

Attitude and Risk Perception of Dementia in Older and Middle-Aged Adults: A Qualitative Study

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ABSTRACT

The rapidly increasing population of older adults in India posits a huge public health challenge. It is, therefore, essential to focus on the cognitive and neuropsychological health of older adults. Currently, there have been limited attempts to understand dementia and rehabilitation from the lens of the target population. Therefore, the present research, aims to understand the perspectives of dementia among elderly in the community. The participants were probed to understand their knowledge and attitude towards dementia prevention and care. Moreover, an understanding about psychological concerns of older adults, attitude of society towards dementia and reluctance towards receiving mental health care was also gauged. Data was analyzed using thematic analysis. A need for up-to-date information regarding dementia was expressed. Further, need to focus on introducing patient friendly interventions and reducing stigma was also felt. Opinions about treatment, prevention and risk factors were doubtful. Fear, despair, and guilt were common feelings associated with dementia. The findings bring to light the expectations for prevention, care, concerns, and reluctance of older adults related to dementia rehabilitation and care.

Keywords: *Dementia, Older adults, Rehabilitation, Interventions*

India is greying. According to the ministry of statistics and program implementation India, the older adult population is rapidly increasing with 138 million elderly in 2021. It is estimated that by 2031 the population of elderly will increase by 56 million (Nahata, 2021). This is a huge public health challenge for our nation therefore, it is essential that we ensure that the geriatric population receives care not only for their physiological problems but also for mental health related concerns. Research predicts huge national burden due to undiagnosed and neglected mental health concerns of elderly (Kedare and Vispute, 2016). On an average 20.5% of older adults in India suffer from mental health concerns and 17.13 million older adults have diagnosable mental health issues (Tiwari and Pandey, 2012).

Ageing of the brain leads to changes at the physiological and psychological level which interferes with social and occupational functioning of older adults. Older people most commonly face problems like confusion, depression, mood abnormalities, severe injuries due to falling (frailty), slowness of walking and forgetting which are signs of cognitive

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decline and mild cognitive impairment in some older adults. Along with this, comorbid conditions like heart attack, traumatic brain injury, blood pressure, smoking, diabetes etc. make them more susceptible to neuropsychiatric illnesses like dementia (Ravindranath and Sundarakumar, 2021). This impairment is also affected by the socioeconomic status of the older adults. In a meta-analysis conducted in 2021 it was found that 20 per thousand older adults in India suffer from dementia and there is a need to incorporate dementia in national mental health survey of India to make more precise estimates of prevalence (Choudhary, Ranjan & Asthana, 2021).

Further, Dementia in India report 2020 evidenced 5.30 million Indians above 60 years of age suffered from dementia in 2020 which is projected to increase 14 million by 2050. WHO also believes that dementia is a cause of concern worldwide and estimates that dementia cases will increase to 152 million in 2050 with countries like South Asia and India being major contributors (ADI, 2015). Poverty, lack of awareness, self-medication, religious healing, and disregarding symptoms of mental health related illness as part of normal ageing process are some of the major obstacles in receiving care (Prakash and Kukreti, 2013). Studies also suggest that patients with dementia are unable to express and understand their symptoms.

Moreover, India needs to establish dementia care units, rehabilitation centers, dementia day care to meet the challenges posed by rising dementia cases (Lodha and Sousa, 2018). The primary healthcare physicians in India are not trained in caregiving and treatment of illnesses like dementia and depression in elderly despite of it being prevalent in 40-50 percent of the population. This is why dementia symptoms in early stages go unnoticed and causes poor rehabilitation of such patients in later stages of dementia. It is essential that health workers and community health volunteers should be trained to identify and refer elderly patients for timely rehabilitation (Katiyar, Ahmad, Beg and Baqar, 2020).

Considering the research mentioned above the major challenge for dementia is that people with the illness are unable to report and understand their own symptoms. Furthermore, in a country like ours the awareness level about dementia is so low that people mostly mistake the symptoms as part of normal ageing process. The review stated above leads us to a gap in the literature because it focuses on people other than the target population.

To generate awareness understanding the perspective and knowledge of the older adults towards dementia care and treatment is necessary so that the awareness campaigns can build on their concerns. This will help in making the message reach target population more promptly and they will be able to take steps towards slowing the cognitive decline. Further, it will also help increase the reach of older adults towards receiving care in the early stages of neuropsychiatric issues and mental health related concerns when required.

The present study aims to understand the attitude and risk-perception of dementia among older adults in the community through a qualitative approach. The health belief model (HBM) is the most appropriate theoretical basis for the current research as it professes that a particular behavior change is likely to have a positive effect when people perceive health related barriers. That is, people are likely to engage in health promoting behaviors when they perceive them to be susceptible to develop a particular health problem. This perceived threat can instigate behavioral changes, health motivation and self-efficacy (Akyol et al., 2020).

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In a study conducted by Kim et al. (2014) in Australia HBM was used as a model to develop a measure of motivation for behavioral and lifestyle change for dementia risk reduction. They concluded that the tool developed was useful in measuring attitude and beliefs and can be used to design interventions for dementia prevention. Further, Choi et al. (2019) were also able to identify the factors influencing dementia preventive behavior in older adults and they also highlighted the importance of interventions focusing on increasing self-efficacy to improve behavior related to dementia prevention. The existing literature on attitude and risk-perception of dementia in older adults is largely conducted in western countries. These research focus on either on older adults who have family members or relatives with dementia and caregivers. Very few research focus on community dwelling older adults without dementia (Heger et al., 2019 and Rosenberg et al., 2020). Moreover, the aspect catering to reluctance in receiving mental health care is barely present in any of the research but is something that has been largely discussed in the papers (Kim et al., 2015 and Matsumoto et al., 2021). Therefore, to bridge this gap this study will focus on generating research on this topic in context of the Indian population and using a qualitative approach it will understand the awareness of older adults with respect to dementia and the reluctance to receive care.

RESEARCH METHOD

The present study is qualitative in nature where the sample was collected from cognitively healthy community dwelling adults (45-65 years). IRB approval was taken before data collection. 6CIT questionnaire was used for screening purposes. A semi-structured interview schedule was created, face validated by experts and then administered to understand the attitude and risk perception of dementia in middle and older adults. The interview was used to gauge feelings related to dementia; attitude towards dementia care; perspective about dementia; psychological concerns of elderly; attitude of society towards dementia and reasons for reluctance to receive care among the elderly. Due to data saturation eight participants were interviewed. Informed consent was taken from all participants to ensure voluntary participation. Later, the interviews were transcribed and field notes for the same were made after every conduction. Further, data auditing was conducted for data validation after which thematic analysis was used for analysing and interpreting the data by transcribing the interviews and then forming open and axial codes, finding the overarching themes based on the commonalities found.

RESULTS AND ANALYSIS

The aim of the current research was to understand the attitude and risk perception of dementia among older adults through a qualitative approach. The major objectives of the study were to understand the existing knowledge about dementia, the feelings associated with ageing and dementia, attitude towards prevention of dementia and reluctance to receive care among older adults. For this research the data was collected using interview method on 8 individuals in the age group 50-75 years. 6 participants in the study were caregivers of patients with dementia and all of them had interacted or seen a dementia patient at some point in their life. After data collection, transcripts of all interviews were made, and open coding was done. Later, themes were identified based on similarities in the data elicited and thematic analysis was done following the Braune and Clarke method. Six global themes namely feelings associated with dementia, attitude towards dementia care, perspectives about dementia, psychological concerns of older adults, attitude of the society towards dementia and reasons for reluctance to receive care were formulated. Each global theme consisted of organizing themes and open codes (Fig 1).

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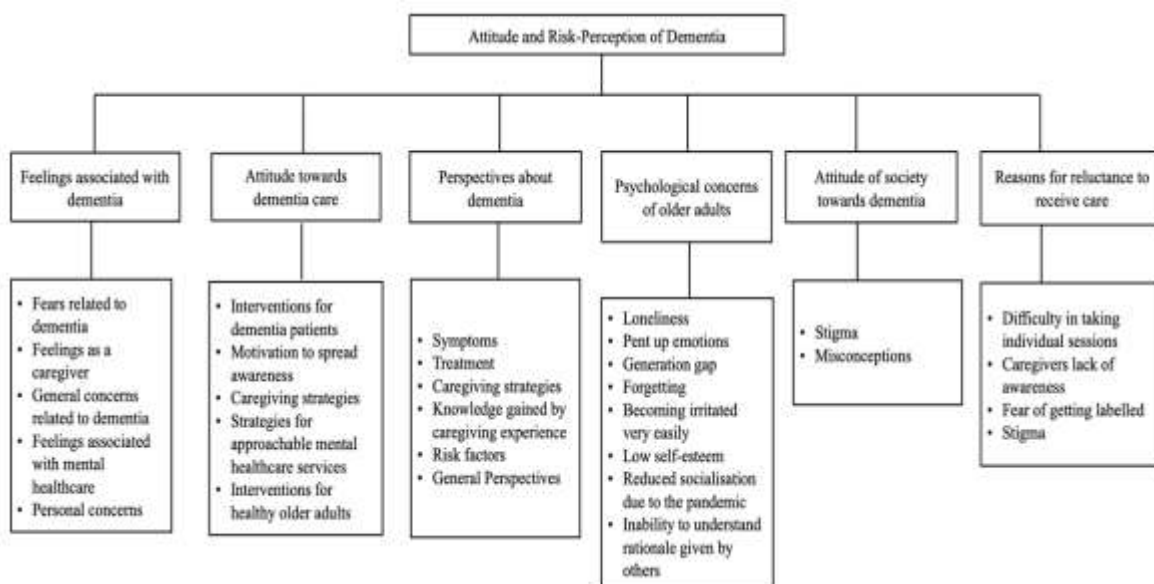


Fig 1. Showing the global themes, organizing themes and open codes.

The first theme identified was “Feelings associated with dementia”, this global theme was used to explain the views of the participants related to dementia especially how they feel about the condition, their observations, how they felt as a caregiver, their personal and emotional concerns. The major fears related to dementia centered around the decreased level of awareness in the community, the fear that the patient might get lost and forget about their identity, they might injure themselves due to the lowered sensitivity to threat, confusion and forgetfulness involved in dementia. Further, participants who lived alone feared lacking a caregiver in case of contracting dementia and the slowing down of the brain. The feelings associated with caregiving by most participants were despair recalling the conditions of the loved ones caused by dementia, the financial, mental, and physical burden involved in providing care, guilt related to ignoring the symptoms of the patients leading to late diagnosis, perceiving the patient incorrectly. There was also a sense of hope among few participants about the betterment of condition of older adults of India in the future. Research has evidenced that common feelings associated with dementia are that of fear, shame, compassion and guilt which often lead to sense of social distance from dementia patients (Low and Purwaningrum, 2020).

‘Late diagnosis, late awareness and they feel this thing that she is old, and she is forgetting all these things. They relate it with ageing problem, but this is not an ageing problem this is a disease.’

There were many general concerns regarding dementia shown by the participants which were related to misdiagnosis, uncertainty about causes of dementia, difficulty in accepting dementia symptoms being shown in the patients as a caregiver, need for close observation for change in any routine habits of older adults, excessive caring being harmful for dementia patients, and the need to find if dementia exists in early ages. Furthermore, the participants also felt that in terms of providing mental health care there is a need to identify the population that needs counselling/therapy, ensuring willingness to take therapy, there are many who are reluctant to take therapy and, doctors words are more acceptable than psychologists in our Indian society.

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The personal concerns expressed related to dementia were the fear of being at risk due to hereditary concerns and maintaining an active lifestyle.

'Personally, I feel you can't do much about it. It has to happen. As one grows old things will happen one or the other things will happen.'

Research indicates that in India low levels of awareness about dementia are one of the major barriers in reducing the treatment gap due to which only 1 in 10 people with dementia receive a diagnosis, treatment, or care (Nulkar, Paralikar & Juvekar, 2019). This highlights the need for generating awareness about dementia (symptoms, treatment, and causes) in India. Studies suggest that early signs of dementia are often considered to be part of normal ageing and are often neglected by both caregivers and health policy makers. This often leads to negligence and misdiagnosis of dementia (Sinha, 2011; Strom et al., 2021). Caregivers of persons with Dementia in southern India have reported feeling distressed, frustrated, and overwhelmed with caregiving experience (Narayan et al., 2015). Further, it has also been found that early dementia symptoms exist in individuals in early 40s (Tallapalli et al. 2020; Vajpai et al. 2020).

'It starts after 60s 70s. I can understand research will also be done. What if dementia is shown in lower age also. You never know.'

Therefore, there is relevant literature consistent with the findings of the current research. There is an increasing caregiving burden, need to raise awareness about dementia, many personal and mental health concerns prevalent among older adults in the society. Hence, it is required that the public health policy makers devise strategies to address the caregiving burden and provide easy access to mental healthcare professionals to people in need.

Attitude towards dementia care was the second theme formulated. It was used to understand the attitude of older adults towards helping dementia patients, in what ways they feel mental health services can be made approachable to older adults, their level of motivation to spread dementia relate awareness, what can be focused upon by caregivers while dealing with dementia patients and how can we generate awareness among healthy older adults about dementia. The participants mostly believed that interventions for dementia patients should focus on making them oriented to the present, providing them with proper treatment assistance most importantly medications, engaging them in recreational activities common for all age groups, adhering to a healthy lifestyle and forming support groups for them. Indulging dementia patients in creative activities, holding routine meetings where they can communicate, and, ensuring that they are following a routine and are engaged most of the time were some important components for ensuring wellbeing of dementia patients as per the participants. There was an average level of motivation among participants to spread awareness about dementia. The major motivating factors were providing care for loved ones who had dementia. Further, it was also seen that for participants who did not provide care but had an interaction with a dementia patient also experienced a change of attitude towards them and wanted to generate awareness about it.

'They should make some efforts some combination for both styles, our age group styles, and their age group styles. That would be better for young people, old people and coming generations.'

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Participants who had been caregivers or had an experience with a dementia patient believed that caregiving practices should be talked about in the society and the caregivers should be made aware about dementia so that they can provide better care. They believed that caregivers should be understanding and empathetic, they should avoid rationalizing what has been said by the patient. Most importantly, it was felt that most caregivers are unable to accept even after diagnosis that their loved one has dementia, and these are the symptoms manifested. This often leads to ignorance and neglect towards the patients needs. Therefore, there is a need for acceptance of dementia symptoms by caregivers.

'I see my sister's suffering. You know, one of my colleagues was also like that, but that time I was not aware that this is the disease. So even I used to say, he is crazy and getting old. He doesn't know anything. But now when I see from so close, I am very, very sympathetic, and empathetic. And I want to see that you know, nothing of this sort happens in my known people. You also can hear myself and so I try to tell people that we should be watchful of this.'

It is also essential that the patients are not made to feel guilty about their symptoms and this can come only after acceptance of the illness by the caregivers. Another aspect pointed out is making the patients live in the same environment where they lived for a longtime rather shifting to a new one as it might help in maintaining a sense of calm in them. The need for making mental health care more approachable for older adults was felt by most participants due to the increase in loneliness and other concerns among elderly. Social media campaigns, making knowledge about mental health care inclusive in all disciplines to highlight its importance and need, community outreach program specifically focusing on elderly were the major strategies suggested by the participants for making mental health services more approachable.

Awareness can also be spread at school level so that children having grandparents at home if they notice any symptoms of common mental health issues among elderly, they can provide the authentic references provided to them to help their grandparents. It was pointed out that going door to door for approaching elderly, making the residential welfare associations organize routine recreational and awareness activities, mental health camps can be suitable strategies for keeping a check on elderly and their mental health. Moreover, the participants felt that nowadays elderly face complex issues due to technical upheaval which they can't comprehend, loneliness, overthinking and many other factors making it a need for them to receive therapy, but they are not aware how to approach professionals. A participant also mentioned that circulating self-check questionnaires pertaining to mental health issues on social media by influencers can also be a way to make mental health services approachable for elderly. It can also be circulated in form of a screening tool on social media and references can be provided in case it is suspected that the person might be having dementia symptoms.

'Second the person should be kept in the same circumstances that they have been or the same environment that they have been in for...For the better part of their lives. So, if they are at the same place, it is possible that with love, care and with some medication people can recover.'

Many inputs were also gathered about creating awareness among healthy older adults regarding dementia. The participants believed that creating dementia related advertisements, TV series can be a good mode to generate awareness among older adults. Awareness

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campaigns on social media, in hospitals can also prove to be helpful. There needs to be a connected web of psychologists and doctors so that they can educate healthy older adults about the symptoms of dementia, how can it be prevented, what can they do for someone who is facing this issue and how to help them receive care.

'Awareness, awareness right from the beginning. Even the schoolchildren should know that when their grandparents are at home, they should give time to the grandparents or to other people. Even there should be that this can happen. The awareness should be from right from level one to whichever.'

One of the major objectives of the research was to understand the existing knowledge about dementia. To cater to this, the participants were asked to explain their understanding of dementia, what are the symptoms, risk factors and treatment they know of. The knowledge gained from the caregiving experience and risk factors were also explored. All of this was covered under the theme, perspectives about dementia. The participants mostly attributed dementia as forgetting things. Mostly attributed to older adults. Very few participants who were mostly caregivers pointed out the mood changes, gait abnormalities, aggressive behaviour as a part of dementia. It was believed by most participants that late diagnosis of dementia leads to poor consequences. They also pointed out there is a lack of evaluative procedures for dementia diagnosis. The recovery can be either complete or partial in case of dementia. Few also believed that medication is not required for treatment of dementia, it is not an illness and is only forgetting common among all older adults. These responses highlight lack of awareness about dementia among participants. For caregivers, the participants believed that they should try giving the patient insight and try to make them improve their everyday life functioning by trying to make them independent.

'Dementia is basically...according to my knowledge...is forgetting the things. Forgetting the relations, peoples, and you are forgetting ourselves, our activities, memories.'

'Actually, I don't know... research and medicine and all are there but still according to my knowledge dementia is not at all a disease they make it a disease. Medicines and are not at all needed. Awareness needs to be spread. Precautions need to be taken. If you have any old people like 60 plus in your family, then 90 percent people can forget things that doesn't mean she is suffering from dementia. It is natural process.'

The above statements underline the fact that few people are still not aware of the condition dementia completely because it is the limitation of the neurodegenerative disorder that the patients are disoriented and cannot be given an insight into their illness. The caregiving experience of the participants provided them with a lot of insight into the illness which was shared during the interviews. Most caregivers felt that dementia patients feel very frustrated because they are dependent on others, and they have a low self-esteem. Further, it was also believed that progress of the disease can be slowed down. The caregivers also point out that there are individual differences in experience of dementia and some patients forget things completely whereas others are able to recall few things from the past. They forget instantaneously so they have repetitive thoughts and in extreme cases they start communicating only by gestures and don't use words anymore. Most patients shut themselves feeling guilty. Also, late diagnosis leading to worsening of symptoms of the patient was also pointed out by many participants.

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'Like I've seen live cases in my life. They just keep quiet. They think that they are doing something very wrong, very drastic. So, they just shut that shut themselves up and just try to be quiet.'

The general perspective of the society and the participants gauged about dementia during this research centred around beliefs that dementia is not a clinical problem, education has no role to play in dementia, it is a societal construct with no scientific basis, it is just a normal part of ageing that people forget and that symptoms of dementia develop slowly.

This is not in sync with the present literature that exists because it has been evidenced long back that dementia is a clinical problem and structural and chemical changes in the brain have been found in patients with dementia (Korczyn & Vakhapova, 2007). Further, it has been studied that education status acts as a protective factor for dementia and helps in improving cognitive reserve which could help in coping up with the damage caused by dementia otherwise (Does Education Really Protect against Dementia? 2019). Further, it was mostly thought that isolation, pent up emotions, stressful work life, shift to nuclear family tradition, personality factors and retirement are risk factors of dementia. The participants were very unsure about heredity as a risk factor for dementia. Studies have evidenced that physical activity, diabetes, cardiovascular issues, lack of physical activity, antihypertensives are few of the major risk factor for dementia (Anstey et al., 2019). Research also suggests that genetic and lifestyle factors are the key drivers of dementia, there is a strong association of dementia existing in a family generation after generations (Licher et al., 2019). Hence, this highlights the need to provide psychoeducation to our population about the risk factors, treatment available and symptom manifested in dementia.

Under the fourth theme the psychological concerns of older adults were understood. From the interviews it was highlighted that there is an increase in loneliness among older adults due to shift to nuclear family systems. They feel increasingly worried due to their inability to use technology as appropriately as the younger generation. Generation gap has also become a cause of concern for them. Further, older adults face issues like low self-esteem, forgetting, having a lot of pent-up emotions, and inability to understand the rationale given by others. These cause psychological distress among older adults. Due to the pandemic, there has been reduction in socialisation of older adults which has also impacted their mental health.

Research articles have also identified several mental health concerns of elderly in sync with the above-mentioned results. In a recent meta-analytic review by Hossain et.al. it was evidenced that the burden of loneliness is higher among elderly in comparison to younger adults of India. They also highlighted the need for multipronged interventions for addressing the risk factors and alleviation of burden of loneliness in India (Hossain et. al., 2020). Further, studies have also highlighted that older parents who are left behind by their children have higher levels of mental health problems in comparison to those who are staying with their children. The left behind older parents were found to have higher depressive symptoms, higher levels of loneliness, lower life satisfactions, poorer psychological health, and lower cognitive ability (Thapa, Visentin, Kornhaber, & Cleary, 2018). These concerns provide a cue to policy makers, mental health professionals and social workers to address them and help older adults through community outreach programs and other means.

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'You get irritated very fast because your own absorption comes very slow. You don't get what people are saying. So, you ask questions you again ask questions, people that irritated and you really avoid talking to people.'

Attitude of the society towards dementia was gauged under the fifth theme. Major factors underlying this theme were the stigmas and the misconceptions of the society regarding dementia. The participants mostly identified that stigma still centres dementia and exacerbates the difficulties on both the patient and the caregiver's part. Common stigmas reported by the participants were that the people feel that the individual is doing things intentionally to gain attention and never fathom that they might be experiencing these concerns due to an underlying neurodegenerative disease. Further, many participants felt that due to low awareness about dementia people ignore symptoms considering them to be a part of normal ageing. These findings are supported by research (Low and Purwaningrum, 2020).

'Yeah, I have a feeling our society basically thinking anything when mentioned, they start thinking someone has, you know, been as a term that they have gone mad. People start thinking they have to go to asylum, or you know, so they're not in real state.'

'They connect it with brain problem...that he or she is started getting weak brain or dull brain for example getting confused with things that is brain problem, but people are getting confused that that person is getting mad.'

Many participants also felt that people have inhuman attitude towards dementia patients because they perceive them to be a danger which sometimes forces the family to send them to rehab centres and old age homes. As a result, caregivers sometimes conceal that a family has dementia from people around them. Furthermore, research also suggests that healthy outcomes of interventions in terms of general mental health and depression among dementia patients and caregivers are found with use of problem focused coping strategies, acceptance, and socio-emotional support. However, wishful thinking, denial and avoidance coping strategies by caregivers lead to poor outcomes (Gilhooly et. al., 2016). Moreover, even if dementia is diagnosed there is still a taboo related to providing and receiving care from a psychologist in the country which leaves many concerns unaddressed. Most of the participants reported that people feel the person has gone mad and needs to be sent to an asylum and cannot be managed at home. This furthers the stereotypes among the society.

'Ah, most of the people think that they are mentally sick. Instead of understanding the problem they are going through and what they have done all their life suddenly they get a sticker, that they are mentally unstable and should be kept isolated. And the isolation itself is more dangerous for them. It starts affecting people around them and indirectly it starts affecting them also.'

It is well evidenced that dementia patients report agitation, personality changes and other complications depending on the type of dementia which necessitates sending them for neurorehabilitation as the illness progresses (Rao et. al., 2020). This is only done for the safety of dementia patients and their wellbeing so that they receive the care by experts which they require. Some also felt that the society expects dementia patients to perform and interact with them as they used to before diagnosis which also creates several issues for the patients. In a study conducted by Reynolds et al. in 2022 it was found that aging and older adults are often described by the general public using negative stereotypes, such as decline

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in cognitive and mental functioning which results in deteriorating mental health. Moreover, due to the stigma against agitation in dementia many older adults have to be in emergency rooms for weeks due to not getting accepted in long-term care facilities. Sadly, due to the prevailing stigma dementia patients suffer even more due to lack of alternatives provided by the society in such cases (Reynolds, Jeste, Sachdev and Blazer, 2022). This theme therefore presents some crucial factors which needs to be addressed to raise awareness about dementia, neurodegeneration, caregiving, and neurorehabilitation required for dementia by the government and the mental healthcare workers to help the interventions go in tandem with the needs of dementia patients.

Finally, reasons for reluctance to receive care were identified in the last theme. It was found that many older adults felt the need to go for therapy but had some reservations about the same. It was reported by many participants that many don't go for mental healthcare services because of fear of labelling and stigma attached. They also felt difficulty in taking individual sessions. In case of dementia the caregivers lack of awareness about the need for mental healthcare in such conditions was reported to be the major reason for not availing mental healthcare facilities.

'If you say that I'm going only to the psychiatrist or to the mental doctor, I will not go because it's a social stigma. You know, if I go my neighbour oh my god, this lady has gone to the psychiatrist. I think she knows that she's bad. She knows she's not mentally fit.'

'Nobody wants to be labelled mentally unfit. So, it should be part of all the branches of medicine. Part of it if you are treating any disease, any disease, but you should touch on this also.'

Research on challenges to geriatric mental health in India have also pointed out that access to mental health care facilities need to be improved. It is essential that interventions aimed at group geriatric therapy sessions should be developed and the mental healthcare services should be integrated deep into the healthcare system to help improving access (Katiyar et. al., 2020, and Reynolds et. al., 2022).

CONCLUSION

It can be concluded that, the present research was thus able to gauge the attitude and risk perception of dementia from the perspective of middle aged and older adults. It highlights the prevalent misconceptions, stereotypes, and the existing knowledge base of the geriatric population towards dementia. In purview of the above findings relevant intervention programs can be designed for dementia awareness, dementia patients and caregivers.

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Conflict of Interest

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