INTRODUCTION

Dementia has become a global health priority, although progress in low and middle income countries is lacking where the speed of population ageing is faster.

There is as yet no cure for dementia, but there is evidence that formal support services can help to improve the quality of life of persons living with dementia and that of their family caregivers (Downs and Bowers, 2010; Farina et al., 2017).

It is therefore important that a diagnosis is made as early as possible, but contact with services can be delayed if individuals or family members do not recognise the symptoms of dementia.

A barrier to seeking help is the stigma associated with dementia (ADI, 2012), due to underlying negative and inaccurate beliefs about it, particularly that it is the individual’s own fault or due to family neglect (La Fontaine et al., 2007).

In Pakistan there is 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 or stresses, or physical weakness (Qadir et al., 2013).

It is essential that we identify peoples’ understanding, beliefs and attitudes about dementia so as to advocate for the most effective policies and programmes in raising awareness and providing support services to people with dementia and their caregivers.

PAKISTAN AT A GLANCE

In 2015, 11.6 million Pakistanis are over 60 years of age and this figure will rise to 43.3 million by 2050 (Zaidi, 2016).

It ranks low in the Global Age Watch Index: at 92 out of 94 countries (Zaidi, 2013).

It ranks particularly low with respect to health of older persons, with a relatively low life expectancy and even lower healthy life expectancy within the region (Zaidi, 2016).

AIMS

To understand the cultural beliefs, attitudes, views and understanding of dementia in people living with dementia and their families in Pakistan, and in those who have no experience of dementia.

METHODS: FOCUS GROUP DISCUSSIONS (FGDs)

A series of FGDs will be held with members of the general public in Pakistan (n=40).

There will be a total of 4 single-events in Lahore and Karachi. Groups will be split by gender.

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

The vignettes are independently reviewed by dementia experts (UK) and then by senior Pakistani academics and clinicians. Finally, the translated vignettes will be reviewed by a PPI group in Pakistan.

The discussion has been opened up to the group’s understanding of what is happening to the person in the vignette, and probe issues concerning the cause of the condition and how to best support and treat them.

Vignettes are useful tools for FGDs on sensitive topics, because they shift the focus away from the individual and onto the general, making it easier for group members to offer opinions.

METHODS: INDIVIDUAL INTERVIEWS

People with mild dementia (n=20) will take part in a one-off individual semi-structured interview, where they will be asked open-ended questions about their experience with their illness, their understanding of their illness, and how other people have responded to it.

Family caregivers (n=20) will also take part in a one-off individual semi-structured interview, where they will be asked open-ended questions about their family member’s illness, their understanding of the illness, and how they and other family members have responded to it.

METHODS: KEY INFORMANT INTERVIEWS

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

REFERENCES


This project is funded by Age UK, Age International, HelpAge International and Alzheimer’s Disease International.