

Understanding, Beliefs and Treatment of Dementia in Pakistan

FINAL REPORT

By

Asghar Zaidi, Hussain Jafri, Rosalind Willis, Nicolas Farina, Sara Balouch, Irfan Ahmed, Qurat Khan and Rubina Jaffri

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Member of the HelpAge global network

Alzheimer's Pakistan

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September 2019

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Statement by Dr. Yasmin Rashid, Minister of Health Punjab

Pakistan is one of the most populous countries in the world. With 14 million older men and women (aged 60+), Pakistan is placed among the group of only 15 countries worldwide that have more than ten million older people. The population of older persons in Pakistan is predicted to increase to 44 million by 2050.

This trend of population ageing has vast implications for our nation's economic, social, and political futures. While we celebrate increasing life expectancy in Pakistan, we also need to proactively confront this change.

As population ageing continues to accelerate, the number of dementia cases is also expected to increase, expected to double nearly every 20 years. Greater priority is assigned to dementia all around the world, for the fact that it has large human and financial costs for governments and for individuals.

To address these challenges, we need to stimulate greater investment and innovation in dementia research. In this way we can raise awareness about how best to improve the prevention, diagnosis and treatment of dementia. Underlying all of this is the aim to improve quality of life for people with dementia.

With these broad objectives in mind, we are now embarking on developing the national strategy of dementia in Pakistan. It will provide comprehensive and sustainable dementia diagnosis, care, rehabilitation and supportive services across Pakistan.

Our mission is to make dementia a national health priority in Pakistan and channel the flow of required resources to provide prevention options, early diagnosis, support services, research, capacity building and policy development for dementia. The Government will spearhead the move towards managing dementia, while engaging all relevant stakeholders across the public and private sectors.

I am pleased to see the key findings of the research included in this report. Such a study of beliefs, attitudes and awareness about dementia have important implications as it provides evidence on treatment seeking behaviour and pathways to care. I consider this study novel as it helps us identifying the interaction between dementia symptoms and how social and religious norms cause distress among people living with dementia and their family caregivers.

I commend Professor Zaidi's untiring work in leading this project and all the members of the research team from Pakistan and England. But, most importantly, I wish to thank all of the people who took part in the interviews for generously sharing their time and experiences.

Statement by Chris Roles, Managing Director, Age International

Age International, as the UK member of the global HelpAge network, exists to respond to the needs and rights of older people in low- and middle-income countries.

With our partners, we seek out opportunities both to respond to the pressing and growing challenges associated with population ageing, and to share learning from our programmes, and commission research, in order to raise awareness and understanding of what needs to, and can be, done.

Addressing the changing health needs of populations with growing numbers and proportions of older people is a core part of Age International's focus. And we are pleased to align ourselves with organisations and networks that are responding to the rapid and unprecedented increase in the number of older people living with dementia.

As we do so, we are aware of the very wide range of levels of public understanding and attitudes about dementia in the countries where we support work, and the very great need for health and social policies and systems to adapt - or, rather, be transformed - to better diagnose, treat and support those living with dementia.

Supporting the research described in this report has been one contribution we have been pleased to make to add to the body of knowledge and understanding about, and the treatment of, dementia, and it has been a privilege to work with academic, health and civil society partners in Pakistan and in the UK on this project.

We hope that the findings of the report, and the discussion it provokes, will contribute to the development of public understanding, and of policy and practice in Pakistan, and be a support to those organisations working for that transformation in the response to the already significant and growing challenge that dementia poses.

We hope too that the report will prompt further ideas for research, and that Age International will be able to play its part in making this happen.

We are especially thankful to, and record our good wishes to the older people, their caregivers and wider families who participated in this study.

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EXECUTIVE SUMMARY

Background

Despite being a global health priority, progress towards the understanding and treatment of dementia in low- and middle-income countries has been slow (ADI, 2015; WHO, 2017). This issue is of importance given the rapidly ageing populations in these countries, which in turn will lead to a greater number of dementia cases placing further stress upon a country's health and social care system. The informal care burden is also likely to be higher in these countries, partly because of low social services but mainly because the round-the-clock care is required for those with advanced stages of dementia.

Background

There is also lack of social science research in countries like Pakistan. Little is known about the prevalence and experience of dementia in Pakistan. The 10/66 research project carried out population-based research into dementia in low- and middle-income countries, but Pakistan was not among its research sites (Prince, 2010).

Pakistan 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). Despite the rising number of older persons in Pakistan and their low socio-economic status, there is very little research on issues linked with old age, especially the rising public health concerns of dementia (Zaidi et al. 2019).

Research needs to be undertaken to identify peoples' understanding, beliefs and attitudes about dementia to advocate for the most effective policies and programmes in raising awareness as well as providing formal support to people with dementia and to their caregivers to reduce their burden and stress. The current study has aimed to fill this gap with a case study of Pakistan.

This study summarises the findings of individual interviews with people living with dementia and their family caregivers in Pakistan. The study also analyses the understanding of the general population and stakeholders about dementia and its care in Pakistan.

Such a study of beliefs, attitudes, and awareness about dementia has important implications as it affects treatment seeking behaviour and pathways to care. The study is novel in identifying the interaction between dementia symptoms and Islamic obligatory daily prayers, and how this causes distress among people living with dementia and family caregivers.

From past research in Pakistan, it is evident that there is also limited awareness among the general public about dementia and it is often believed to occur as a part of normal ageing process, secondary to traumatic events, stressors or physical weakness. Research carried out in the UK and in other countries outside the UK also show that the stigmatisation, or fear of it, has led some South Asian families to conceal the person with dementia and therefore inhibit access to appropriate health and social care services.

Methods

The study interviewed a total of 40 dementia patients and caregivers in the two most populous cities: Karachi and Lahore. Focus group discussions involved a further 40 participants, equally divided between men and women. Eight clinicians and academics took part in the key informant interviews.

Three research instruments have been prepared and used by the research team based in England and Pakistan:

- The guidelines for individual interviews for persons with mild dementia explore their pathways to diagnosis; facilitators to accessing care services; any cultural or religious factors affecting their diagnosis, experience and attitudes; and experiences of stigma.
- The guidelines for individual interviews with family caregivers draws insights on how family caregivers cope, what barriers do they face, and what help they would be willing to accept based on the complexities of the cultural and religious values in Pakistan.
- The third instrument explores perceptions of dementia, its treatment and care in a focus group of adult Pakistanis who did not have a prior experience of dementia. Two vignettes, depicting someone with mild dementia and someone with severe dementia, were used to facilitate focus group discussions.

In addition, the guidelines for the interviews with key informants were also prepared that provided important contextual information for Pakistan. For example, the key informants provided insights concerning the availability and adequacy of the health care provisions for dementia patients and support available for family caregivers.

Interviews were conducted in Urdu, translated to English, and respondents' views were analysed thematically using an induction led approach.

Whilst this method provides interesting insights into experiences of dementia in Pakistan, it is far from being a representative sample of all those living in Pakistan. In particular, there is a pressing need to understand whether the findings are the same in rural areas of Pakistan, where healthcare services are more dispersed, there is greater poverty and religious beliefs might be more varied.

Key findings

Lack of awareness

One of the key findings is the lack of awareness of dementia and its symptoms among most of the participants. Respondents attributed the condition to a range of factors, such as overworking, stress, shock, social isolation and in more extreme cases, black magic. These misconceptions have led to misunderstandings about care and prognosis.

A strong minority of Pakistanis do possess an understanding about dementia. This finding also points to diversity within this group and the dementia awareness appears to correlate with social status. For example, in the interviews of people with dementia, those who had a biomedical understanding of dementia tended to have a higher socio-economic status or had medical practitioners in the family. Thus, they had greater opportunities to acquire knowledge about dementia.

Stigma

Concerning stigma, there was a diversity of experiences. Discussions in the focus groups reported that the potentially stigmatising attitudes towards dementia in public arise mainly due to negative and inaccurate beliefs about the causes of dementia. Some felt that the person with dementia or their family were to blame for the condition. It was often viewed that the family held responsibility for providing care and that seeking help outside of the family is interpreted by others as disrespectful (as strong family beliefs and image conscious society in Pakistan demand that you personally take care of your elders).

In the individual interviews for people with dementia many people did not report experiencing stigma from community members and reported support in view of dementia persons' age and debility. A possible reason for people with dementia not being mistreated by community members may be that these people are still in the milder stage of dementia. They are able to go out-and-about by themselves, do shopping, etc. The symptoms that community members observe (getting lost on the way home from the mosque, forgetting to bring groceries home after shopping) are not socially unacceptable behaviours. Therefore, community members respond with kindness and try to help, and they accept it as part of the ageing process.

In contrast some caregivers reported a stigmatising experience. This may be due to the fact that we interviewed caregivers of people in the moderate to severe stages of dementia. In contrast to people with mild dementia, if these people were displaying more socially unacceptable symptoms like aggression or swearing in public then they would be responded to in a more negative way by family members and neighbours.

Caregivers burden

Caregivers also spoke of feeling isolated, with more women than men expressing concerns about how they must neglect other duties such as childcare, household tasks and their jobs. They also spoke of the effects on their own health and feelings of frustration and guilt that they felt helpless to treat dementia and could only observe the progressively worse suffering that it causes.

Different reasons were given for why people with dementia and caregivers do not have access to extra support. A strong barrier to seeking help is the stigma associated with dementia due to underlying negative and inaccurate beliefs in society. There is also 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. Furthermore, most people are unaware of any formal social services available to them, whilst many have viewed family care as being superior (and an obligation) to what little external care services exist. The financial capability is another barrier in getting formal help from outside home.

Religion

Religion stands out as an important theme throughout the analysis, but the interaction between dementia and Islam is less clear.

Observant Muslims are expected to perform prayers five times daily following a strict routine. Failure to perform these prayers can lead to a strong sense of guilt as well as a risk of societal disapproval leading to further isolation. Cognitive impairment interferes with one's ability to perform this routine correctly and many participants discussed the difficulties they experienced. Family members assisted people with dementia with the prayer routine to enhance spiritual wellbeing. Those who are extremely cognitively impaired may be exempted from the obligation, thus potentially relieving guilt.

Some scholars have argued that people with a cognitive impairment such as dementia ought to be exempted from obligatory prayers, because they do not have the 'clear mind' essential to engage in prayer. No mention of such an exemption was made by participants in the present study, so this knowledge does not seem to be common in Pakistan.

Recommendations

Important policy recommendations stemming from this research include:

- Developing a national campaign to raise awareness of dementia, highlighting symptoms and their progression, and how to seek help and diagnosis.

- A national screening programme to identify dementia cases will be extremely beneficial, as would increasing the affordable, visible and accessible specialist dementia services, such as the day care centres, dedicated hospital wards and staff and support groups.
- Better formal home-based support for care should be provided as families are more likely to accept home-based care than institutional care.
- Family caregivers need to be advised to enable prayers, e.g. by assisting with ritual ablutions and placing of prayer mats, if the person with dementia wishes to continue praying.
- Strong communication strategy is required from experts, religious and community leaders to raise awareness about the disease as well as to enhance the acceptability of seeking help from outside home and to learn to exercise exemption from prayers for those with mental disorders.
- A greater emphasis on evidence informed policymaking is essential, with knowledge translation from the research in Pakistan and from different regions of the world.

Raising awareness among dementia patients and their caregivers must be accompanied by an increase in the availability of health and social care, otherwise it would be counterproductive in raising stress linked with the disease. The findings of the research also have the potential to be relevant for South Asian families with strong cultural and religious identities living in Britain. 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 local authorities.

Future research

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 also be of good value, provided the policies implemented are culturally sensitive.

We need to upscale and expand dementia research within Pakistan. Tied with this, a nationally representative survey of Pakistan could help us better identify whether certain demographics or cultures predict attitudes and knowledge of dementia. Not only will this improve our understanding of dementia attitudes and knowledge in Pakistan, but it would better inform policy makers whether certain groups need to be targeted as a priority or whether different awareness campaigns are needed.

In future research, it would be advantageous to conduct the analysis in Urdu, before translating into English, but this was not logistically possible in this study.

1. Introduction

1.1 Motivation

Dementia is the collective name of a progressive disorder caused by a range of brain diseases, with Alzheimer's Disease being the most common. Alzheimer's causes a gradual loss of brain tissue. Proteins build up in the brain to form structures called plaques and tangles. These structures disrupt connections between nerve cells, causing them to die. The disease also causes a shortage of important chemical transmitters in the brain (Piggot and Court, 2008).

Dementia is a progressive disease, which means that, over time, more areas of the brain become damaged, causing new symptoms to develop and existing symptoms to become more severe. According to one estimate, close to 46.8 million people are currently living with dementia worldwide, 58% of which reside in low and middle-income countries. 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. Problems with the activities of daily living (ADLs) and behavioural and psychological symptoms are also common in dementia, including agitation, aggression, apathy or disorientation in time and space. Dementia is not only a disease for older ages but can also occur in younger persons, although it becomes more prevalent as age increases (Prince et al 2014). Dementia has become a global health priority (WHO, 2017), especially in the resource constrained low- and middle- income countries where the speed of population ageing is faster (Zaidi, 2015).

This report synthesizes the findings of a project analysing experiences of people living with dementia and their caregivers in Pakistan. It also analyses the understanding of the general public about dementia and its care in Pakistan. The key informants' interviews help in appreciating better the socio-economic context of Pakistan.

There is currently no definite 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. One of the barriers to identifying an early diagnosis arises if individuals living with dementia or their family members do not recognise the symptoms of dementia (Regan 2014). *The first piece of research in this project concerns the experiences of those diagnosed with the mild stage of dementia.*

The burden of informal caring for family members can also be particularly serious. In the UK, for example, it has been estimated that informal care outweighs all formal sources of care (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 their 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- and middle-income countries like Pakistan 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 that 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 second piece of research undertaken in this project is about the caregivers' experiences.*

A further barrier to seeking help is the stigma associated with dementia (ADI 2012), due to underlying negative and inaccurate beliefs in society. For example, the misconstrued belief that the diseases arise because of individual's own fault or due to family neglect (Giebel et al 2015; La Fontaine 2007). This highlights a need for increased awareness of the understanding and beliefs surrounding dementia across cultures (Gabriele and Borin 2014).

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 also 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). This is in part related to differences in understanding about dementia, stigma, or barriers to accessing services. *The third and final piece of research reported here concerns the general public's belief and attitudes towards people with dementia.*

The interviews with key stakeholders provided the context. 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. The current study has aimed to fill this gap.

1.2 Project implementation

The project's implementation took place in four phases:

1. **The Inception phase** started in the first week and continued approximately for the first four months of the project. It covered preparation of the interview guidelines for persons living with dementia, for their caregivers and for key informants. The guidelines for the focus group involved preparing the vignettes and questions for the discussion. The inception stage included collection of literature on the specific topics to be covered in the study.

   The survey instruments were prepared in English, and subsequently translated to Urdu by the teams in Karachi and Lahore. The consistency check of the translation was undertaken by comparing the translations provided by the two teams in Pakistan.

   Training was provided to the enumerators of the individual interviews and facilitators of the focus group discussions. The Ethics approval was obtained from the University of Southampton and the Aga Khan University Karachi. The Patient and Public Involvement (PPI) was conducted in Lahore by Alzheimer's Pakistan ensuring that the data collected in the tools mentioned above stays meaningful, and its ethical quality and impact optimised.

2. **The data collection** work started in summer 2017 in Lahore and Karachi. It involved conducting interviews and focus group discussions and the preparation of the transcripts (in Urdu and English). The data collection work went exceptionally well, largely attributed to the excellent work of the research team at Alzheimer's Pakistan in Lahore and at HANDS Karachi. The team from Age Khan University facilitated the recruitment of dementia patients and their caregivers. The data collection work benefitted from the direct involvement of the project partners from the United Kingdom in conducting some early individual interviews with the patients and the caregivers, assisting with facilitating the focus group discussion and conducting majority of the key informant interviews.

3. **The Analysis phase** started upon the availability of the data from Pakistan. The preparation of the themes and data entry started upon the availability of first 2-3 transcripts of the interviews. The transcripts were analysed using thematic analysis (Braun & Clarke, 2006). Project team meetings took place to determine the themes for the analysis of data collected. This included training for the software (NVivo), by the CI at University of Southampton, to handle qualitative data. The analysis stage reviewed additional literature on the specific topics for the preparation of the three peer reviewed papers.

4. **The Dissemination phase** started as soon as interim findings were available. It involved a meeting with the members of the Scientific Advisory Board, and hosting of events in Lahore and Karachi. Another event took place in London upon the completion of the final report. Some dissemination activities also took place during the lifetime of the project, at the project inception and the data collection stage.

2. Context in Pakistan

According to World Bank, Pakistan is categorised as amongst the low- or middle-income country and it is currently the sixth most populous in the world. It had an older population (age 60+) of approximately 12.5 million in 2017. In percentage terms, it constitutes only about 6.5 per cent to 7 per cent of the total population, but they are by no means an insignificant segment of the population in terms of their number. Pakistan belongs to a group of only 15 countries worldwide that have more than 10 million older people. In the future, the rising life expectancy will lead to an increasing number of old and very old people in Pakistan. By 2050, the number of older persons age 60 or above living in Pakistan will reach 40 million.

Pakistan has a 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 extremely low in the Global AgeWatch Index, at 92 out of 94 countries, which is a means of ranking countries according to the circumstances of their older people, including health, income, employment and social connectedness (Zaidi 2013). Pakistan 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 (HelpAge International, 2015).

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 (Prince, 2010). However, there is a dearth of dementia related research in Pakistan and subsequently limited resources to deal with this rising epidemic (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 Sanober, 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 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 oldest 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 the parents 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, often reporting that the patient has always had such symptoms, and/or their memory is excellent as

they remember each 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 in Pakistan 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 changes in hobbies and socialization 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).

As there is so little evidence from Pakistan, it is deemed relevant to also look at literature from the Pakistani diaspora, or other South Asians abroad, for transferable knowledge. Please see Annex A for a broader narrative of experience of dementia in South Asian communities in the UK and in other countries outside Pakistan.

3. 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 aspects are researched using the data collected: (1) What are the circumstances of older people living with dementia, including income, material security and support in relation to the costs of care? and (2) What level of services and access to health care is available for dementia?

Data were collected using qualitative research methods, namely the 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 was analysed using thematic analysis (Braun and Clarke 2006).

Due to the structural inequalities in Pakistan, people who have successfully accessed mental health services and gained a diagnosis of dementia are more likely to be of a higher socio-economic status (SES). As we set out to recruit people with a diagnosis of dementia, and caregivers of people with a diagnosis, the socio-economic profile of our participants was, predictably and unavoidably, high. The general public interviewed in the focus group discussions did not have such a bias: based on the household monthly income, on average over half of participants had an income less than Rs. 40,000, which is not considered high SES.

3.1 Data collection

The study interviewed a total of 20 people with dementia and 20 caregivers in Karachi and Lahore. Focus group discussions involved a further 40 participants, equally divided between men and women. Eight people took part in key informant interviews.

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 people with no experience of dementia, and
IV. Key informant interview guide for stakeholders.

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

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 persons with dementia	10	Karachi	AGA Khan Hospital
2.		10	Lahore	Alzheimer's Pakistan
3.	B. Individual interviews with caregivers	10	Karachi	AGA Khan Hospital
4.		10	Lahore	Alzheimer's Pakistan
5.	C. Focus Group Discussions	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	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 with caregivers were supplemented with closed-ended questions to explore socioeconomic status of people with dementia and availability of public healthcare information. The 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 stayed meaningful, and its ethical quality and impact optimised. Alzheimer's Pakistan undertook appropriate involvement with family caregivers and people with dementia in the design and conduct of the project. Through the PPI in the dissemination strategy, potential beneficiaries of the research were informed ensuring that findings are accessible to a wider community.

I. Individual interviews

The topics covered with people living with dementia and their family caregivers were similar, but the wording was 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?', respectively. The topic guide below demonstrates the topics that the interviews covered. In addition, these questions were followed with more structured questions about socioeconomic 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 research question 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.

II. Focus Group Discussions

A series of FGDs was held with members of the public with no family experience of dementia 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. The vignettes were culturally adapted from a study that explored awareness and understanding of dementia in minority ethnic groups (La Fontaine et al., 2007).

The vignettes were also independently reviewed by dementia experts in our research team in the 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 probed issues concerning the cause of the condition and how best to support and

treat them. Vignettes are considered useful tools for FGDs on sensitive topics, because they shift the focus away from a specific individual, making it easier for group members to offer opinions.

III. Key Informant Interviews

The Key Informant Interviews were a one-off individual semi-structured interview with key stakeholders in Pakistan, for example practitioners and policymakers. 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.

3.2 Data 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 from cognitively impaired individuals and for the cultural and religious sensitivities. They were trained to use the study instruments by the research team.

All interviews and FGDs were 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 research team in the UK, where further quality checks on the translations were undertaken. The finalised English transcriptions were used by researchers for the analysis.

The data coding was carried out by researchers from the UK (Southampton and Brighton), using a specialised software NVivo, and coding decisions were independently reviewed by other members of the research team. All qualitative research methods were analysed using thematic analysis, driven by the data (Braun & Clarke, 2006). An initial analysis meeting was held in Southampton to discuss how coding was to be carried out. Subsequently, another meeting provided an opportunity to discuss the analytical approach adopted by the researchers.

Three pieces of research were undertaken:

I. 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.
II. Family caregivers of people with dementia, and the challenges they have experienced; what support they have and wish for; how the dementia affects them.
III. Members of the public, and their understandings of dementia; stigma related to dementia; barriers to accessing care services.

The views of key stakeholders regarding the dementia programmes and policies in Pakistan provided the context. The findings of the project were presented in events in Lahore and Karachi, under the lead of Alzheimer's Pakistan and HANDS Pakistan, respectively. In partnership with Age International and Age UK, one event will be organised in London to present the findings of the project relevant to the British audience. Another dissemination event took place in Bradford, on 28 February 2019, with the help of a grant from Alzheimer's Disease International (ADI). The findings were also presented at conferences in the UK (British Society of Gerontology) and internationally (IFA conference in Toronto, and the AAIC, Chicago).

4. Interviews of persons with dementia

Aim: This part of the project set out to explore people with dementia's pathways to diagnosis; facilitators to accessing care services; any cultural or religious factors affecting their diagnosis, experience and attitudes; and experiences of stigma. Further discussion on the topic is included in Willis et al. 2018.

4.1 Background

There is only a small amount of literature about the experiences of people with dementia in Pakistan, so this review also draws on the transferable knowledge from Pakistani and South Asian people around the world. Such literature commonly focuses on dementia awareness, experiences of stigma, and access to health and social care services.

A study of people with dementia and their family caregivers in Karachi reported that only half knew what their diagnosis was (Khan, Khan, Khan, & Najam, 2017). This finding is not specific to Pakistan, however. South Asian caregivers of people with dementia in the UK also reported that they had not heard of the term 'dementia' before their relative received a diagnosis (Adamson, 2001; Bowes & Wilkinson, 2003). The understanding of dementia and its causes is low in most studies of Pakistanis and South Asians in other countries. For example, dementia is incorrectly thought to be a normal consequence of ageing (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007; McCleary et al., 2013; Næss & Moen, 2015; Qadir, Gulzar, Haqqani, & Khalid, 2013; Turner, Christie, & Haworth, 2005). Similarly, dementia is incorrectly thought to be caused by a family rift, stress, the 'evil eye', the fault of the person with dementia, or lack of family care (Adamson, 2001; Bowes & Wilkinson, 2003; La Fontaine et al., 2007; MacKenzie, 2006; McCleary et al., 2013; Qadir et al., 2013; Turner et al., 2005). However, some South Asian participants correctly understood the causes and progression of dementia (Adamson, 2001).

Several studies have reported that mental illness in general, and dementia in particular, are stigmatised among South Asian communities (Giebel et al., 2015; MacKenzie, 2006; Nielsen & Waldemar, 2016). One of the sources of stigma was a fear that dementia was contagious, which again stems from a lack of understanding of the nature of dementia. This stigmatisation, or fear of it, has led some South Asian families to conceal the person with dementia and therefore inhibit access to appropriate health and social care services.

South Asians have been shown to be typically less likely than the majority population in a range of country contexts to use dementia services (Giebel et al., 2015; McCleary et al., 2013). In Pakistan, access to care is made more difficult by the relative lack of services for dementia (Khan, 2014; Khan et al., 2017). Furthermore, it has been reported that medical practitioners in Pakistan have a low level of awareness of dementia, which will further inhibit diagnosis and access to services (Ahmad et al., 2013).

4.2 Methods

Ten interviews with people with dementia were conducted in Karachi (4 female, 6 male), and ten in Lahore (5 female, 5 male). Table A.1 provides other important characteristics of the 20 participants. Several of the participants with dementia were accompanied to the interview by a caregiver. This was usually a family member, and one was a paid home-help. The strengths of the research include the fact that people with mild dementia were successfully recruited to take part, that a balance of male and female respondents was recruited, and that two recruitment locations were involved, adding heterogeneity. The limitations include the similarly mid to high socio-economic status of the participants and that they all lived in urban areas.

During the interviews, participants were asked how they first recognised they had memory problems, their understanding of what caused their memory problems, how they feel about it, how their family and people in the neighbourhood have responded, their access to medical services, any changes they have made to their lives, and their advice for other people with the same issues.

Thematic analysis of the interviews was carried out, following a combination of deductive and inductive perspectives (Braun & Clarke, 2006). The themes were: pathways to diagnosis; understanding of diagnosis; stigma; and religion.

4.3 Results

I. Pathways to diagnosis

There were three main pathways to diagnosis, which were named 'Sought help for dementia symptoms', 'Already in the system', and 'Serendipity'. Those who 'Sought help for dementia symptoms' recognised that there was something wrong, and so they accessed health services. Many started by consulting a family member who was a physician. This demonstrates the importance of social and financial capital and is likely linked to the higher SES of participants. Some of those 'Already in the system' already knew about psychiatric services, either due to their own prior medical history or that of a family member.

> "Interviewer: Can you tell me about how you got in touch with the clinic about your memory?
>
> Person with dementia: My daughter was already treated by Dr [name] in Aga Khan [hospital] so we thought to consult for me…as well." (Person with dementia 06, Karachi, male)

The 'Serendipity' group accessed services almost by accident. A health professional, when consulted for another matter, recognised the symptoms of dementia and encouraged the participants to seek specialist attention. In these cases, the participants had not realised that their symptoms were problematic.

II. Understanding of diagnosis

Despite the fact that all of the people with dementia who were interviewed had a formal diagnosis of dementia, only some of them (and their caregivers) understood what dementia means. Some of the participants had a biomedical understanding of dementia. They correctly

identified that dementia can be caused by stroke, that it is not a normal part of ageing, and that the condition is progressive and affects activities of daily living.

> "Interviewer: What is this disease about? Do you know anything about it?
>
> Person with dementia: Yes she [the doctor] told me.
>
> Interviewer: What?
>
> Person with dementia: That it is related to forgetting things. [The doctor told me] that with time slowly, slowly the patient's condition happens to be such that they even forget that they have to go to the washroom. This is how she explained it to me." (Person with dementia 03, Lahore, female)

However, several of the participants had misapprehensions about the causes of dementia. Incorrect causes cited included shock, depression, stress, old age, bereavement, 'black magic', or thinking too much.

> "Interviewer: What has happened to you? What are the issues?
>
> Person with dementia: Just my confusion is increasing day by day due to over thinking." (Person with dementia 09, Karachi, male)

III. Stigma

Literature commonly reports that people from South Asian backgrounds fear that their community holds stigmatising attitudes towards dementia. However, our data showed little evidence of stigmatising experiences from members of the local community. Only one participant reported that somebody made fun of the dementia symptoms. In contrast, most participants had positive stories to tell about how they were treated by the local community.

A possible reason for not being treated badly by community members may be that these people with dementia are still in the mild stage. They are able to go out-and-about by themselves, do shopping, etc. The symptoms that community members observe (getting lost on the way home from the mosque, forgetting to bring groceries home after shopping) are not socially unacceptable behaviours. Therefore, community members respond with kindness and try to help. In contrast, if the people with dementia were displaying other symptoms like aggression or swearing in public, that would likely be socially unacceptable and would be responded to in a more negative way.

For example, one person was shown home because they got lost after prayers at the mosque, while another person who left their shopping behind at the grocery store had it delivered by the shopkeeper.

> "Interviewer: What happens when you forget groceries at the store?
>
> Person with dementia: … The shopkeeper knows that I forget. At times [the shopkeeper] used to come to my home [with the forgotten items]." (Person with dementia 04, Lahore, male)

On the other hand, there were reports of family members treating the person with dementia badly. There were stories of family members disbelieving that the dementia existed, while others referred to the person with dementia as 'insane'. There were some supportive attitudes from family members, which was said to be due to being educated and therefore having a

greater understanding of medical matters. Therefore, this poor treatment by family could be improved by raising awareness of the nature of dementia.

IV. Religion

Several of the participants reported that the symptoms of dementia caused problems for performing the five obligatory daily prayers of Islam. Forgetfulness meant that participants forgot to pray, that their mind wandered while saying their prayers, or that they had forgotten verses from the Quran that they had previously memorised. The symptom of poor orientation in time meant that participants did not know when it was the correct time of day to offer prayers.

> "Person with dementia: Sometimes I don't have any idea that it's morning. To offer prayer is also very difficult. I usually ask a family member … 'Have I offered Zuhr [second daily] prayer?' If they see me while offering they say 'Yes, you have done it'." (Person with dementia 10, Karachi, female)

Caregivers also reported that prayer time was difficult, and that their family member repeatedly asked them if it was prayer time or forgot to pray at the correct time. Another caregiver reported having to assist their family member with dementia to lay their prayer mat in the correct orientation towards Kaaba/Mecca, because the person with dementia's orientation in space had deteriorated.

> "Caregiver: I have this issue that I have to remind him to pray.
>
> Interviewer: Does he pray alright?
>
> Caregiver: Sometimes he offers two rakats [kneeling and prostration], sometimes one.
>
> Interviewer: Does he find out the direction of Kaaba?
>
> Caregiver: No, He does not know that. I prepare the prayer mat for him. If he does it he doesn't do it right." (Caregiver of person with dementia 01, Lahore)

Finally, one caregiver had a challenging relationship with their family member with dementia, who refused to pray at the correct times but instead tried to pray in the bathroom, which is inappropriate.

4.4 Conclusions

Overall, it can be seen that participants with high social capital were advantaged in accessing health services and obtaining a diagnosis more smoothly. Experiences of stigma were not common, but low educational level was assumed by participants to lead to stigmatising attitudes towards dementia. Despite the fact that all participants had received a diagnosis of dementia, some still did not fully understand the nature of dementia as a progressive brain disease. Finally, the dementia symptoms impacted seriously on the ability to practice daily prayers.

Key findings from the present study are that:

- It is possible to successfully obtain a diagnosis of dementia in Pakistan, despite the relative lack of services and low public awareness of dementia;
- Access to services was facilitated by health professionals who recognised dementia symptoms and who referred people on to appropriate services;
- A high level of education made understanding symptoms and knowing about services more likely, and was also assumed by participants to lead to lower levels of stigma;
- Even though all participants had a diagnosis, the understanding of the causes and prognosis of dementia was poor in some cases;
- Levels of stigma in the community were lower than expected from past literature;
- Dementia symptoms caused problems in performing the five obligatory daily prayers.

One of the limitations of the study is the high socio-economic status of the participants, which indicates that their experiences would not be shared by people of lower status, who may have greater difficulty accessing services.

5. Interviews of family caregivers

Aim: This part of the project seeks to draw insights on how family caregivers cope, what barriers do they face, and what help they would be willing to accept based on the complexities of the cultural and religious values in Pakistan (further discussion is included in Balouch et al. 2019).

5.1 Background

In Pakistan, dementia caregivers are predominantly female family members (Qadir, Gulzar, Haqqani, & Khalid, 2013). This can cause immense pressure on them leading to caregiver burden, which is related to diminished physical health (Schulz & Sherwood, 2008), depression (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014), poor quality of life (Riedijk et al., 2006) and increased financial burden (Wimo, Jönsson, Bond, Prince, & Winblad, 2013).

Furthermore, understanding how a society's culture, beliefs and dementia awareness affect help-seeking and how care is delivered is of great importance. To our knowledge there are only very few studies on dementia attitudes and experiences of dementia caregivers in Pakistan (Ali & Bokharey, 2015, 2016; Khan, Khan, Khan, & Najam, 2017; Qadir et al., 2013). Ali & Bokharey (2015) found high levels of stress, sleep disruption and fatigue, which were made worse by maladaptive thinking patterns, in eight dementia caregivers in Pakistan. Ali and Bokharey later suggested an interaction between maladaptive emotions and behaviours, and how that might play a role in caregiver burden and quality of life (Ali & Bokharey, 2016).

Qadir and colleagues found that caregivers in Rawalpindi/Islamabad lacked awareness of dementia, were conflicted by emotional and religious commitments to care and reported high psychological, physical and economic burden (Qadir et al., 2013). Finally, in a survey of the caregivers of people with dementia, and members of the general public (n=38), Khan et al. (2017) found that only half of the people with dementia and caregivers were aware of their diagnosis. Memory loss was the most distressing symptom, followed by depression, anxiety and incontinence.

Further research is required to explore experiences and knowledge of dementia in Pakistan, in order to influence public policy and increase dementia awareness in Pakistan. Thus, the current study explored dementia awareness in dementia family caregivers in Pakistan, how culture and religion play a role in their caregiving, what barriers they face and what help they would be willing to accept based on the complexities of their cultural and religious values.

5.2 Methods

Twenty family caregivers of people living with dementia were recruited from two major metropolitan cities in Pakistan (10 from Karachi; 10 from Lahore). Semi-structured interviews were carried out in Urdu, transcribed and then translated into English for qualitative analysis. The translated transcripts were coded and key themes were drawn from common codes.

The caregivers were mostly female in both cities (14 females overall). On average, male caregivers were 62 years old (SD = 14.21) and tended to be older than the female caregivers (M=

48 years, SD = 9.43). Based on the career information we have available, it appears that the caregivers interviewed were of high SES. The relationship of caregivers to the people with dementia included mostly partners.

Eight of the females and five of the males interviewed were receiving home-help (paid help for household chores and personal care to the person with dementia). Six of the caregivers from Lahore and 10 from Karachi mentioned that the person they were caring for had other diseases, health conditions or disabilities, in addition to their dementia (i.e. multimorbidity).

Most caregivers mentioned that the person they were caring for was receiving or had previously received conventional treatment (e.g. acetylcholinesterase inhibitors) for their dementia (7 from Lahore; 7 from Karachi), whilst 6 caregivers told us that the persons they were caring for were currently not on any treatment for their dementia (5 from Lahore; 1 from Karachi). Four caregivers stated that the persons they were caring for had received or were receiving alternative treatment for their dementia (e.g. natural remedies, homeopathy).

5.3 Results

Five key themes were drawn from the data, namely: Knowledge and awareness; Stigma; Religion; Use of day-centres and home-help; and Barriers.

I. Knowledge and awareness

Caregivers were asked about their knowledge of dementia and what they think causes it. Nine of the caregivers had not heard of dementia or Alzheimer's disease prior to diagnosis.

> "No, we never thought that 'what is this?', because I had no idea and I didn't know what is Alzheimer's." K1 (female, Karachi)

Prior to a diagnosis being made caregivers mistook the early symptoms for a number of different anomalies, such as depression and normal ageing, but also more obscure things, such as the adverse effect of eating Betel nuts and evil possession. In terms of dementia causation, 13 caregivers attributed dementia to 'tension' (e.g. stress, shock or emotional trauma) as the most prominent belief.

> "It's like we should take tension, but in our lives we can't live with taking tension from everything. When we take tension, it (puts pressure on) our brain and leads to (such diseases)." L1 (female, Lahore)

Other causes for dementia that were mentioned included a trauma, loneliness, lack of social interaction, genes, blood pressure and stroke.

II. Stigma

The caregivers generally believed that dementia was not taboo in their own families or their own SES class. They believed that dementia should not be hidden from others.

> "No. We felt no need to hide it and it isn't a thing to hide really." L10 (male, Lahore)

When asked whether memory and psychological issues were stigmatized in Pakistani society, K5 (female, Karachi) said:

> "Not amongst the educated, they can differentiate between 'what is mental illness?', 'what is depression?', 'what is dementia?'. Psychiatry…there will be psychological reasons [and] they hide from the people. Less educated and families that come from lower income groups cannot differentiate."

Caregivers had mostly received positive reactions from the community, in the form of members of the community caring, being helpful, sympathizing, and praying for the person with dementia, being respectful and understanding.

> "No why would they make fun. They feel bad that a person who was so outgoing and helpful is going through such an issue." L1 (female, Lahore)

However, caregivers had also received negative community reactions, and these included, physical abuse, not caring, others making fun, others using stigmatizing language, others not visiting anymore, and others talking behind their backs or 'back biting'.

III. Religion

All caregivers felt they had a duty to care for other family members and were reluctant to admit that the caregiving was a burden.

> "No I never think that he is burden for us...My parents told me one thing after marriage that taking care of your husband is your prime responsibility and take it as Jihad [a personal struggle in devotion to Islam], so I take it as my responsibility…." (K8, Female, Karachi).

As a result of this duty, putting one's relative inside a care-home or nursing home was considered shameful.

IV. Use of day-centres and home-help

Six caregivers had accessed one of two day-centres in Karachi and Lahore. Five of these caregivers had accessed the day-centre in Lahore and had positive experiences and views of the day-centre.

> "Yes, we used to take her to the day-centre. She felt very relaxed there. She was engaged in different activities…She was happy, and the main thing is that due to the activities she had to do there, she came home tired." L4 (female, Lahore)

However, the remaining one caregiver, who had accessed the day-centre in Karachi had a negative experience.

Six caregivers in Lahore and seven in Karachi had hired attendants to assist in care and/or household chores (home-help). Almost all the male caregivers had received home-help (5 out of 6), but approximately half of the females had accessed home-help (8 out of 14).

> "…her mental condition became worse. So, some of my relatives advised me to appoint attendant for her who will take care of her because it's not possible for you and us to look after her……So that's why I have appointed attendant. There are two attendants one for day

and one for night, and she is day attendant. They are both helpful, and I am so much thankful to both of them." K3 (male, Karachi) recounts when his children moved abroad.

V. Barriers

In times when caregivers had not received any support or treatment for their relative with dementia, we delved further to find out what the barriers were.

A lack of resources: The most prominent barrier expressed by 16 caregivers (8 from Lahore; 8 from Karachi) was a lack of resources (e.g. lack of funds, no transportation, lack of support services, doctors being too busy and unavailable treatment). One respondent explained why he could not take his wife with dementia to the day-centre,

> "Like she cannot climb up or down the stairs, so how can we take her there?" (L8, male, Lahore)

Caregivers wished for more day-centres that were easier to travel to:

> "There should be a number of day centres in every area so that people who cannot go far can have access to them. And so, people can go there on foot" (L4, Female, Lahore).

They also wished for dementia support groups and better training for healthcare staff.

Mistrust of external support: Some caregivers were reluctant to receive support from outside of the family, as they were wary about external care (including some of those who had received home-help). They did not believe that the care could be as good as the family care.

> "Only those people can care for you, who actually feel anything for you." Sometimes it was the person with dementia who refused external support. L9 (female, Lahore)

A lack of awareness: A lack of dementia awareness led two caregivers to delay treatment for the person with dementia, because they were either scared of the diagnosis or thought the condition would get better naturally. Seven caregivers were unaware of any day-centres, even though they lived in a city with a day-centre. All caregivers believed that raising awareness of dementia was necessary in Pakistan and the most common suggestions on how to do this was through online/social media, TV/radio and printed media.

> "….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." K4 (female, Karachi)

> "What could be done is that a TV commercial could be run." L1 (female, Lahore)

Interestingly, when caregivers were asked how dementia awareness could be raised in Pakistan, only two caregivers thought mosques would be an appropriate platform for raising awareness. Five caregivers felt it was not an appropriate place for raising awareness about health issues or had doubts about it. The reasons given were that women rarely attend mosques, mosques are for character building not for health issues, mosques are *"tangled in their own problems"* (L8, male, Lahore) and L4 (female, Lahore) recalled a time when an ill person was trying to raise money for their treatment in a mosque, but nobody was listening: "*I think hardly anyone helped*

him out. Nobody listens." Thus, L4 had no confidence in using mosques as a platform for raising awareness.5.3 Conclusions

The dementia caregivers interviewed had some knowledge of dementia. However, there were inaccuracies in their knowledge, often attributing dementia to stress, and many had not even heard of dementia or Alzheimer's disease prior to the diagnosis. There was an overwhelming belief from the caregivers that Pakistani people had little or no awareness of dementia and all caregivers felt a need to raise dementia awareness in Pakistan, through social media, TV and radio.

Interestingly, the caregivers and their families believed that dementia should not be taboo. However, they had received a mixture of positive and negative reactions from the community. The general belief was that only in lower SES communities or in uneducated people, taboo and stigma of dementia exists. This may be due to the fact that the caregivers interviewed were relatively educated and from a higher SES. It may also mean that the caregivers were caring for relatives in the milder stages of dementia, whose symptoms might not be as noticeable to the community. Thus, future research should aim to interview caregivers in more deprived areas and caregivers of relatives with severe dementia.

In line with previous research (e.g. Shaji, Smitha, Lal, & Prince, 2003), caregivers believed in a religious duty to care for their relatives, thus nursing homes were frowned upon. In contrast, however, day-centres and home-help were accessed and often viewed positively by those who used them. This appears to be a compromise in order to cope with the strains of caregiving, but without abandoning their duty to care.

As expected, a lack of resources (e.g. a lack of funds, dementia services and transportation) exist in Pakistan and this created a barrier for some caregivers and people with dementia receiving support or dementia treatment. There was also a lack of awareness of not only dementia in general, but also a lack of awareness about existing services, which prevented or delayed seeking support or treatment. However, a mistrust of external support also created a barrier to receiving support. This is in line with a research showing a general mistrust of health care services and conventional medicine amongst ethnic minorities living in Western countries (Kenning, Daker-White, Blakemore, Panagioti, & Waheed, 2017). More work needs to be done in Pakistan to build public trust of health care services and conventional medicine.

6. Focus Group Discussions

Aim: This part explores perceptions of dementia, its treatment and care in a group of adult Pakistanis residing in two urban centres (further discussion is included in Farina et al. 2019).

6.1 Background

Raising awareness of dementia is a worldwide priority, as set out in World Health Organisation's Global action plan on dementia (World Health Organisation, 2017), in part because raising awareness is a key pathway to enhance timely diagnosis and reduce stigma (Mukadam and Livingston, 2012). However, before this can be initiated, it is important to establish what people's attitudes, beliefs and knowledge currently are in Pakistan. We have very little knowledge about what the general public views of dementia are, and it is important not to assume that literature derived from Pakistani immigrants living abroad will be the same as those living within Pakistan.

6.2 Methods

Across Lahore and Karachi, 40 participants completed the FGDs. On average participants were 37.2 years old. The majority of participants, to their knowledge, had never encountered someone with dementia (n=30, 81.1%), spoken to family or friends about dementia (n=27, 73.0%), been taught about dementia in school (n=35, 94.6%) or watched a TV shows or movies in which a character has dementia (n=24, 64.9%).

From the FGDs of the general public in Pakistan, five key themes were identified: 1) Dementia awareness, 2) Responsibility, 3) Religion, 4) Barriers to healthcare, and 5) Identified support needs. All themes were inductive, and thus driven by the data. The final coding and formation of themes were discussed amongst members of the research team and broader scientific advisory board (composed of Pakistani clinicians and academics) to ensure the findings remained valid.

6.3 Results

I. Dementia Awareness

Participants tended to some basic awareness of dementia, but had very little knowledge of dementia, identifying a variety of causes of dementia and its symptoms. Commonly, participants felt that the symptoms described in both vignettes were due to normal age-related decline. However, many participants also incorrectly identified that the cause of dementia was due to life-stresses, often referred to as 'tension'. This had consequences on how participants viewed the prognosis of the illness.

> "Commonly, this is because of old age that it is an ailment." Female, Karachi

> "…if her household takes little more care and she also takes care herself…Then her ailment will disappear." Male, Karachi

II. Responsibility

Responsibility featured heavily throughout the FGDs, with participants commonly identifying that the responsibility of accessing or providing dementia care lies with either the person with dementia or their family. The perception that it was the family's responsibility to provide care was driven, in part, by societal norms. This sometimes led to an emphasis of children taking a greater responsibility.

> "To look after Mother and father (parents) is the responsibility of the children." Female, Karachi

III. Religion

Closely related to responsibility, religion was also used to provide context into why the family members should provide care for someone with dementia. Religion was also used as a means of describing how best to treat dementia as well as to inform its prognosis. A common theme, particularly amongst the Karachi FGDs, was that prayer could be a means of preventing or treating 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

IV. Barriers to healthcare

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 occasionally identified as a key barrier to accessing support and healthcare. Some of the participants also felt that the current healthcare system was a barrier to receiving care. Either because of feelings that the doctors were not sufficiently trained, that they did not have the patients' best intentions, or that they would make an incorrect diagnosis. A smaller group of participants identified that stigma may act as a barrier; either from the stigma derived from receiving a formal diagnosis or the fact that getting external help would be seen as a failure on the part of the family.

> "Household members would like to (medically) treat her, but there is also no money…" Male, Karachi

> "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

It was only within perceived barriers, where the gender of participants appeared to influence responses. Female participants were more likely to highlight that the family dynamics could act as a barrier, with views of certain family members being prioritised over other. For example, if was felt that if the daughter identified a need for additional support this could be overridden by the son.

V. Identified support needs

Despite individuals' limited knowledge of dementia, participants identified that more could be done for people with dementia in Pakistan. Most frequently, participants identified the need to raise more awareness about dementia. A portion of participants suggested that TV and radio was the best means of raising awareness, though others felt that using a strategy similar to those

used to raise awareness of Polio and Dengue Fever would be the more effective. For example, In the case of Polio a mass media campaign and targeted community engagement was used to raise awareness, but this was complimented with support from international leading Islamic scholars.

Participants also identified that the there was a need for new facilities and specialists, and that they should be accessible and low-lost.

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

6.3 Conclusions

As a whole the findings highlight that the general public in Pakistan had little awareness of dementia, this subsequently led to normalising and stigmatising attitudes. The lack of awareness about dementia has a profound impact on how the public see the condition. Not only does it lead to misconceptions about prognosis and treatment, but it also affects how people perceive duty of care. For example, if the symptoms of dementia are seen as being due to life-stressors, then it is either the person with dementia or their family's responsibility to remove them. Irrespective of these misconceptions, religion obviously plays an important role in shaping attitudes within Pakistan. Teachings that children should look after the parents in old age, whilst admirable, does overlook the complexities of dementia, its progression, and the needs of the carer. Having children as the de facto carer, could lead to increased burden, stress, resentment, and reduced quality of care.

Despite participants having little to no contact with dementia, it was positive that they were able to identify barriers and support needs associated with dementia. Many of which tied in with healthcare services more broadly (e.g. affordable, accessible). Understanding that there is a need to raise awareness of dementia is very positive as it increases the likelihood of accepting the message when presented.

Every effort was made to encourage participation from people with a range of social and economic backgrounds. However, it is important to note that participants were primarily recruited from two metropolitan centres, and therefore may not capture the views from Pakistanis residing in more deprived, rural areas. It is also possible that certain demographics may have chosen to not participate in the FGDs because of their views on the topic. For example, if members of the public did not have any opinions about dementia then they may not have wanted to participate in the research, this might have been the case for those who are less educated, or those less aware of dementia. In addition, the settings of the FGDs may have influenced who participated. Within Karachi, the FGDs were held in a community setting within Korangi, a quite deprived district, which may have been off-putting for those with a higher socioeconomic status.

7. Recommendations for policy and research

7.1 Policy recommendations

Following from the individual interviews with persons living with dementia and with caregivers and from the insights obtained with the help of focus groups discussions, these policy recommendations can be made:

1. A national screening programme to identify dementia cases would be beneficial, as would increasing the number and reach of dementia services. More funding should be made available for affordable, visible and accessible specialist dementia services, such as day care centres, dedicated hospital wards, staff and support groups.
2. A scheme to raise awareness of dementia symptoms and appropriate care is recommended. Despite having a diagnosis, the participants' understanding of the meaning of diagnosis was quite mixed. Some participants drew on a medical model of dementia, while others blamed stress, bereavement, or the 'evil eye'. Low awareness of dementia inhibits diagnosis, access to services, and contributes to stigmatising attitudes from family and community members.
3. We recommend that family caregivers be advised to enable prayers, e.g. by assisting with ritual ablutions and placing of prayer mats, if the person with dementia wishes to continue praying. This could alleviate guilt and stress among people with dementia and family caregivers.
4. We recommend that religious and community leaders in Pakistan could engage with policy makers and physicians to inform the general public about obligations and exemptions on prayers in the case of dementia. Participants reported difficulties carrying out the five daily prayers of Islam, which was a cause of distress to both people with dementia and their caregivers. Some authors have argued that people with a cognitive impairment such as dementia ought to be exempted from obligatory prayers, because they do not have the 'clear mind' essential to engage in prayer. No mention of such an exemption was made by participants in the present study, so this knowledge does not seem to be common in Pakistan.
5. A greater focus should be placed on formal help in the home, as families in Pakistan are more likely to accept and benefit from the home-based care.
6. Work with religious leaders to shape the narrative surrounding dementia in Islam.

On the whole, there is a need to design and implement a national dementia strategy to help lessen the burden of informal support with the help of formal support from the government and the community.

7.2 Recommendations for further research

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 also be of a good value, provided the policies implemented are culturally sensitive.

We need to upscale and expand dementia research within Pakistan. Whilst this work provides an interesting insight into experiences of dementia in Pakistan, it is far from being a representative sample of all those living in Pakistan. In particular, there is a pressing need to understand whether these findings are the same as in rural areas of Pakistan, where healthcare services are more dispersed, there is greater poverty, and religious beliefs are more varied.

Tied with this, a nationally representative survey of Pakistan could help us better identify whether certain demographics or cultures predict attitudes and knowledge of dementia. Not only will this improve our understanding of dementia attitudes and knowledge in Pakistan, but it would better inform policy makers whether certain groups need to be targeted as a priority or whether different awareness campaigns are needed.

In future research, it would be advantageous to conduct the analysis in Urdu, before translating into English, but this was not logistically possible in this study.

Our work in this project offers only a first step, and there is so much more that needs doing to better understand the social and economic consequences of dementia in Pakistan and other low- and middle-income countries.

References

Abojabel, Hanan, and Perla Werner (2016) "Exploring family stigma among caregivers of persons with Alzheimer's disease: The experiences of Israeli-Arab caregivers." Dementia (2016): 1471301216673920.

Adamson, J. (2001). Awareness and understanding of dementia in African/Caribbean and South Asian families. Health & Social Care in the Community, 9(6), 391-396.

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver Burden: A Clinical Review. JAMA, 311(10), 1052–1060. https://doi.org/10.1001/jama.2014.304

ADI (2012) World Alzheimer Report 2012: Overcoming the stigma of dementia, London: ADI.

Ahmad, A., Owais, K., Siddiqui, M., Mamun, K., Fao, F. and Yousufzai, A. W. (2013) 'Dementia in Pakistan: National guidelines for clinicians', Pakistan Journal of Neurological Sciences, 8(3), pp. 17-27.

Ali, S., & Bokharey, I. Z. (2015). Maladaptive cognitions and physical health of the caregivers of dementia: An interpretative phenomenological analysis. International Journal of Qualitative Studies on Health and Well-Being, 10. https://doi.org/10.3402/qhw.v10.28980

Ali, S., & Bokharey, I. Z. (2016). Caregiving in dementia: Emotional and behavioral challenges. Educational Gerontology, 42(7), 455–464. https://doi.org/10.1080/03601277.2016.1156375

Awan, Safia, et al. "Validation study of the Mini-Mental State Examination in Urdu language for Pakistani population." The open neurology journal 9 (2015): 53.

Balouch, S., Zaidi, A., Willis, R., & Farina, N. (2019). 'Dementia Awareness, Beliefs and Barriers in Low and Middle Income countries: Experiences of Family Caregivers in Pakistan', under review (copy available upon request).

Bowes, A., & Wilkinson, H. (2003). 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. Health & Social Care in the Community, 11(5), 387-396.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', Qual Research in Psych, 3(2), pp. 77-101.

Brondani, M.A., MacEntee, M.I., Bryant, S.R. and O'Neill, B. (2008) 'Using Written Vignettes in Focus Groups Among Older Adults to Discuss Oral Health as a Sensitive Topic', Qualitative Health Research. 18(8): 1145-1153.

Bryman, A. (2015) Social Research Methods, 5th edition. Oxford: Oxford University Press.

Dickson-Swift, V., James, E.L. and Liamputtong, P. (2008) Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks, Cambridge: Cambridge University Press.

Downs, M. &. Bowers, B. (Eds)(2010) Excellence in Dementia Care: Research into Practice. Maidenhead: Open University Press.

Farina, N., Zaidi, A., Willis, R., & Balouch, S. (2019). Attitudes, knowledge and beliefs about dementia: Focus group discussions with Pakistani adults in Karachi and Lahore. Ageing and Society, 1-16. https://doi:10.1017/S0144686X19000862

Forbat, L. (2003). Concepts and understandings of dementia by 'gatekeepers' and minority ethnic 'service users'. Journal of Health Psychology, 8(5), 645-655.

Giebel, C. M., et al. (2015). South Asian older adults with memory impairment: improving assessment and access to dementia care. International Journal of Geriatric Psychiatry, 30(4), 345-356. https://doi.org/10.1002/gps.4242

Gabriele, C. and G. Borin (2014). "Understanding dementia in the sociocultural context: A review." International Journal of Social Psychiatry: 0020764014560357.

Greenwood, N., Ellmers, T. and Holley, J. (2014) 'The influence of ethnic group composition on focus group discussions', BMC Medical Research Methodology, 14, pp. 107.

Hailstone, J., Mukadam, N., Owen, T., Cooper, C., &. Livingston, G. (2016). The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. Int. Journal of Geriatric Psychiatry.

Hall, S., Longhurst, S. and Higginson, I.J. (2009) 'Challenges in conducting research with older people living in nursing homes', BMC Geriatrics 9(38).

Heggestad, A. K. T., Nortvedt, P. and Slettebo, A. (2013) 'The importance of moral sensitivity when including persons with dementia in qualitative research', Nursing Ethics, 20(1), pp. 30-40.

Hinton, L., Franz, C., & Friend, J. (2004). Pathways to dementia diagnosis: evidence for cross-ethnic differences. Alzheimer Disease and Associated Disorders, 18(3), 134-144.

Jolley, D., Moreland, N., Read, K., Kaur, H., Jutlla, K., & Clark, M. (2009). The Twice a Child' projects: learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services. Ethnicity and Inequalities in Health and Social Care, 2(4), 4-9.

Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M., & Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. BMC Psychiatry, 17. https://doi.org/10.1186/s12888-017-1474-0

Khan, Q. (2014) 'Dementia: Challenges of practice in Pakistan', Neurology, 83(22), pp. 2091-2092

Khan, Q. and Aisha Sanober (2016) "Jinn Possession" and Delirious Mania in a Pakistani Woman." The American journal of psychiatry 173.3 (2016): 219-220.

Khan, Q., Khan, Y. H., Khan, M. Z., & Najam, S. (2017). Dementia survey amongst attendees of a dementia awareness event in Karachi, Pakistan. *HSOA Journal of Alzheimer's and*

Neurodegenerative Diseases, 3(014), 1-5. doi:http://dx.doi.org/10.24966/AND-9608/100014

Khan, Q., Khan, Y. H., Khan, M. Z., & Najam, S. (2017). Dementia survey among Attendees of a Dementia Awareness Event in Karachi, Pakistan. Pakistan Journal of Neurological Sciences (PJNS), 12(4), 34–41.

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. Health & Social Care in the Community, 12(5), 398-406.

La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S., & Oyebode, J. R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. Journal of Advanced Nursing, 60(6), 605-614.

Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. The British J. of Psychiatry, 193(3), 240-246.

Lawrence, V., Samsi, K., Banerjee, S., Morgan, C. and Murray, J. (2010) 'Threat to valued elements of life: the experience of dementia across three ethnic groups', The Gerontologist, 51(1), pp. 39-50.

Luengo-Fernandez, J., Leal, J. and Gray, A. (2010) Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom, Cambridge: Alzheimer's Research Trust.

Martin-Cook, K., Remakel-Davis, B., Svetlik, D., Hynan, L.S., & Weiner, M.F.(2003). Caregiver attribution and resentment in dementia care. AmericanJournal of Alzheimers Disease and Other Dementias, 18(6), 366_374.

McCleary, L., Persaud, M., Hum, S., Pimlott, N. J. G., Cohen, CA, Koehn, S., Leung, K. K., Dalziel, W. B., Kozak, J. and Emerson, V. F. (2013) 'Pathways to dementia diagnosis among South Asian Canadians', Dementia, 12(6), 769-789.

Mackenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. Dementia, 5(2), 233-247. https://doi.org/10.1177/1471301206062252

Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. International Journal of Geriatric Psychiatry, 26(1), 12-20. https://doi.org/10.1002/gps.2484

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, *8*(4), 377–386. https://doi.org/10.2217/ahe.12.42

Merrell, J., Kinsella, F., Murphy, F., Philpin, S. and Ali, A. (2005) 'Support needs of carers of dependent adults from a Bangladeshi community', Journal of Advanced Nursing, 51(6), pp. 549-557.

Moriarty, J., Sharif, N. and Robinson, J. (2011) Black and minority ethnic people with dementia and their access to support and services. Research Briefing 35, London: Social Care Institute for Excellence.

Naess, A. and Moen, B. (2015) 'Dementia and migration: Pakistani immigrants in the Norwegian welfare state', Ageing and Society, 35(8), pp. 1713-1738.

Nielsen, T. R., & Waldemar, G. (2016). Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. International Journal of Geriatric Psychiatry, 31(3), 222-230.

Nijjar, M. K. (2012). Perspectives on ageing in South Asian families. Retrieved from http://www.wisdominpractice.org.uk/wp-content/uploads/2014/08/ageing-south-asian-families-summary.pdf

Office for National Statistics. (2012). Ethnicity and National Identity in England and Wales: 2011. Retrieved 8 January 2017.

Petersen, R. C. (2004) 'Mild cognitive impairment as a diagnostic entity', J of Internal Medicine, 256(3), 183-194.

Piggott, M.A. & Court, J. (2008) 'Neurochemical pathology of neurodegenerative disorders of old age'. In Jacoby, R., Oppenheimer, C., Dening, T., and Thomas, A. (Eds)(2008) *Oxford Textbook of Old Age Psychiatry.* Oxford: Oxford University Press, pp.85-101.

Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). World Alzheimer Report 2015: The Global Impact of Dementia. London: Alzheimer's Disease International.

Prince, M., et al. "Dementia diagnosis in developing countries: a cross-cultural validation study." The Lancet 361.9361 (2003): 909-917.

Prince, M., et al. (2014) Dementia UK Update: Second Edition, London: Alzheimer's Society.

Purandare, N., Luthra, V., Swarbrick, C., & Burns, A. (2007). Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. International Journal of Geriatric Psychiatry, 22(8), 777-781.

Qadir, F., et al. (2013) "A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia." Care Management Journals 14.4 (2013): 230-240.

Quinn, Catherine, Ian Rees Jones, and Linda Clare (2016) "Illness representations in caregivers of people with dementia." Aging & mental health (2016): 1-9.

Regan, J. L. (2014) 'Redefining dementia care barriers for ethnic minorities: the religion-culture distinction', Mental Health, Religion & Culture, 17(4), pp. 345-353.

Riedijk, S. R., Vugt, M. E. D., Duivenvoorden, H. J., Niermeijer, M. F., Swieten, J. C. van, Verhey, F. R. J., & Tibben, A. (2006). Caregiver Burden, Health-Related Quality of Life and Coping in Dementia Caregivers: A Comparison of Frontotemporal Dementia and Alzheimer's Disease. Dementia and Geriatric Cognitive Disorders, 22(5–6), 405–412. https://doi.org/10.1159/000095750

Shaji, K. S., Smitha, K., Lal, K. P., & Prince, M. J. (2003). Caregivers of people with Alzheimer's disease: A qualitative study from the Indian 10/66 dementia research network. International Journal of Geriatric Psychiatry, 18(1), 1–6. http://dx.doi.org/10.1002/gps.649

Schneider, J., et al. (1999) 'EUROCARE: A cross-national study of co-resident spouse carers for people with Alzheimer's disease: I - Factors associated with carer burden', Int Journal of Geriatric Psych, 14, pp. 651-661.

Schulz, R., & Sherwood, P. R. (2008). Physical and Mental Health Effects of Family Caregiving. The American Journal of Nursing, 108(9 Suppl), 23–27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

Turner, S., Christie, A., & Haworth, E. (2005). South Asian and white older people and dementia: a qualitative study of knowledge and attitudes. Diversity & Equality in Health and Care. Retrieved on 7th December 2016.

Uppal, G., & Bonas, S. (2014). Constructions of dementia in the South Asian community: a systematic literature review. Mental Health, Religion & Culture, 17(2), 143-160. https://doi.org/10.1080/13674676.2013.764515

Uppal, G. K., Bonas, S. and Philpott, H. (2014) 'Understanding and awareness of dementia in the Sikh community', Mental Health, Religion & Culture, 17(4), pp. 400-414.

Willis, R. (2012) 'Individualism, collectivism and ethnic identity: Cultural assumptions in accounting for caregiving behaviour in Britain', Journal of Cross Cultural Gerontology, 27(3), pp. 201-216.

Willis, R., A. Zaidi, N. Farina, and S. Balouch (2018) 'Experiences of people with dementia in Pakistan: Help seeking, understanding, stigma, and religion', Gerontologist. 2018 Nov 17. doi: 10.1093/geront/gny143. https://doi.org/10.1093/geront/gny143

Wimo, A., Jönsson, L., Bond, J., Prince, M., & Winblad, B. (2013). The worldwide economic impact of dementia 2010. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *9*(1), 1-11.e3. https://doi.org/10.1016/j.jalz.2012.11.006

World Health Organisation. (2017). *Dementia: a public health priority*. Geneva, Switzerland: World Health Organization. Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/

Zaidi, A. (2015). *Ageing and Development*. GSDRC Professional Development Reading Pack no. 25, prepared for DFID, Birmingham, UK: University of Birmingham.

Zaidi, A. (2016). 'In Pakistan, old age means being in the throes of joblessness, poor health, loss of control over life', The News International, Pakistan.

Zaidi, A. (2013). *Global AgeWatch Index (2013). Purpose, Methodology and Results*. Report prepared for HelpAge International, Centre for Research on Ageing, University of Southampton, the UK.

Zaidi, A., Stefanoni, S. and Khalil, H. (2019). *Moving from the Margins: Promoting the Rights of Older Persons in Pakistan*. Policy Brief. British Council Islamabad and HelpAge Pakistan.

Annex A: Experience of dementia among South Asian diaspora

A.1 Understanding of dementia among South Asians in the UK

South Asian populations represent one of the largest ethnic groups within England and Wales (ONS, 2012). In view of limited evidence about perceptions of dementia in Pakistan, we draw *a priori* some insights from research in the South Asian communities living in the UK.

South Asian communities within the UK 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 caregivers 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 previously (Uppal and Bonas 2014; Uppal et al 2014).

There are also cultural differences in caring attitudes and accessing what public support is available. The British South Asian caregivers 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 caregivers 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; Niijar 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.

A.2 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 shameful and that it is the family's responsibility to provide care to the person with dementia. These findings suggest 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.

Annex B: Key demographic characteristics of participants

B.1 Key characteristics of the persons living with dementia

Interview location	Participant number	Sex	Age	Tenancy status	(Former) Occupation
Karachi	01	Female	80-89	Owner Occupier	Housewife
Karachi	02	Male	60-69	Not known	Business
Karachi	03	Female	50-59	Owner Occupier	Housewife
Karachi	04	Female	70-79	Not known	Artist
Karachi	05	Male	70-79	Not known	Business
Karachi	06	Male	60-69	Renter	Not known
Karachi	07	Male	60-69	Owner Occupier	Mosque administrator
Karachi	08	Male	70-79	Owner Occupier	Not known
Karachi	09	Male	60-69	Owner Occupier	Business
Karachi	10	Female	70-79	Owner Occupier	Pharmacist
Lahore	01	Female	70-79	Not known	Housewife
Lahore	02	Female	70-79	Owner Occupier	Teacher
Lahore	03	Female	40-49	Renter	Housewife
Lahore	04	Male	90-99	Owner Occupier	University faculty
Lahore	05	Male	60-69	Not known	Contractor
Lahore	06	Male	70-79	Owner Occupier	Radio worker
Lahore	07	Female	80-89	Owner Occupier	Housewife
Lahore	08	Male	60-69	Renter	Teacher
Lahore	09	Female	80-89	Not known	Housewife
Lahore	10	Male	70-79	Not known	Engineer

B.2: Summary of caregiver demographics

	Lahore		Karachi	
	Male	**Female**	**Male**	**Female**
N	**4**	**6**	**2**	**8**
Mean age (range)	**56 (45-72)**	**45 (35-54)**	**74 (68-80)**	**50 (35-62)**
Occupation type				
Housewife/husband or unemployed	0	5	0	6
Professional	0	1	0	1
Managerial	1	0	0	0
Clerical	0	0	0	1
Sales	0	0	0	0
Mechanical	1	0	0	0
Service	1	0	0	0
Operators	0	0	0	0
Farming	0	0	0	0
Retired[1]	1	0	2	0
Relationship to person with dementia				
Partner	2	2	2	4
Offspring	2	0	0	1
Daughter-in-law	0	3	0	1
Other relative[2]	0	1	0	2

B.3: Demographic details of participants across the four FGDs

	Male – Lahore (n=10)	Female – Lahore (n=10)	Male – Karachi (n=10)	Female – Karachi (n=10)
	M (SD) [Range]	**M (SD) [Range]**	**M (SD) [Range]**	**M (SD) [Range]**
Age	37.7 (19.6) [17-68]	33.8 (11.0) [21-52]	33.7 (12.5) [22-64]	43.2 (7.8) [28-55]
Household Size	6.1 (1.7) [4-8]	7.1 (2.4) [4-12]	6.0 (1.6) [2-8]	6.9 (4.4) [2-15]
	N (valid %)	**N (valid %)**	**N (valid %)**	**N (valid %)**
Household Monthly Income (Rs)				
20,000 or less	1 (11.1%)	3 (37.5%)	1 (10.0%)	4 (40.0%)
20,001 to 40,000	4 (44.4%)	2 (25.0%)	8 (80.0%)	5 (50.0%)
40,001 to 60,000	1 (22.2%)	1 (12.5%)	0 (0.0%)	1 (10.0%)
60,001 to 80,000	1 (11.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
80,001 to 100,000	0 (0.0%)	0 (0.0%)	1 (10.0%)	0 (0.0%)
100,001 or more	2 (22.2%)	2 (25.0%)	0 (0.0%)	0 (0.0%)
Highest Education				
Graduate degree or higher	1 (11.1%)	3 (37.5%)	0 (0.0%)	2 (20.0%)
Undergraduate degree	3 (33.3%)	1 (12.5%)	0 (0.0%)	0 (0.0%)
A level or FSc	3 (33.3%)	1 (12.5%)	5 (50.0%)	0 (0.0%)
O level or matriculation	0 (0.0%)	0 (0.0%)	3 (30.0%)	2 (20.0%)
HSSC	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
SSC	1 (11.1%)	2 (25.0%)	1 (10.0%)	2 (20.0%)
Primary or less	1 (11.1%)	1 (12.5%)	0 (0.0%)	4 (40.0%)
Other	0 (0.0%)	0 (0.0%)	1 (10.0%)	0 (0.0%)
Professional Status				
Retired	2 (22.2%)	0 (0.0%)	1 (10.0%)	0 (0.0%)
Unemployed	2 (22.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Employed	5 (55.5%)	4 (50.0%)	9 (90.0%)	4 (20.0%)
Homemaker	0 (0.0%)	4 (50.0%)	0 (0.0%)	6 (60.0%)
Marital Status				
Never Married	2 (20.0%)	3 (37.5%)	3 (30.0%)	0 (0.0%)
Currently Married	7 (70.0%)	5 (62.5%)	6 (60.0%)	8 (80.0%)
Widowed	0 (0.0%)	0 (0.0%)	1 (10.0%)	2 (20.0%)
Home Ownership				
Owned	3 (33.3%)	7 (87.5%)	8 (80.0%)	7 (70.0%)
Rented	2 (22.2%)	1 (12.5%)	2 (20.0%)	2 (20.0%)
State	2 (22.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Family	2 (22.2%)	0 (0.0%)	0 (0.0%)	1 (10.0%)

Rs = Pakistani Rupees, SD = Standard Deviation, SSC = Secondary School Certificate , HSSC = Higher Secondary School Certificate, FSc = Faculty of Science.

Annex C: Survey instruments used in the Study

C.1 Instructions for interviews with persons living with dementia

The semi-structured interview guide below is intended to elicit lengthy answers from persons with memory problems. It is not intended to be followed like a questionnaire. Instead, you should listen carefully to the participants' answers, and ask follow-up questions based on what they have said to elicit further information. Each interview should take approximately 60 minutes.

We have suggested some follow-up probing questions below, but you may ask different follow-up questions depending on what each participant says. There are no correct answers – we are looking for experiences and perceptions. Every participants' experience may be different.

If a participant does not understand a question, try to rephrase it in simpler language. If a participant is feeling unwell or distressed, please pause the interview recording. Ask them if they would like to stop the interview, or if they are happy to continue. If they want to stop, ask them if they would like you to come back on another day. If not, they can withdraw from the study.

Opening statements

Thank you for agreeing to take part in this interview. Please confirm that you have read and understood the Participant Information Sheet and have completed the consent form. Please confirm if the respondent would wish to have a relative or friend present during the interview (if this is not already the case).

I have a few questions to ask you. There are no right or wrong answers to these questions, I just want to know your opinions and experiences.

If there is a question you do not want to answer, just say so, and I will move on to the next one.

If there is a question you do not understand, just say so, and I will try to rephrase it.

Interview questions

1. **To start off, please can you tell me how many people live in your household?**
    a. What relation are they to you?
    b. Who owns the property you live in?
    c. How long have you lived in that property?

2. **Can you tell me about how you first realised you were having difficulties with your memory?**
    a. What sort of things did you forget?
    b. Did you have any other kinds of difficulties?
        i. For example, with cooking or preparing food by yourself?

ii. For example, communicating with other family members (either in person or in writing)

c. What did you think was causing this <u>when it first happened</u>?
   i. Did you think this was just a natural consequence of getting older? Or was it linked to a disease?

d. What did your family think was causing this <u>when it first happened</u>?
   i. Did they think this was just a natural consequence of getting older? Or was it linked to a disease?

3. Do you know any better now what is causing your memory problems?

a. Is there a name for it?

b. What do you know about it?

4. How do you feel about your memory problems?

a. Does it cause much difficulty in your everyday life?

b. Do you get any help because of your memory problems?
   i. If yes, what sort of help? Who helps you?
   ii. If no, do you think you need any help? What sort of help?

c. Do you find your memory problems to be embarrassing?
   i. If yes, what is the most embarrassing thing about it?

5. How does your family feel about your memory problems?

a. Your family who lives with you in the same household?

b. And what about your family who live elsewhere?
   i. Do they all have the same opinions?
   ii. Do you think the views held are largely due to our culture and/or religion?

6. Have you told other people in your neighbourhood about your memory problems?

a. If yes, how have they responded?

b. If no, why not?

7. Do you undertake any activities to improve your situation

a. Is there anything that makes your memory better?

b. Is there anything that makes your memory worse?

8. How do you think your memory problems will progress?

a. What does the future hold for you?

b. How do you feel about your future?

9. **Have you made any changes to your life because of your memory problems?**
   a. If yes, what sort of changes?
   b. If no, do you think you might have to make any changes in the future? What sort of changes?

10. **Can you tell me about how you got in touch with the clinic / hospital about your memory?**
   a. Who decided to get medical help? Was it you? Or your family?
   b. What happened at the clinic/hospital?
   c. Did they tell you what was causing your memory problems? If yes, what did they say?
   d. Did they offer you any treatment?
      i. If yes, what sort of treatment? Did it help?
      ii. If no, is there any treatment that you think would help?
   e. What did the doctor/nurse at the clinic/hospital tell you about what lies in the future?

11. **Do you have to pay for your medical treatment?**
   a. If yes, do you get any help to pay? Who from?

12. **Is there any advice you would give to someone else who was experiencing the same memory problems as you?**

13. **Do you know anyone else who is experiencing similar problems to you?**
   a. If yes, who is that?
   b. How are they dealing with it?

14. **Do you have a job?**
   a. If yes, what sort of job do you do? How has your memory problems effected your work?
   b. If no, have you ever worked? If yes, what sort of job did you do? Did your memory problems contribute to you stop working?

15. **Is there anything else you would like to say? Do you have any questions for me?**

C.2 Instructions for interviews with caregivers of People with Dementia

The individual interviews with caregivers of people living with dementia problems seek to collect information about attitudes and views of dementia, level of knowledge, and factual information; material and social circumstances of people living with dementia; and access to health care services for people with dementia.

The semi-structured interview below is intended to elicit lengthy answers from participants. It is not intended to be followed like a questionnaire (except the start-up questions and some questions which require Yes or No as a response). Instead, the interviewer should listen carefully to the participants' answers, and ask follow-up questions based on what they have said to elicit further information.

Each interview should take approximately 60 minutes. We have suggested some follow-up probing questions below, but you may ask different follow-up questions depending on what each participant says. There are no correct answers – we are looking for experiences and perceptions. Every participants' experience may be different.

If a participant does not understand a question, try to rephrase it in simpler language.

If a participant is feeling unwell or distressed, please pause the interview recording. Ask them if they would like to stop the interview, or if they are happy to continue. If they want to stop, ask them if they would like you to come back on another day. If not, they can withdraw from the study.

Interview questions

Thank you for agreeing to take part in this interview. Please confirm that you have read and understood the Participant Information Sheet and have completed the consent form. Please confirm if the respondent would wish to have a relative or friend present during the interview (if this is not already the case).

I have a few questions to ask you. There are no right or wrong answers to these questions, I just want to know your opinions and experiences. If there is a question you don't want to answer, just say so, and I will move on to the next one. If there is a question you don't understand, just say so, and I will try to rephrase it.

Part 1: Condition of person cared for

1. **What do you think your relative is suffering from?**

   a) Do you think it's a disease?

   If the answer is YES, what is the name of this condition? And why do you think this happens?

   If NO, do you think this could possibly be due to normal process of getting older?

   Is there any other explanation in your mind that may be causing this?

b) What were the initial symptoms/problems you noticed when this problem (dementia/ difficulties with memory) started?

c) What other symptoms of this condition you can identify that developed later and/or are present now?

d) Can you say whether there any other problems/symptoms that developed during this time that you do not attribute to this condition?

2. **How do you think this condition (dementia/ memory problems) has affected his/her ability to function?**

a) Think about all his/her activities inside the house with other co-residents, such as cooking.

b) Think about his activities outside the house, in social gathering such as weddings.

3. **What do you think can happen to your relative in the future?**

a) How will this condition progress?

b) Do you think it will cause physical impairments or increase in dependence (such as needing help in eating, toileting, bathing etc.)?

c) Are you worried about the future?

4. **Did you seek any help or treatment for your patient for this condition?**

If YES, what kind of help? Was it helpful?

5. **Do you think this disease may affect other family members of the patient?**

Is there any genetic predisposition?

6. **Do you think there may be ways of preventing or delaying this condition?**

If YES, can you describe?

7. **What do you think can help improve your understanding of this condition (select all that the respondent consider relevant)?**

a. Playing ads/educational programs on TV ☐
b. Reading about this in newspapers ☐
c. Ads on social media such as face book, you tube, whatsapp ☐
d. Sending information through phones (such as texts) ☐
e. Discussing in mosques/community centres ☐
f. Discussing with primary care providers/doctors ☐
g. Distributing flyers at homes ☐
h. Putting billboards/signs on main roads/streets ☐
i. Putting educational brochures in community clinics, outreach clinics, diagnostic centres, pharmacies ☐
j. Others ☐

Part 2: (Material/social/ Familial circumstances)

8. **Are you the primary caregiver for this patient? This means you are responsible for taking care of the needs of the patient and/or patient spends most of the time with you).**

   If answer is Yes, go to Question number 9.

   a. Yes ☐
   b. No ☐

   If answer is NO, who do you consider the primary care giver? Relationship with the patient?

   Why do you consider that person primary caregiver?

   1. Provides financial support ☐
   2. Takes care of physical needs ☐
   3. Spends most of the time with the patient ☐
   4. Makes decisions on his/her behalf ☐
   5. Any other reason: Specify ☐

9. **For how long have you been looking after the person since the first signs of dementia appeared (approximately)?**

   - Less than half a year ☐
   - Half a year to 1 year ☐
   - 1 to 2 years ☐
   - 2 to 3 years ☐
   - 3 to 4 years ☐
   - 4 to 5 years ☐
   - More than 5 years ☐

10. **Do you and the patient live in the same house?**

    Yes ☐ No ☐

    If answer is Yes, how many hours a day do you spend caring for the patient?

    1. 30-60 mins ☐
    2. 2-4 hrs ☐
    3. 6-12 hours ☐
    4. > 12 hours ☐

    If the answer is No, how often do you see the patient?

    1. 1-2 times/week ☐ 2. 3-5 times/week ☐
    3. Every day ☐ 4. Once or twice a month ☐
    5. Less than once a month ☐

11. **Does anyone else help you in providing this care?**

    A. No one else ☐
    B. Son ☐
    C. Daughter ☐
    D. Daughter in law ☐
    E. Son in law ☐
    F. Patient's sister/brother ☐

G. Neighbors/Friends ☐
H. Community organization I. Paid help ☐

If yes, how do they contribute in his/her care?

1. Financially ☐ 2. Take care of physical needs ☐ 3. Other: Describe ☐

How much time do they spend with the patient?

1. Less than an hour a day ☐
2. 3-6 hours a day ☐
3. 8-12 hours a day ☐
4. > 12 hours a day ☐
5. Night time ☐

12. Do other relatives/friends know about the patient's condition?

If Yes: ☐ How did they find out?

If No: ☐ Do you hide it from them?

Why? Is there a cultural and religious reason to hide the information about the patient's condition?

13. Do you avoid inviting people or visiting them due to embarrassment caused to you by the patient's behavior?

Yes ☐ No ☐

If the answer is Yes, what are the behaviors that cause embarrassment?

Do people make fun of the patient or make derogatory comments? How does that make you feel?

Part 3: Views and experiences of the caregiver

14. What activities do you help with?

(more than one answer possible)

- Showering and /or dressing/undressing ☐
- Toileting ☐
- Taking medication ☐
- Eating meals ☐
- Walking, standing ☐
- Household tasks ☐
- Cooking, food preparation ☐
- Transport, driving ☐
- Shopping ☐
- Managing finances, collecting pension, funds etc. ☐
- External activities (such as in a club or association) ☐
- Odd jobs (including cleaning, gardening, repairs, maintenance) ☐
- Coping with fears, anger or confusion ☐
- Other, namely: .....

15. Have you given up your activities/social life/hobbies due to caring for the patient?

Yes ☐ No ☐

16. Do you think caring for the patient has compromised your physical health?

Yes ☐ No ☐ If yes, how?

17. Do you think the caregiving role is imposed on you and you don't have a choice?
Yes ☐ No ☐ If yes, is this due to the culture and/or religion?

If the answer is No, how do you feel about being a caregiver?

18. Do you blame yourself or feel guilty for not taking good enough care of the patient?
Yes ☐ No ☐

If Yes, what do you think you can do better/need to improve?

19. What do you consider the most demanding aspect of caregiving?
What do you think is the most difficult symptom/behaviour to manage?

20. How do you deal/cope with the stress of caregiving?
Are your beliefs important in this respect?

21. In relation to your caring role, what would you change if you have a choice?
What do you think can be helpful in supporting you care better for the patient?

Part 4: Treatment/Resources

22. Is he on any medication for dementia?
If the answer is Yes, can you name them?

23. How many times has she/he visited a health care service in the last 6 months for treatment of dementia?
A. Once or twice every month ☐ B. 3 or more times ☐ C. 1-2 times ☐ D. No visit ☐

Where did you visit?

A. Doctor ☐ B. Clinic ☐ C. Dispenser ☐ D. Government hospital ☐ E. Private hospital ☐

F. Nurse ☐ G. Health Worker ☐ H. Homeopathic doctor ☐ I. Hakeem ☐ J. Spiritual healer ☐ K. Others: Specify

24. Can you name the medical conditions/problems he/she has for which he/she also takes medication?
Answer for all problems other than dementia

25. Do you purchase medication for his/her health related issues from the pharmacy without consultation with the health care provider, and by seeking advice from other family members/neighbours/friends?
A. Yes ☐ B. No ☐, if yes, why?

26. Do you think caring for the patient puts a great financial constraint on you and your family?
A. Yes ☐ B. No ☐

27. **. Are you aware of any place that offers care for dementia patients? Such as day care, nursing home, memory clinic, etc.**

    Yes No

    If the answer is Yes, Have you used it? If Yes, Do you find it helpful? How? If No Why?

    If answer is No, Do you think such a place may be helpful? How?

28. **Are you aware of any other useful resources for dementia patients/caregivers (such as support groups, online resources, social media campaigns, mobile apps/SMS texts, hotlines, ID bracelets, navigators, etc.)?**

    If the answer is Yes, Which ones? Are they helpful? Do you have any suggestions to improve them?

    If the answer is No, do you have any suggestions?

29. **Is there anything else you would like to say?**

30. **Do you have any questions for me?**

C.3 Indicative Focus Group Schedule

MODERATOR INTRODUCTION AND PURPOSE OF GROUP

Hello. My name is xxxx. I'd like to start off by thanking each of you for taking time to participate today. We'll be here for about an hour.

The reason we're here today is to gather your opinions and attitudes about issues surrounding dementia. I'm going to lead our discussion today. I will be asking you questions and then encouraging and moderating our discussion.

I also would like to reiterate that this focus group will be tape recorded. The identities of all participants will remain confidential. The recording allows us to revisit our discussion for the purposes of developing research papers and presentations.

GROUND RULES

To allow our conversation to flow more freely, I'd like to go over some ground rules.

1. *Only one person speaks at a time. This is doubly important as our goal is to make a written transcript of our conversation today. It is difficult to capture everyone's experience and perspective on our audio recording if there are multiple voices at once*
2. *Please avoid side conversations.*
3. *Everyone doesn't have to answer every single question, but I'd like to hear from each of you today as the discussion progresses.*
4. *This is a confidential discussion in that I will not report your names or who said what to anyone else. Names of participants will not even be included in the final report about this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.*
5. *We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without fear your comments will be repeated later and possibly taken out of context.*
6. *There are no "wrong or right answers," just different opinions. Say what is true for you, even if you're the only one who feels that way. Don't let the group sway you. But if you do change your mind, let me know.*
7. *Let me know if you need a break. The bathrooms are* ***[location to be mentioned]****. Feel free to enjoy a beverage and a snack available.*
8. *Are there any questions?*

INTRODUCTION OF PARTICIPANTS

Before we start, I'd like to know a little about each of you. Please tell me:
your name? *Where are you from?*

FOCUS GROUP QUESTIONS (50 MINUTES)

PRESENT THE FIRST VIGNETTE (MRS SHABNAM). GIVE UP TO 5 MINUTES TO READ THROUGH THE VIGNETTE. IF NECESSARY, PLEASE READ THE VIGNETTE.

- *What do you think is happening to Mrs Shabnam in the story?*
- *How do you think Mrs Shabnam's family feels about her problems?*
- *What do you think Mrs Shabnam's family should do about it?*
- *What do you think are the personal barriers to Mrs Shabnam, or her family, from seeking help?*
- *What will happen to Mrs Shabnam in the future?*

PRESENT THE SECOND VIGNETTE (MRS GULNAR). GIVE UP TO 5 MINUTES TO READ THROUGH THE VIGNETTE. IF NECESSARY, PLEASE READ THE VIGNETTE.

- *What do you think is happening to Mrs Gulnar in the story?*
- *How do you think Mrs Gulnar's family feels about her problems?*
- *What do you think Mrs Gulnar's family should do about it?*
- *What do you think are the personal barriers to Mrs Gulnar, or her family, from seeking help?*
- *What will happen to Mrs Gulnar in the future?*

ASK PARTICIPANTS TO THINK BACK TO BOTH STORIES. REVEAL/CONFIRM THAT BOTH STORIES WERE ABOUT DEMENTIA, AT DIFFERENT STAGES OF THE CONDITION.

- What is dementia?
  - What is the cause of dementia?
  - What type of treatments are available for dementia?
- Who do you think should be responsible for looking after people with dementia? (e.g. Family, government)
  - Why? How do your religious beliefs and culture influence this decision at all?
- What are the advantages of seeking help from a doctor for dementia?
  - Do you see any disadvantages from seeking help from a doctor?
- ***WHAT SUPPORT SHOULD BE AVAILABLE TO PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS?***

CLOSING (2 MINUTES)

Thanks for talking about these issues. Your comments have given us lots of different ways to see this issue. I thank you for your time and request you to fill in a questionnaire.

Vignettes for Focus Group Discussions

Case 1: Mrs Shabnam, 72 years old

Mrs Shabnam used to be very proud of her appearance and was actively involved with the family. She looked after her grandchildren happily and willingly, and never missed an opportunity of visiting other members of her extended family.

However, things have changed since she was diagnosed with diabetes 6 months ago. A couple of months later, her family began noticing that she was becoming more changeable in her mood, becoming tearful at times for no apparent reason and taking less pride in her appearance. She has also now lost interest in providing care for her grandchildren and does not wish to make efforts to visit family and friends.

After her daughter-in-law persuaded her to attend her older grandson's wedding, it became apparent that she was having some difficulty in remembering the names of family members she had not seen for a while. During the wedding, her niece sat with her and began discussing the last family gathering, Mrs Shabnam's 70th birthday celebration. But she seemed confused and had difficulty remembering the gathering properly and who had attended. She found it much easier to join in a conversation about a wedding in Multan 40 years earlier. To the embarrassment of the Mrs Shabnam, she also found herself getting lost coming back from the bathroom at the venue.

Since the wedding, the family has been talking about the changes they are observing in her. Members of Mrs Shabnam's family are telling her daughter-in-law to take her to a local doctor; others are just saying there is nothing that can be done, it is just a part of the process of getting older.

Case 2: Mrs Gulnar, 72 years old

Mrs Gulnar and her husband live with their son, daughter-in-law and their two grandchildren. Mrs Gulnar is in reasonably good physical health.

For the past 3–4 years, Mrs Gulnar's family has noticed that she is becoming more and more withdrawn, inactive, and careless about her appearance. She has also become very forgetful, often not recognizing close family members. However, she does remember details of her younger days and can spend hours talking about the events of her youth, even though she has great difficulty recalling things that happened yesterday.

Her daughter-in-law has always found her difficult to get on with, but more recently, her whole family have found that she is moody and gets upset and annoyed over little things. Due to the changes in Mrs Gulnar's mood, the family have started to become careful to avoid saying or doing things that may irritate her and tend to keep the grandchildren out of her way.

She does not go out now and spends most of her time in her room doing nothing in particular. Her family have noticed that when she is left on her own, she mutters and mumbles to herself. When asked what she is talking about she does not reply.

Her daughter-in-law has to help her to get up in the mornings and she needs help with washing and dressing, because she seems unable to do these things for herself. From time to time Mrs Gulnar even struggles to get to the toilet, leaving her daughter-in-law to clean up the mess. Mrs Gulnar also sometimes wakes up at odd hours of the night and starts trying to get ready for the day, insisting that it is morning. Her husband has a hard job persuading her to get back to bed at these times.

The family does not leave Mrs Gulnar on her own and her daughter-in-law spends a large part of the day caring for her. Her daughter-in-law has begun to find her continual demands for her presence tiring and stressful. She is finding it more and more difficult to cope with Mrs Gulnar's behaviour and has been thinking of asking for help from other family members to get some respite. However, Mrs Gulnar's son will not agree to this. He will not even discuss it because he says it is his duty to look after his mother.

Demographics: Focus Group

Please complete these questions for each attendant after you have finished with the Focus Group Discussion.

- Age: _____ Gender: _____

- What is your level of Education: _____

Graduate degree or higher (University)	1
Undergraduate degree (Bachelors)	2
A level or FSc	3
O level or matriculation	4
Higher secondary school certification (HSSC)	5
Secondary school certification (SSC)	6
Primary or less	7
Other (Specify)	8

- What is your monthly household income: _____

Please look at the options below and tell us which bracket does the average household monthly income for your household in 2016 fall under. This should include cash income and the monetary value of non-cash income.

Less than 5,000	01	5,001 to 10,000	02	10,001 to 15,000	03
15,001 to 20,000	04	20,001 to 25,000	05	25,001 to 30,000	06
30,001 to 35,000	07	35,001 to 40,000	08	40,001 to 45,000	09
45,001 to 50,000	10	50,001 to 55,000	11	55,001 to 60,000	12
60,001 to 65,000	13	65,001 to 70,000	14	70,001 to 75,000	15
75,001 to 80,000	16	80,001 to 85,000	17	85,001 to 90,000	18
90,001 to 95,000	19	95,001 to 100,000	20	More than 100,000	21

- What is your household size: _____

- Please tell us about your professional status: _____
(e.g. Retired, homemaker, unemployed, business owner, professional, administrative, clerical, daily wages)

- What is your current marital status: _____

1. Never married
2. Currently married
3. Divorced
4. Separated
5. Widowed

- What is the tenancy / ownership status of the house you live in: _____

1. Owned by the respondent
2. Rented
3. Provided to respondent family by the state
4. Provided to the respondent by family or relatives
5. Provided to the respondent by other persons
6. Other (Specify)

These statements are about your level of experience or contact with people living with dementia… (Please circle a number for each statement)					
	Never	Rarely	Occasionally	A moderate amount	A great deal
I have come across people living with dementia	1	2	3	4	5
I have spent time with people living with dementia	1	2	3	4	5
I have spent time with a family friend who is living with dementia	1	2	3	4	5
I have spent time with a family member living with dementia	1	2	3	4	5
I have looked after someone living with dementia	1	2	3	4	5
I have watched TV shows or movies in which a character has dementia	1	2	3	4	5
I have come across adverts (e.g. billboards, leaflets) about dementia in my community	1	2	3	4	5
I have come across people living with dementia on social media (e.g. Twitter, Facebook)	1	2	3	4	5
I have searched for information on dementia on the internet	1	2	3	4	5
I have learnt about dementia in school	1	2	3	4	5
I have spoken to family or friends about dementia	1	2	3	4	5



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Alzheimer's Pakistan

UNIVERSITY OF Southampton

HANDS

brighton and sussex medical school

SGD @F@ JG@M TMHUDQRHSX