga Khan University Research Ethics Review Committee (4832-Psy-ERC-17).

Data collected was entered and accessed via SPSS 14.0.

Results

50 people attended the session out of which 38 returned filled questionnaires. 11 out of 38 identified themselves as dementia patients and 8 identified themselves as caregivers (50% of the total sample). 19 participants (50%) did not identify with either group and were people from the general public. 9 out of 19 (47%) patients/caregivers identified the type of dementia as Alzheimer's and the rest were not aware with the type of dementia. None of the participants identified any other type of dementia among the choices given including Lewy body dementia, frontotemporal dementia and vascular dementia. All 19 patients/caregivers with dementia identified forgetfulness as the most prominent as well as the most distressing symptom. 7 people from the general public also reported having forgetfulness and 4 out of these 7 also reported it as distressing. Anger/aggression was marked as the second most prominent symptom by all 8 caregivers and 5 dementia patients. Low mood/anxiety was also reported as a prominent symptom by 9 patients and 4 caregivers and all of these also marked it as the second most distressing symptom. 2 people from general public also reported depression/anxiety as distressing. Difficulty performing ADLs was also reported distressful by 4 patients and 4 caregivers. Question about engaging in hobbies/activities was marked positive by 7 patients and 5 caregivers (12/19, 63%). 4 patients and 3 caregivers marked this as negative. The most common activity reported was "watching TV" (10/12), followed by "going out for shopping/eating" (8/12), and "reading" (7/12). More than one choice was marked by many people. "Exercise" and "listening to music" was marked by the least number of people (3 each) (Table 1).

Variables	N=38 n (%)
1. Informant	
Dementia patients	11 (29.9)
Caregivers of dementia patients	8 (19.4)
Others	19 (50.6)
2. Type of Dementia	
Alzheimer's	9 (23.7)
Lewy Body dementia	0
Frontotemporal dementia	0
Vascular dementia	0
Don't know	17 (44.7)
Not specified/Don't Know	12 (31.6)
3. Most prominent symptoms	
Memory problem/forgetfulness	26 (68.4)
Anger/aggression	13 (34.2)
Low mood/anxiety	13 (34.2)
Suspiciousness	5 (13.2)
Hearing voices/seeing things	9 (27.7)
4. Most difficult to manage/distressful symptoms	
Memory problem/forgetfulness	23 (60.5)
Depression/anxiety	15 (39.5)
Suspiciousness	5 (13.2)
Hearing voices/seeing things	7 (18.4)
Anger/aggression	6 (15.8)
Confusion/wandering/leaving the house	7 (18.4)
Inability to walk/falls	4 (10.5)
Difficulty/inability to control urine/bowel, bathing/changing clothes	8 (21.1)
5. Does patient engage in any hobbies/activities he/she likes?	
Yes	12 (31.6)
No	8 (21.1)
Missing data	18 (47.4)
6. If yes, which one?	
Watching TV	10 (26.3)
Listening to music	03 (7.9)
Reading	07 (18.4)
Going out for shopping/eating	08 (21.5)
Exercise	03 (7.9)

Table 1: Dementia symptoms.

Among the caregiver related questions, almost all identified themselves as primary caregivers and half of them identified patient as their mothers. 7/8 caregivers reported bearing the financial cost related to patient care and living in the same house with the patient. 3 patients reported bearing financial cost themselves. 7/8 caregivers also reported spending more than 2 hours with the patient every day and involvement of other people in patient's care. 6/19 patients /caregivers reported having paid help to care for the patient. The activity was reported to be helpful by 17/38 (45%) among which 6 were patients, 5 were caregivers and 6 people from general public. 55 % of the participants showed willingness to participate is such activities in future (Table 2).

Discussion

This survey was conducted to study knowledge about dementia and care arrangements among the attendees of a dementia awareness event held at a tertiary care university hospital in Karachi. 50% of the people who returned filled questionnaires were dementia patients and caregivers and 50% were people form general public which may include people with normal cognition usually from older age group and some younger medical students and hospital employees. About less than half of patient/caregiver group was aware of their diagnosis and all identified it as Alzheimer's dementia. The rest half were not

Variables	N=38 n (%)
1. Are you the primary caregiver for the patient?	
Yes	07 (18.4)
No	12 (31.6)
Missing data	19 (50.0)
2. Relationship of patient with caregiver	
Wife	1 (14.2)
Father	1 (14.2)
Mother	4 (57.1)
Daughter	1 (14.2)
Father/mother in law	1 (14.2)
Any other	1 (14.2)
3. Do you bear financial costs related to patient care?	
Yes	10 (26.3)
No	6 (15.8)
4. Do you and the patient live in the same house?	
Yes	14 (36.8)
No	09 (23.7)
Missing data	15 (39.5)
5. Number of hours spent with patient every day	
Less than 30 mins	5 (13.2)
31-60 mins	2 (5.3)
Two hours	1 (2.6)
More than two hours	8 (21.1)
6. Other than you how many other people are involved in patient's care?	
None	0
One	2 (5.3)
Two	1 (2.6)
Three	1 (2.6)
Four	3 (7.9)
Five	2 (5.3)
7. Do you have servant/maid/paid help to care for patient?	
Yes	06 (15.8)
No	16 (42.1)
Missing data	16 (42.1)
8. Do you think today's activity was helpful?	
Yes	17 (44.7)
No	03 (7.9)
Missing data	18 (47.4)
9. Would you like to participate in such activities in future?	
Yes	21 (55.3)
Missing data	17 (44.7)

Table 2: Caregiver related questions.

aware of the type of dementia. No one marked Lewy body, frontotemporal or vascular dementia as their diagnosis. This reflects that patients/caregivers may be more familiar with Alzheimer's dementia than other dementias. It is however also known that Alzheimer's is the most common type of dementia [14]. It may also mean that due to lack of expertise among health care providers in this domain many people are diagnosed with Alzheimer's dementia than other types of dementias. This information is important in devising public awareness campaigns and improving healthcare provider education. Forgetfulness was identified as the most common and most distressing symptom of dementia by all patients and caregivers in our survey. This is similar to the results from dementia registry study published in Islamabad, Pakistan [15] which reported 81% people with dementia presenting with memory loss as the main symptom. This provides good insight into people's knowledge about recognizing forgetfulness as dementia symptom and interventions or management strategies based around this symptom would also be desirable as it is also reported to be the most distressing symptom. This is an interesting finding as some data from western literature suggests that forgetfulness is the most frequent but least distressing symptom [16], whereas disruptive behavior was least frequent but most distressing. In joint family socio-cultural setting in Pakistan and other South Asian countries where there may be multiple caregiver's available, disruptive behavior may be less distressful as compared to a single caregiver taking care of the patient. Anger/aggression was marked as dementia symptom by all caregivers and less number of patients themselves where as low mood/anxiety was reported as prominent and also distressing symptom by more number of patients than caregivers. World literature also suggests that anger/aggression contributes significantly to caregiver burden [17] and in a country like Pakistan where almost all dementia carers are informal carers and family members of patients it is not surprising that this is reported by more number of caregivers. Prevalence of depression [18] and anxiety [19] is also reported to be high in dementia patients in world literature and compromises the quality of life of these patients. Difficulty performing ADLs is reported as equally distressful by patients and caregivers in our study. This was also identified as a theme in another study addressing caregiver distress in families of dementia patients in Rawalpindi, Pakistan [20]. This is known to increase dependence, caregiver burden and mortality in general [21] and may be more difficult to manage in a resource poor setting such as Pakistan and other LMICs [22].

More than half of patients/caregivers in our survey reported that the patient engaged in hobbies or activities and watching TV was reported to be the most common activity. Exercise and listening to music were reported by the least number of people. This is in keeping with the sedentary life style of elderly population in Pakistan and is particularly the case in people with dementia. According to the conventional role of "being old" in Pakistani society people are generally expected to stay at home after retirement, spend time praying and performing religious activities, "look religious" such as by growing beard, giving up "young attire" and sticking to more conservative forms of dressing, spend time with grand kids, stay passive, give up responsibilities and have the next generation take over before they die. Community organizations, social clubs, libraries, parks, gyms, old age societies and day care centers are almost nonexistent [23]. Elderly however usually go to the local mosque for prayers five times a day. Watching TV is the most accessible and affordable activity available to most especially in urban setting. This information also brings to attention a very important area to explore in caring for such patients and to devise methods at the community level to identify and engage them with the health care system such as through community health workers, workers in local mosques, or by using electronic media. Physical exercise was only reported by 3 participants of the survey as an activity. The role of physical exercise in prevention or modification of dementia and brain aging is well recognized [24,25]; however there are multiple cultural and social factors, non-availability of space, unsafe environment etc. which make this an unfavorable practice in local setting. Similarly listening to music was also reported by just 3 participants as an activity. This may also have cultural and social explanations among others. This is important contextualized information and emphasizes the need of devising culturally acceptable interventions to prevent and manage cognitive decline in such settings.

Among the caregiver related questions about half identified themselves as children of patients with dementia in our study. A study from Lahore, Pakistan [11] reported spouse followed by children as primary caregivers. In a WHO report, children/children in law were identified as primary caregivers of most dementia patients in rural and urban areas of India [26]. In our study most caregivers reported bearing financial cost related to patient care, living in the same house with the patient, spending more than 2 hours with the patient every day and involvement of other people in patient's care. In traditional Pakistani society [11] as well as in India [26] majority of patients with dementia and their adult children live in the same house and may have more than one family members involved in their care. Due to lack of social security, financial support, public health insurance systems, older people in general and people with dementia in particular are financially dependent on their caregivers as indicated in our survey. About one third patients in our survey reported to have paid help available however as this was a self-reported, non-descriptive questionnaire we are not able to comment on the type of help however having maids for domestic help in Karachi and other urban areas is very common and available at low wages; it is highly likely that these are unprofessional and untrained domestic workers. This scenario may be completely different in low socio-economic and rural areas of Pakistan, as also reported in a study in rural India with 0% of people having paid help available [27]. These are informal and untrained caregivers and have limited understanding of dementia symptoms. They may also have other professional and domestic responsibilities which may compromise patient care and vice versa. Impact of joint family system, family dynamics, and financial needs of care giving are important aspects to explore in future research.

About half of the total number of participants reported that awareness session was helpful and showed willingness to participate in such activities in future. This is important to recognize information needs of caregivers and to design effective supportive interventions and educational activities. Based on this finding, we started a dementia education and support program for caregivers at the AKUH which is ongoing. A study conducted in Southern India also revealed that family caregivers of people with dementia reported feeling distressed and wished to participate in educational programs but many had unrealistic expectations for what they wanted to learn [28].

This study has many limitations. First is the small number of participants. The total number of people (patients/caregivers/general public) who attended the session was 50. This is a small number keeping in view the fact that Karachi is a very large city with an estimated population of over 27 million, that the event was advertised in two leading newspapers in both English and Urdu languages, the hospital is located in an accessible, densely populated area and the event was free with no prior registration required. This could have many explanations such as less awareness about dementia among public with common belief in Pakistani society that forgetfulness is a part of normal aging, and stigma attached to the issue. Due to small sample size we recommend replicating the findings by large scale surveys. Second the findings from these participants may not be generalizable as the survey is done in an urban setting and in a private hospital which caters to affluent class. However this was a public event which was advertised in local newspapers and was free for all to make it easy for general public to attend. Third, the questionnaire was written in English language and people with no or low formal education or those unable to read and understand English may not have participated in the survey. Urdu is the national language of the country and is read and understood more commonly than English which is considered a foreign or second language. Fourth people with dementia may have had difficulty reading, understanding, remembering, or providing correct information due to cognitive deficits. Fifth we think it would have been useful to design separate questionnaires for patients, caregivers and general public to reduce ambiguity and missing information and also because of the fact that people with dementia and caregivers may have different opinions and perceptions about symptoms, burden etc. Adding open ended or descriptive answer choices and using mixed method study design would be more useful for such research in future studies.

However we think that such surveys may be very useful in exploring awareness about dementia and care arrangements for those suffering from dementia and need to be replicated in different settings in the country. For future work, questions pertaining to attitudes and awareness of advance care planning could be explored as well. Advance care planning would be especially relevant for the early stages of dementia, when patients still retain mental decision capacity. Advance care planning has also been shown to reduce decisional conflict and caregiver stress [29].

Conflict of Interest

The authors have no conflicts of interest to declare.

Author Contributions

Dr. Qurat-ul-Ain Khan was involved in formulating study concept and design including designing the survey questionnaire. Dr. Yusra Hanif Khan was involved in acquisition of subjects. Mohammad Zaman Khan performed data analysis. Dr. Shireen Najam helped in preparation of manuscript.

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