



Understanding, Beliefs and Treatment of Dementia in Pakistan: Interim Findings

By

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EXECUTIVE SUMMARY

Dementia has become a global health priority, and still progress towards its understanding and treatment in low and middle-income countries has been slow. This is despite the fact that the speed of population ageing in these countries has been faster. There is as yet no cure for dementia but formal support services can help to improve the quality of life of persons living with dementia and their family caregivers.

It is therefore important that the disease is diagnosed as early as possible. One of the barriers to seeking help is the stigma associated with dementia, due to underlying negative and inaccurate beliefs about it, particularly that it is the individual's own fault or due to family neglect. It is essential that we identify peoples' understanding, beliefs and attitudes about dementia in Pakistan to advocate for the most effective policies and programmes in raising awareness and providing support services to people with dementia and their caregivers.

This report provide interim findings of the project, titled 'Understanding, Beliefs and Treatment of Dementia in Pakistan, whose aim is to understand the cultural beliefs, attitudes, views and understanding of dementia in people living with dementia and their families in Pakistan, and in those who have no experience of dementia.

The project provides insights on three levels: 1) at the individual level, on the basis on interviews of persons living with dementia and their caregivers; 2) at the community level, on the basis of focus group discussion with public who did not have any direct contact with dementia patients or their caregivers; 3) at the society level, on the basis of interviews with key informants.

One of the most striking finding is that there is often a lack of awareness of dementia and its symptoms, often attributing it to the norms of getting old, leading to misconceptions about care and prognosis. We recommend that a national campaign to raise awareness about dementia in essential, in terms of how to identify dementia, what its risk factors are and how to seek help. The TV, radio and social media tools should be used for this purpose.

Religion features heavily in the FGDs, usually providing rationale and meaning to a complex topic. One other top level insight is that there is very little clarity on whether dementia patients are exempted from their religious duties (e.g. praying five times a day; fasting; observing other rituals) – this lack of clarity generate great deal of stress for the patients and their caregivers and it is a major source of shame and stigma for their families. A fatwa of some sort clarifying the confusions about obligations for the praying will support initiatives to improve care provision to dementia families in Pakistan as well as in Britain. It is essential that religious leaders also speak out about dementia, both in terms of raising awareness, but also the acceptability to seek for help when needed

Furthermore, additional funding needs to be allocated for specialist dementia services, including specialist wards/hospitals, day care centres, home help and support groups (both for caregiver and patients), and for increased dementia healthcare staff and better training for staff. A key finding is that raising awareness among dementia patients and their caregivers will have to accompany availability of health and social care, otherwise it would be counterproductive. Can this finding be relevant in Britain as well? Better awareness among South Asian families in Britain will need to be matched with availability of more culturally sensitive services by the NHS and by the local authorities.

Research and evidence-informed policymaking is scant in Pakistan. The knowledge transfer from the research on dementia carried out elsewhere in the world, typically in high income, developed countries like the United Kingdom, will be of a good value, provided the policies implemented are culturally sensitive.

1. Introduction and motivation

Dementia is a progressive disorder caused by a range of brain diseases, with Alzheimer's disease being the most common. According to an estimate, close to 46.8 million people are currently living with dementia worldwide, 58% of which are expected to reside in low and middle-income countries (LMICs) and this figure is expected to rise to 68% by 2050 (Prince et al 2015).

Dementia affects a whole range of cognitive abilities, particularly memory but also language, judgement and perception. The problems with the activities of daily living (ADLs) and behavioural and psychological symptoms (BPSD) are also common in dementia, including agitation, aggression or apathy.

Dementia is not only a disease of older ages but observed at younger ages, although it becomes more prevalent as age increases (Prince et al. 2014). Therefore, dementia has become a global health priority, especially in the resource constrained low- and middle-income countries where the speed of population ageing is faster (Zaidi 2015).

There is currently no cure or effective medical treatment for dementia, but there is evidence that formal support services can help to improve the quality of life of persons living with dementia (Downs and Bowers 2010) and that of their family caregivers (Farina et al. 2017). It is therefore important that a diagnosis is made as early as possible, but contact with services can be delayed if individuals or family members do not recognise the symptoms of dementia (Regan 2014).

A further barrier to seeking help is the stigma associated with dementia (ADI 2012), due to underlying negative and inaccurate beliefs about it, particularly that it is the individual's own fault or it arises due to family neglect (Giebel et al 2015; La Fontaine 2007). This highlights a need for increased awareness of understanding and beliefs about dementia across cultures (Gabriele and Borin 2014).

The burden of informal caring for the family members and friends can be particularly serious. In the UK, for example, it has been estimated that informal care outweighs all formal sources of care and is worth £12.4bn a year (Luengo-Fernandez et al 2010). Providing care for a person with dementia has both positive and negative aspects: some family members gain a sense of fulfilment when the care burden is manageable (Merrell et al 2005; Age UK 2017), while others report physical and mental health problems (Schneider et al 1999).

The informal care burden is likely to be even higher in low-income countries where public health resources are scarce. Moreover, as dementia progresses, round-the-clock care is required; it is at this point that many family members find they are unable to cope without formal help. Caregivers also often draw on ideas of culture or religion to explain their caregiving decisions, but contrary to popular perceptions this may not lead to differences in levels of informal care provision (Willis 2012).

The beliefs, attitudes, and awareness about dementia among the public have important implications. Patients' and caregivers' perception of symptoms not only affects treatment seeking behaviour and pathways to care but may also affect caregiver burden

and stress (Martin-Cook et al 2003). For instance, people from South Asian backgrounds in the UK are likely to receive a dementia diagnosis later than their White British counterparts (Moriarty et al 2011), related to differences in understanding about dementia, stigma, or barriers to accessing services.

1.1 Context in Pakistan

According to the World Bank, Pakistan is a lower middle income country in South East Asia and is currently the sixth most populous in the world and is expected to become the third most populous country by 2050. In 2015, 11.6 million Pakistanis are over 60 years of age and this figure will rise to 43.3 million by 2050. Pakistan has an extremely poor record of accomplishment when it comes to addressing issues associated with social and economic rights of older persons (Zaidi et al 2018). It ranks depressingly low in the Global Age Watch Index: at 92 out of 94 countries. It ranks particularly low with respect to health of older persons, with a relatively low life expectancy and even lower healthy life expectancy within the region (Zaidi 2013).

The 10/66 Dementia Research Group, formed from the platform of Alzheimer's Disease International, has done significant research work in many LMICs including India; however there is a dearth of dementia related research and subsequently limited resources to deal with this rising epidemic in Pakistan (Khan 2014; Qadir et al 2013).

Pakistan is an Islamic country where 97% of the population is Muslim, health literacy and awareness of mental health issues is very low, and the society is heavily influenced by religious, cultural and mythical beliefs (Khan and Sanobar 2016). Religion and culture play an important part in peoples' perceptions and understanding of different phenomena including disease symptoms and pathology in general, and in shaping the role and identity of older people in the society in particular (Ahmad et al 2013; Awan et al 2015; Khan 2014; Qadir et al 2013).

As opposed to Western societies where the concept of individualism is often more prevalent, Pakistani society is socio-centric and relational where the individual is viewed as a body in relation with others in the society (Gabriele and Borin 2014). A joint family system is common in which two or more generations live together. The older person, usually the oldest male member, is considered the head of the household due to patriarchal patterns of the society. Older people, especially parents, are the most respected of family members and serving them is considered a strict religious and social obligation for the younger generation especially for sons and daughters and this increases several fold if they are unwell due to dementia or any other such incapacitating disease (Qadir et al 2013; Quinn et al 2016).

In Pakistan, there is also limited awareness among the public about dementia and it is often believed to occur as a part of normal ageing process, secondary to traumatic events or stressors, or physical weakness (Qadir et al 2013). Family also downplay cognitive difficulties largely, often reporting that patient has always had such symptoms and/or their memory is excellent as they remember each single detail of past events (Awan et al 2015; Khan and Sanobar 2016). Due to the joint family system, decline in instrumental activities is often explained to be because of the limited need of older

people to participate in activities because of grown up sons and daughters taking over. This role switch often happens in families when sons get married and their wives are expected to take over the responsibilities. In addition, people take pride in having older members of the family especially parents give up instrumental activities and hand over the responsibilities to the next generation (as observed in the experiences of Israeli-Arab caregivers) (Abojabel and Werner 2016).

Older people are also expected to have inclination that is more religious and to engage more in religious activities as opposed to other hobbies and socialization and thus such changes are often not considered pathological. Some people attribute cognitive difficulties merely to lack of education and fail to appreciate changes or decline in functioning in low educated individuals. Behavioural and psychological symptoms such as personality changes, paranoia, and inappropriate behaviour may also be directed towards the new family member such as daughters-in-law, and the patient's behaviour is often perceived as hostile, manipulative, or attention seeking. As a result, this may cause serious problems in family dynamics and even hostile behaviour towards the patient. However, caring for parents and older family members is generally done in homes even until the terminal stages of dementia. There is serious stigma attached to the notion of moving older people to nursing homes which is synonymous to abandoning them and giving up duties and responsibilities as a child (Khan 2014; Khan 2016).

Good public health centres and specialised nursing homes for the elderly are almost non-existent in Pakistan and there is no government policy for people living with dementia. There is a lack of important social science research in Pakistan and work needs to be done to identify peoples' understanding, beliefs and attitudes about dementia to advocate for the most effective policies and programmes in raising awareness and providing support services to people with dementia and their caregivers.

1.2 Understanding of dementia among South Asian communities in the UK

South Asian populations represent one of the largest ethnic groups within England and Wales (Office for National Statistics 2012), and in the presence of limited evidence about perceptions of dementia in Pakistan, we can infer potential lessons from research in these UK communities.

- South Asian communities within the UK have been found to have poorer knowledge about dementia and its symptoms compared to their White British counterparts (Purandare et al 2007; Turner et al 2005).
- Notably, one study identified that South Asian carers had not heard about dementia prior to their relative being diagnosed (Adamson 2001).
- Alongside gaps in knowledge about dementia, South Asian communities within the UK have been shown to have negative beliefs about the condition, with some believing the cause of the dementia was the fault of the individual or as a result of lack of family care (La Fontaine et al 2007).

It is therefore unsurprising that South Asians within the UK tend to use the word 'dementia' as a stigmatising rather than neutral term (Bowes and Wilkinson 2003). This

may in part be due to an absence in equivalent term within some South Asian languages. For example, in Urdu, the closest synonym for 'dementia' is 'crazy' or 'insane' (Forbat 2003). It is also possible that South Asian spirituality and religion may affect peoples' attitudes toward dementia, however, this has not been fully explored (Uppal and Bonas 2014; Uppal et al 2014).

There also appear to be cultural differences in caring attitudes and what support is accessed. UK South Asian carers tend to have traditional ideologies, and therefore put the person with dementia's needs above their own, whilst seeking professional help is seen a failure of caregiver responsibility (Lawrence et al 2008). There are also beliefs in UK South Asian communities that there is little value of getting a diagnosis of dementia (La Fontaine et al 2007; Mukadam et al 2011).

Willingness to seek help about memory problems within UK South Asian communities has also been found to be tied with social pressures from significant others, who have their own beliefs about dementia whilst there is also a stigma surrounding seeking help (Hailstone et al 2016). South Asian carers often had the sole responsibility for care, and did not receive help from other family members. (Katbamna et al 2004). Notably, a reluctance to access health services has not solely been attributed to South Asian communities' attitudes. A lack of knowledge about dementia from healthcare professionals and a lack of cultural sensitivity may act as additional barriers for South Asian groups from accessing services (Geibel et al 2015).

In summary, there are a number of differences between South Asian and White British communities when it comes to perceptions about dementia. Cultural attitudes, beliefs of health care and dementia knowledge all act as barriers for South Asian communities in the UK to seek help with dementia (Mukadam et al 2011). Creating a culturally sensitive healthcare system (Jolley et al 2009; Nijjar 2012), alongside improving attitudes towards dementia (Hailstone et al 2016) were identified as key pathways to improve help-seeking behaviours for dementia within the UK.

1.3 Understanding of dementia among South Asians in other countries

Research into South Asian perceptions about dementia, though predominantly found within the UK communities (Giebel et al 2015), exist in other non-UK countries. These findings from South Asian communities outside of the UK provide additional context as well as generalisability. Naess and Moen explored the response processes surrounding signs and symptoms of dementia in Norwegian-Pakistani families (Naess and Moen 2015). The study focused on understanding the interaction between the Pakistani culturally defined system of care with the Norwegian healthcare culture of public care and biomedical intervention. It showed that according to the Pakistani culture, caring for older people is the responsibility of the family, especially the younger family members, who will also expect to be looked after by their children when they grow old. The signs of dementia were also 'normalised' and attributed to 'normal ageing' in line with previous evidence (McCleary et al 2013).

More recently, Nielsen and Waldemar compared the knowledge and perceptions of dementia amongst four ethnic groups in Copenhagen. Pakistani people were more likely

to hold normalising and stigmatising views of dementia than Danish and Polish people. Level of education and acculturation influenced dementia knowledge (Nielsen and Waldemar 2016).

McCleary and his colleagues sought to explore and describe the experiences of South Asian Canadian people with dementia and their families at a time prior to being diagnosed with dementia (McCleary et al 2013). Interestingly, all families in this study initially considered the early signs of dementia to be 'normal' and this contributed to a delay of 1-4 years between the first signs of dementia to seeking professional support.

They found that dementia diagnosis normally occurred after an acute medical problem or hospital admission, which was in line with other cross-ethnic comparisons of pathway to dementia diagnosis. Thus, dementia was only diagnosed due to another health concern taking precedence, suggesting a need for increased awareness of dementia signs in the South Asian community. Stigma, which is normally a common theme in South Asian immigrants' experience of dementia in the UK (Mackenzie 2006) did not emerge as a theme in this study, most likely due to the sample being limited to persons who had eventually sought medical care and thus were more open to sharing their experiences.

In summary, the attitudes and experiences of South Asian communities in other non-UK countries appears to be similar to those living in the UK. There is a general lack of knowledge whether signs of dementia are part of normal ageing, a sense that dementia is not shameful and that it is the family's responsibility to provide care to the person with dementia. These findings suggests a fundamental need for raising awareness and changing negative beliefs about dementia in South Asian communities, in order for South Asian people with dementia to access health care services a lot earlier.

2. Research methods

The principal research question addressed in this research is

- What are the cultural beliefs, attitudes, views and understanding of dementia in people living with dementia and their families in Pakistan, and in those who have no experience of dementia?

To the extent possible, two additional secondary research questions are answered using the data collected:

- What are the circumstances of older people living with dementia, including income, material security and support in relation to the costs of care? and
- What level of services and access to health care is available for dementia?

The research questions are answered primarily using qualitative research methods, specifically a combination of semi-structured individual interviews, Focus Group Discussions (FGDs), and Key Informant Interviews (KIIs). Qualitative methods are appropriate when seeking to explore a research topic about which little is known (Bryman 2015), and when examining sensitive, hard-to-enumerate issues (Dickson-Swift et al 2008). The qualitative data is analysed using thematic analysis (Braun and Clarke 2006).

2.1 Data collection

Four data collection instruments were used:

- (i) semi-structured interview guide for people with dementia,
- (ii) semi-structured interview guide for caregivers of people with dementia,
- (iii) Focus group discussion topic guide for members of the general public, and
- (iv) key informant interview guide for stakeholders.

All these topic guides were created in English, and then translated into Urdu. The translations were checked for the comprehension by all the three project partners in Pakistan. The interview topic guides and FGD guides were piloted during the inception stages with a small number of people in Pakistan in order to test appropriateness of the wording and question order.

Individual interviews are supplemented with closed-ended questions to explore socio-economic status of people with dementia and availability of public healthcare information, to answer two secondary research questions mentioned above, to be analysed using descriptive statistics. KIIs provided further information about the services available as well as linkages between different policy programmes.

The Patient and Public Involvement (PPI) with key stakeholders ensured that the research stays meaningful, its ethical quality and impact optimised. Alzheimer's Pakistan undertook appropriate involvement with family carers and people with dementia in the design and conduct of the project. Through the contribution of PPI in the dissemination strategy, potential beneficiaries of the research will be identified and informed ensuring that findings are accessible to a wider community.

Table 1: Key features of the data collection work in Lahore and Karachi, 2017

	Modes of data collection	Sample	Location	Recruitment responsibilities
1.	A. Individual interviews with dementia patients	10	Karachi	AKH
2.		10	Lahore	Alzheimer's Pakistan
3.	B. Individual interviews with caregivers	10	Karachi	AKH
4.		10	Lahore	Alzheimer's Pakistan
5.	C. Focus Group Discussions (FGD)	10 men	Karachi	HANDS
6.		10 women	Karachi	HANDS
7.		10 men	Lahore	Alzheimer's Pakistan
8.		10 women	Lahore	Alzheimer's Pakistan
9.	D. Key Informants Interviews (KIIs)	4	Karachi	HANDS
10.		4	Lahore	Alzheimer's Pakistan
11.	PPI for testing of interview guidelines and vignettes	4	Lahore	Alzheimer's Pakistan

The data from Karachi and Lahore allows a comparison across two provincial capitals of Pakistan with different socio-demographic and economic profiles. In each site, four sets of people were recruited and interviewed during 2017 (see Table 1).

Individual interviews

The topics covered with people with dementia and their family caregivers are similar, but the wording is different to reflect their different roles, e.g. 'What were the first symptoms you experienced?' or 'What were the first symptoms you noticed in your relative?' The topic guide below demonstrates the topics that the interviews covered. In addition, these questions were followed with more structured questions about socio-economic circumstances, living arrangements, use of health services, etc.

The topic guide for individual interviews included: (i) How symptoms first manifested, and how they were understood by individual/family? (ii) How did individual/family respond to symptoms? At first? Later? (iii) What do you expect will happen in the future? (iv) What was the trigger to access health services? (v) What help was offered/received? (vi) In your experience, how have other people in the community responded?

The individual interviews with people with dementia and family members provided the data for the three research questions about attitudes and views of dementia; material and social circumstances of people living with dementia; and access to health care services for people with dementia.

Focus Group Discussions

A series of FGDs has been held with members of the public in Pakistan (n=40). There were four single-events in Lahore and Karachi. Groups were split by gender.

Two vignettes were presented to participants, describing a person with dementia at different stages of the disease (see example below). The vignettes were culturally adapted from a study that explored awareness and understanding of dementia in minority ethnic groups within the UK (La Fontaine et al., 2007).

The vignettes were also independently reviewed by dementia experts (UK) and then by Pakistani project partners. Finally, the translated vignettes were reviewed by a PPI group in Pakistan.

The discussion provided the group's understanding of what is happening to the people in the vignette, and probe issues concerning the cause of the condition and how to best support and treat them. Vignettes are considered useful tools for FGDs on sensitive topics, because they shift the focus away from the individual, making it easier for group members to offer opinions.

Key Informant Interviews

The Key Informant Interviews (KIIs) were a one-off individual semi-structured interview with key stakeholders in Pakistan, for example practitioners and policymakers where they were asked open-ended questions about the public policy programmes and services currently in place in Pakistan to address the issues of people with dementia.

2.2 Data collation and analyses

The interviewers were all experienced qualitative interviewers who live and work in Pakistan. They were briefed about the project, in particular about the ethics of getting consent for interviews and for the cultural and religious sensitivities. They were trained to use the instruments by HANDS, Alzheimer's Pakistan, the AKH and the PI. All interviews and FGDs are audio recorded using digital recorders, to allow for transcription and sharing of files between the research team. The audio recordings were transcribed verbatim (word-for-word) in Urdu by HANDS and Alzheimer's Pakistan. These transcripts were then translated into English. Both Urdu and English transcripts (word documents) were electronically sent to the Southampton team in the UK, where we undertook further quality checks on the translations. The finalised English transcripts were used by researchers for the analysis.

The data coding was carried out by researchers from the UK sites (Southampton and Brighton) using a specialised software NVivo which were independently reviewed by other members of the research team. All qualitative research methods were analysed using the thematic analysis, driven by the data. An initial analysis meeting was held in Southampton in November 2017 to discuss how coding was to be carried out. Subsequently, in February 2018, another meeting held that provided another opportunity to discuss face-to-face the analytical approach adopted by the researchers.

The analysis are undertaken within the four work packages in order to answer the research questions.

1. People with dementia, and their pathways to diagnosis; facilitators of accessing care services; cultural and religious factors affecting their diagnosis, experience and attitudes; health services used; stigma.
2. Family caregivers of people with dementia, and the challenges they have experienced; what support they have and wish for; how the dementia affects them.
3. Members of the public, and their understandings of dementia; stigma related to dementia; barriers to accessing care services.
4. Description of views of key stakeholders regarding the dementia programmes and policies in Pakistan.

Four peer review papers will be completed for these four work packages by the end of the project. The interim findings from these papers have come together in this report. The Executive Summary and Policy Brief based on the key findings and steps will be prepared alongside the final report.

The findings will be presented in one large event in Lahore, under the lead of Alzheimer's Pakistan. In partnership with Age International and Age UK, one event will be organised in London to present the findings of the project.

3. Interim findings

Understanding people's attitudes of dementia in Pakistan is the first stage in reducing stigma and improve health and social care toward the condition in the country. Whilst this research is limited to Pakistan, understanding different cultural views of dementia globally is vital.

It is envisaged that there will be stigma toward dementia both from families living with the condition and the public in Pakistan. It is likely that better dementia education to people in Pakistan is needed to change these attitudes.

3.1 Individual interviews of persons with dementia

Ten interviews were conducted with People living with Dementia (PwD) in Karachi and ten in Lahore. In Karachi, there were four female PwD and six male PwD participants. In Lahore, there were five female PwD and five male PwD participants.

In all interviews, at least one family caregiver was also in attendance and sometimes helped to answer the questions. In nine of the interviews (8 from Lahore and 1 from Karachi), the caregiver answered most of the questions on behalf of the PwD. For this reason, there are more codes about carer issues (for example, discussions of the effects on the carer) in the Lahore interviews than in the Karachi interviews. This should not be taken to mean that there is less carer burden in Karachi; this is just an effect of the role of the person who answered the questions in each location. It could also potentially mean that the PwD in Lahore were at a more severe stage of dementia, which is why the carers needed to respond for them more frequently.

How problem was first recognised?

The most common symptom that was first noticed was forgetfulness, although other symptoms mentioned included an inability to perform at previous levels (DIY, making decisions) or physical symptoms (weakness, vomiting, headaches, paralysis, brain haemorrhage, a fall).

Help seeking

All participants had sought help from a doctor, although one person reported also seeking spiritual or religious help. Five participants employed a house cleaner or servant to assist in the home (with ADLs or IADLs).

Causes of dementia

Eight participants said that dementia was caused by old age, but six participants disagreed and said that it was not just old age that caused these problems. A common concept was that dementia was caused by doing too much of something, including working too much, thinking too much, or having stress or 'tension'.

Other people said it was too little of something, such as too little social interaction or lack of stimulation. Other factors thought to lead to dementia included bereavement, a shock, or mistreatment from family. Two people mentioned black magic. Causes that are physical included a fall, blood loss, blood pressure, brain tumour, brain weakening or malfunctioning, 'paralysis attacks', and medication side effects. Five participants believed that dementia was genetic. Finally, emotional causes were cited including sadness or another mental illness.

Current symptoms

A whole range of symptoms was mentioned, including cognitive and behavioural symptoms. Common among these were agitation or anger felt by the person with dementia, ADL or IADL problems (such as bathing, eating, cooking), forgetfulness, inability to recognise people, and disorientation in time or place. A particular feature of disorientation in time and place that distressed the PwD and caregivers was its influence on religious activities, explored in the next section.

Symptoms: Disorientation and its effects on religious activities

In dementia, one of the typical symptoms is a loss of orientation to time and place. This can affect, for example:

- not knowing what year it is or what day of the week it is,
- not knowing whether it is day or night,
- not knowing what floor of a building you are on, and
- not being able to find your way outdoors (navigation problems).

Many of the participants (both carers and PwD) spoke about how the PwD has lost their sense of time of day and do not know when to pray. As timing of daily prayers is very important in Islam, this is a very difficult symptom for Muslim carers/patients to deal with. Associated with this is the difficulty the PwD have with directions/orientation, meaning that they cannot lay their prayer mats correctly (towards Mecca/Kabbah). Finally, the forgetfulness caused by dementia means that some PwD cannot keep track of how many rakats (acts of kneeling and prostration) they have done, and so they do not offer the correct number of rakats. This could be a distinctive feature of how dementia causes distress among Muslim participants.

Example quotation to illustrate:

"[Carer] *I have this issue that I have to ask him for prayer.*

[Researcher] Does he pray alright?

[Carer] *Sometimes offer two rakat, sometimes one.*

[Researcher] Does he find out the direction of Kabbah?

[Carer] *No, he does not know that. I prepare the prayer mat for him. If he does it he doesn't do it right"*

The quote from another interview are: “[Carer] *She also does not know about day or night, we have to tell her the time, like we tell her that it is time to pray. She is saying that you are lying.*”

Another problem faced by a caregiver was that the person with dementia recited verses from the Quran while in the washroom, which is not an appropriate place to pray.

"M: She has another issue. She recites Quranic verses in the washroom, even if we tell her that it is wrong."¹

Understanding of dementia progression

Many participants understood the progressive nature of dementia, and correctly anticipated a deterioration in symptoms. Some participants held on to hope for improvement. In some cases, this was phrased as a trust in Allah that things will get better rather than a definite expectation of a cure. A small number of participants believed that they would be cured with medication.

Beliefs about what will help

A wide range of suggestions were made about what ought to be done to help a person with dementia, now and in the future. The most commonly mentioned suggestions included diet (particularly almonds), not allowing the PwD to be unsupervised, exercise (both physical and mental), writing notes or a diary to keep track of things, and social interaction.

Cultural expectations

It can be stated here that in Pakistan the culture (not necessarily the religion) says that old age is about praying and closeness to God. Older people, being closer to death, are expected to be more pious. Thus, this is not just about Islam, it is also found among other cultures (see also the Gerotranscendence theory of Tornstam).

The dementia means that the PwD are not able to follow all the expected behaviours around praying, so the cultural expectation is challenged. The caregivers find this difficult to cope with. The people with dementia may experience guilt if they have insight that they have missed prayers.

Religion and fear

This section is about why carers provide care, and therefore it overlaps with the section below. The religion and fear theme is about the reasons why caregivers care. In Pakistan, this is almost entirely due to religious obligation and fear of God.

"R: I mean you guys are her family, what do you feel?"

¹ The washroom is not a clean room, so it is inappropriate in the culture to recite holy verses in the washroom.

M: We know that she has a problem. We face some difficulties but because of the fear of God and our good upbringing, we have kept her in a good environment. We try to manage her even if she becomes really stubborn."

The carer in the interview says that the reason they continue to provide care is "the fear of God" and "Allah is still watching". Also, "our good upbringing". This is despite the fact that the PwD being very agitated shouting and swearing, and telling her carers that they are lying about everything. The carer is afraid of punishment if they cease caregiving.

Fear of God seems different from a joyful willingness to fulfil one's religious obligations. It seems like they are very unhappy with the caregiving role and find it very difficult. There is no love there, only obligations and fearfulness. Does this mean the quality of care suffers? Therefore, the PwD suffers. The carers are certainly suffering.

Why do carers care: due to what neighbours (the community) will say. So far, we have not found any obvious evidence that carers are concerned about what the neighbours will say if they stop caring.

3.2 Individual interviews of family caregivers

These findings are drawn from all 20 interviews conducted with caregivers (10 from Lahore; 10 from Karachi). Caregivers were mostly female (Karachi = 8; Lahore = 6). Due to the unequal gender split, gender comparisons are made using percentages, rather than actual numbers. However, no significance testing is carried out, thus patterns in data are discussed descriptively. The themes that emerged are largely guided by the interview questions. Many sub-themes are drawn from the interviews, but only those that the majority of caregivers discussed are reported here.

Changes observed in person with dementia

Caregivers spoke a lot about the changes they had noticed in the PwD as a result of their dementia. The changes they spoke mostly about were a decline in activities of daily living (such as bathing, cooking, etc.), forgetfulness, social withdrawal, communication, deteriorating, and aggression.

Interestingly, over 70% of women spoke about aggression in the PwD, compared to only 50% of men. Aggression was spoken about by eight caregivers in Lahore and five in Karachi.

"He used to fight a lot, throw things away, hit people, kids, his daughter and even me." Female, Lahore

This gender difference in aggression could be a reflection of a wider problem in Pakistan, where domestic abuse and aggression towards women is rife (Human Rights Watch, 2017).

The changes observed in social withdrawal and communication suggest that the caregivers interviewed value socialising and communication with family and friends.

“(In such gatherings) she would become (and feel) uncomfortable. She would like (wants) to talk but was not able to do. She would become worried. We have noticed that we could not keep her (in the gathering) for long. So, after eating we would leave early. Nevertheless, we tried to keep her in the family as long as possible”. Female, Karachi

The fact that caregivers noticed that the PwD’s condition was deteriorating, suggests an awareness of the fact that dementia is insidious.

“This was back in 2013. In 2014 his condition became worse. My mother started to feed him because he could not eat by himself. From 2010 to 2014 he became really deteriorated.” Male, Lahore

Additionally, most caregivers spoke about the PwD suffering from other health conditions (multimorbidity) and this existed for all ten PwD in Karachi and six in Lahore, highlighting a greater caregiver burden.

“Before that she was diabetic and had blood pressure issue as well but this was not very severe, but after this (dementia) it kept on increasing.” Female, Lahore

Impact to caregiver

Apart from the obvious, providing care to the PwD, both males and females felt that caring for the PwD had led to isolation (trapped at home, reduced contact with family and friends) and stress (or ‘tension’). Isolation was commented on by six caregivers from Lahore and six from Karachi. However, stress was discussed by seven caregivers in Lahore and only three in Karachi.

“I have become isolated.” Male, Lahore

“Yes! Of course it affects the caregiver physically and mentally both ways. It gets stressful.” Female, Karachi

Interestingly, more females than males spoke about how the caregiving had affected their other duties (such as childcare, housework, employment), detriment to their own health, frustration/irritation, guilt, upset by other people’s reaction and worried about getting dementia themselves. More males than females spoke about not being embarrassed by the PwD and that they were worried about symptoms getting worse.

On the issue of burden, five caregivers admitted that caring for PwD was a burden, but six caregivers either felt no burden or did not want to admit to this (most of which were female). For example:

“If we think of it as a burden, then it will be a burden. If you had a baby who is disabled, then of course you wouldn’t leave them behind either.” Female, Lahore

Finally, caregivers found the most difficult part of caregiving was dealing with personal hygiene and toilet issues:

“In the beginning (at start) I had little difficulty like taking her to the washroom. But, I never discussed this or told anybody. I did not even share it with my husband. I had little bit (of difficulties) and (sometimes) I felt like crying. In the beginning I felt it and sometimes after washroom, I would go to my room. When I came out then, sometimes the children would say (ask) have you cried? I never took this. (I) might have feelings, but I never took it this way.” Female, Karachi

Managing the PwD behavioural problems was also an issue for caregivers and this was only mentioned in female caregivers:

“Everything is difficult. She is an Alzheimer patient. She kicks on my chest, on my face. She kicks so hard that it gives me an excruciating pain and still I don’t mind it.” Female, Lahore

Beliefs about the causes of dementia

Caregivers, regardless of gender or city, mostly believed that dementia is due to ‘tension’ (stress, shock or emotional trauma).

“It’s like we should take tension but in our lives we can’t live with taking tension of everything. When we take tension, it (put pressure on) our brain and leads to (such diseases).” Female, Lahore

Caregivers (mostly females 64%, compared to 33% of males) also believed that there is a genetic predisposition for dementia and this was discussed fairly evenly across cities.

“...now I feel very much afraid because it is hereditary and now I have also become forgetful.” Female, Karachi

Beliefs about dementia care

Caregivers alluded to many different beliefs in their interviews, but the belief that was the most widespread was that caregivers felt it is the family’s duty or responsibility to look after the PwD. This largely stems from Islamic teachings, where taking care of parents is a duty. There were no differences amongst gender or city in this belief.

“I did not sacrifice anything. My siblings and I consider it our duty.” Male, Lahore

“My parents told me one thing after marriage that taking care of your husband is your prime responsibility and take it as “Jihad” so I take it as my responsibility, when I don’t understand him in start of my marriage I said to my mother why did you do my marriage I will do anything except marriage you can send me to the mountains of Pakistan, I can join army & save my country at border so she said taking care of your husband and family is the biggest jihad more than to save the country she always said the human serving is the best thing now taking care of your husband is your duty.” Female, Karachi

Support received

Support for the PwD was mostly conventional healthcare and family support (practical, financial or emotional). Both types of support were high across cities and there were no differences in terms of the gender of the caregiver.

“Yes. We go everywhere people tell us. We have also consulted a psychiatrist. WE went to General Hospital, CMH, other private hospitals, basically we have gone everywhere someone has pointed us. We have consulted almost 25 doctors, I have not brought his reports now but we have gone to almost 25 doctors. We have gone to Faisal town, Johar town, even Faisalabad (for his treatment).” Male, Karachi

“...but now as well I have my father and husband, so they all put effort to take care of her.” Female, Karachi

Interestingly, home help or ‘attendants’ (i.e. hired help to aid household chores and/or PwD care) were employed by six caregivers in Lahore and seven in Karachi. A higher proportion of male than female caregivers received home help.

“So that’s why I have appointed attendant. There are two attendants one for day and one for night, and she is day attendant. Both are too helping and I am so much thankful to both of them.” Male, Karachi

Treatment received

The type of treatment that the PwD received for their dementia was mostly conventional. Conventional treatment was taken up by all male caregivers, but only 57% of the female caregivers. There appeared to be no difference in access to conventional treatment between cities. However, some caregivers commented that the medication that the doctor prescribed was expensive and friends/family living abroad, who were in the healthcare profession had to send it to them:

“Yes a lot gradually but yes... and we immediately started giving him Aricept... Okay yes that so nice it was diagnose after the MRI Dr M prescribe Aricept which was at that time 2007 and 2008 it was more than 10 years so.... It was very difficult to get because it was very expensive but then there I have some friends in US she is psychiatrist she brought some for me and my cousin is a psychiatrist he sent some to me so Alhamdulillah [thank God]...” Female, Karachi

Six caregivers mentioned that the PwD was not taking any medication for dementia (five were female caregivers and five lived in Lahore).

“No medicine for Alzheimer’s” Female, Lahore

Reasons for not receiving support

There were many different reasons for why PwD and their caregivers did not receive support, including the cost, family living abroad, external care not as good as family care and unable to transport the patient to care services, amongst others. However, the reason that most people gave was being unaware of help or services and this was regardless of city or gender.

Suggestions about dementia in the wider society of Pakistan

Caregivers had many different suggestions on how the growing problem of dementia must be addressed in Pakistan, including better training for healthcare staff, more daycentres needed, more online support needed, and more support groups needed, amongst other suggestions.

“I just say that day care centers should be established in all areas. And it should not be one, there should be a number of day care centers.” Female, Lahore

“I think the caregivers in Pakistan are not particularly trained for Alzheimer. If it was up to me I would like to provide a service that has properly trained care givers who are not only trained psychologically and mentally but also physically. Although we do have trained caregivers but they are not as educated as I expect them to be.” Male, Lahore

“...I have seen people with Autism or other problems; they have support groups which are very helpful. You learn to deal and learn from others experience. You learn a great deal because you are going through these. There should be support groups; there is for the Diabetes. There should be (support groups) in this there is no issue.” Female, Karachi

However, the suggestion that most caregivers mentioned was that awareness about dementia needs to increase in Pakistan and TV, radio and online tools for increasing awareness featured quite highly

“Yes awareness is necessary for people. In my family nobody knows, even in my in-laws, nobody know about dementia, I told them about dementia.” Female, Karachi

“What could be done is that a TV commercial could be run.” Female, Lahore

“...like social media that informs that what it is, what kind of disease it is. I have read and learnt lot of things relating to the disease of my mother-in-law from Internet. My husband has also read about it.” Female, Karachi

3.3 Focus Group Discussions

Dementia awareness

The majority of participants identified a variety of causes of dementia or its symptoms. Most prominently, participants felt that the symptoms were due to normal age-related decline.

“Commonly, this is because of old age that it is an ailment.” Female, Karachi

Many participants did however incorrectly identify that the cause of dementia was due to life-stresses, often referred to as “tension”.

“...because of the tension, the person has the disease of forgetting.” Female, Karachi

“It happens because of worries.” Male, Karachi

Tension was a common feature in all three sets of data analysed so far (PWD, Caregivers, and FGDs).

Whilst there were a few participants that did understand that the vignettes were about dementia, many attributed the symptoms to other underlying conditions health conditions, most prominently diabetes.

Family

Family featured heavily throughout the FGDs, and commonly was raised in relation to their responsibility of care. The family’s responsibility of care was seen as driven, in part, due to societal norms. This sometimes led an emphasis of individual family members taking a greater responsibility in this role:

“It is your moral responsibility that if (there is a patient in your home), then you should look after them, it’s not just the duty of the daughter in law.” Male, Lahore

Tied with this, participants saw that the cases described in the vignettes, as being the fault of the families. Either because they did not spend enough time or attention with the person with dementia.

Self

Participants in the FGDs identified that there was an element of personal responsibility when it came to dementia and its symptoms. Most prominently, it was seen that the individual acted as a barrier to their own healthcare:

“In my opinion she should remove these barriers herself.” Male, Karachi

In part, this can be explained by the fact that participants felt that the symptoms were as a result of the individuals own actions or weakness that caused the illness.

“She has inherent weakness.” Female, Karachi

Barriers to accessing care

Participants often struggled to identify potential barriers to accessing care for someone living with dementia, aside from self- or family-related barriers (see above). However, finances were identified as a key barrier to accessing support and healthcare.

“Household members would like to (medically) treat her, but there is also no money; so her memory was getting weak that there is no money and treatment cannot be done” Male, Karachi

Some of the participants felt that the current healthcare system was a barrier to receiving care. Either because of feelings that the doctors were not sufficiently trained, or that they would make an incorrect diagnosis.

“If I will take (the patient) to government hospital then the doctor will tell me that this is due to old age so I should take care of them and pray for them”
Female, Lahore

A smaller group of participants also identified that stigma may be a limiting factor, either from the diagnosis or the fact that getting external help being seen as embarrassing.

“That if we will send our parents to day care then what will other people say about us? If we will hire some helper then what will the people think or say about us?” Female, Lahore

Additional support

Most frequently, participants identified the need to raise more awareness about dementia. Some participants suggested using a strategy similar to those used to raise awareness of polio and dengue fever. The government was seen as being primarily responsible for raising awareness.

Participants believed that new facilities (e.g., hospitals) and specialists were needed, though it is important that this was accompanied by more information about how and where to access this healthcare.

“Institutions should be opened immediately and the ones that are open, should provide environment like home.” Male, Karachi

“There is no information available regarding the doctor that where he will be available” Male, Karachi

Participants felt that hospital environment should be accessible, low-cost and relaxing.

Religion

The theme of religion and spirituality featured heavily when describing the treatment and progression of the condition:

“Whoever keeps Allah pleased then, everybody is pleased. Even if we perform Farz² then, it is my conviction that we all can remain safe from disease. Everybody should pray (follow their religion).” Female, Karachi

Religion was also used to explain why the family members should provide care for someone with dementia:

“It is very clearly mentioned in the Holy Quran that you need to treat your parent like your parents treated you when you were young.” Female, Lahore

It would be good to also analyse the accuracy of the FGD participants’ opinions about dementia.

3.4 Key Informants Interviews³

The key findings are summarized along the lines of the questionnaire used for these interviews.

Education and awareness and early diagnosis

Key informants pointed out awareness raising campaign needs to be initiated in the population for early diagnosis. This can be done by raising awareness about what is dementia and what services can be used for dementia patients. Both print and electronic media should take part with supplementation of public awareness seminars in different towns and cities of the country.

Quote: “Campaigns, I guess, should focus on the fact that that there are different forms of normal ageing, forgetfulness comes with normal ageing. That is not simply attributed to the fact that people are going to be old and what is important at that age”.

Stigma and discrimination

There is strong stigma associated with dementia and similar mental health problems. However, it is also believed that the raising awareness about dementia alone will not go very far, due to lack of formal health and social care services available. Instead, it is believed that it will be more useful to link it to the reality of wear and tear linked with ageing which needed to be taken care of.

Quote on how best to refer to the challenge of dementia in the absence of formal care services: “... there are certain illness linked with ageing and within this context of advance ageing and we talking about mental health issues, then

² Farz or farīdah is an Islamic term which denotes a religious duty commanded by Allah (God).

³ These are the opinions of our key informants. We do not necessarily accept everything they say as facts.

parking dementia in this context will be more acceptable and more understood. For example, isolation in old age, [and] increase of illnesses in old age is something that happen is more acceptable. Within that context, increase in condition of forgetfulness from normal is a sign of dementia”.

Capacity building and training

In many cases, the family practitioners are the first contact for dementia patients. Hence, training of primary care GPs is considered extremely important. This could be achieved by ensuring that undergraduate and postgraduate curriculum of family practitioners should have dementia as a core subject.

Again, the observation was made that awareness raising activities should be supplemented with the provision of services.

“...but I would also go further than this [viz. the talk of capacity building and training] that raising awareness without providing those services or provision of accessible and affordable services does more harm than good”.

Support services for family members

There is very little available in the form of formal support to caregivers. Families with persons living with dementia will struggle to get specialized services if they are not well off, especially at the primary care level. There is a clear socio-economic gradient: families who come from higher economic class have access to resources and information, specialist, therapist staff and nurses. The middle or low-income groups are fully reliant on their individual and familial informal care resources.

Quote on the desperate situation of low-income groups: *“...they are literally on their own and there is nothing for them. It would be fortunate for them if some specialist found [diagnosed] dementia for them which in most cases is not [a formal] diagnosis. They are really deprived of the services.”*

One key informant made specific suggestions about what needs to be done:

Quote: “I would suggest they should have access to specialist who can make diagnosis and once diagnosis is made, the plan of management should be detailed. Patients’ needs according to severity of diseases needs to be defined. Supporting the family, giving them right information and given them right services and helping them optimize their resource within their family”.

Future programmes, policies and legislations

There is very little or no discussion on what future programmes and policies may be necessary in the treatment of dementia in Pakistan. The same expression is obtained in any planning for the development of minimum standards of care for persons living with dementia?

“No absolutely not - that I am aware” “No dementia strategy yet”

Research and evidence

What research and evidence is needed to raise the awareness about dementia? It is emphasised that more information should be available about the common symptoms, how symptoms change with time and what are different types of dementia.

“I think that sort of research is needed, basic epidemiological research needs to be done which tells us the pattern of dementia in Pakistan. Next step is essential to classify the different types of dementia and to really see what prevalence of each type is”.

“We need to map the prevalence in different ethnicities and to see the onset in different parts such as northern areas and southern areas. This could throw us some protective factors that people in northern areas are protected than southern areas or living in the place and vice versa. These all are the grounds for research and I think given the fact we are low-resource country, basic bench research might be expensive to do, but basic epidemiological research to see pattern, looking at profile this is something can be done easily”.

It can be surmised that the knowledge transfer from the research carried out elsewhere in the world, typically high income and developed countries, will be useful.

When asked about the knowledge of the work in this area in other countries (e.g. WHO Global Observatory on Dementia; good policy practices in other countries, etc.), there were some awareness but without raising much hope for the change happening in Pakistan.

“As far as dementia is concerned, I doubt very much. Brought dementia in policy discourse when mental illnesses has low priority, within that, case dementia which is problem of old age this may be way down in the priority list of policy makers.”

Cultural and religious beliefs and treatment

A commonly held view from our key informants (many of whom are from the healthcare sector) is that there is general reluctance to seek help in anything that is do with the mind. Mental illness, mental disorders and mental problems tend to remain contained in families, as much as possible, until the crisis time when conditions become unmanageable at home. This is not the case for our insights drawn from the interviews with the patients and their carers, all of whom have sought help and had a diagnosis

It is believed that this is due to lack of awareness as common people do not think dementia is an illness, and due to lack of resources and poorly developed public health system. These barriers can prevent people to seek treatment and care and it is believed that all these barriers can be removed through well informed public policy interventions. More research within the context of Pakistan and learnings from other parts of the developing world are deemed essential.

“I believe research is very precious activity for low income countries. Do research here, particularly those who come from abroad - they have ethical responsibility to make sure the research they are conducting over here is of such value that research is in the benefit of people and culturally sound. The dialogue with policy makers is to start early to engage them in the start. After research is conducted the finding should be shared through seminars and publishing reports and it goes beyond to see the policy is developed on the basis of findings”

4. Policy implications

Potential policy implications that result from the findings of individual interviews include:

- recommendations about raising awareness of dementia as not a normal part of ageing, and where to seek help,
- reviewing the information given by health care services to people with dementia and their family members when a diagnosis is made, and
- exploring the appropriateness of giving advice about expectations of prayer when a person is cognitively impaired.

The findings indicate the following policy implications from the interviews of caregivers:

- A national campaign to raise awareness about dementia, in terms of how to identify it, what the risk factors are and how to seek help. Tools such as TV, radio and social media should be used to raise awareness.
- More funding needs to be allocated for specialist dementia services, including specialist wards/hospitals, day care centres and support groups (both for caregiver and persons with dementia), and for increased dementia healthcare staff and better training for staff.
- As families in Pakistan are more likely to accept home help than send persons with dementia to a nursing home, more affordable and more specialist home help services need to be developed.

The policy priorities drawn from the analysis of the Focus Group Discussions are:

- One of the most striking finding in the public is that there is often a lack of awareness of dementia and its symptoms, often attributing it to normal ageing. This leads to misconceptions about care and prognosis. Highlighted within the groups, were the need to raise awareness for dementia amongst the public.
- Religion features heavily in the FGDs, usually providing rationale and meaning to a complex topic. It is essential that religious leaders speak out about dementia, both in terms of raising awareness, but also the acceptability to seek for help when needed.

- The creation of centres dedicated to providing specialist treatment and care for dementia. It is important that these centres are affordable, accessible and a pleasant environment. To ensure that they are accessed, it is essential that these centres are advertised to the local communities.

Key policy implications from the key informant interviews are:

- There is a strong income gradient in understanding about dementia and seeking specialised services. The awareness campaigns about what dementia is and what formal services are available should target low-income groups.
- Training of primary care GPs is considered extremely important, which can be achieved by ensuring that undergraduate and postgraduate curriculum have dementia as a core subject.
- Another finding is that raising awareness among dementia patients and their caregivers will have to accompany availability of health and social care, otherwise it would be counterproductive.
- Research and evidence-informed policymaking is scant. The knowledge transfer from the research carried out elsewhere in the world, typically high income and developed countries, will be of highest value, provided the policies implemented are culturally sensitive.

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