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QUALITY OF LIFE: The Quality of life of older Pakistanis with Mild Dementia: Three cases in Lahore, Pakistan

QUALIDADE DE VIDA: A qualidade de vida de paquistaneses idosos com demência leve: três casos em Lahore, Paquistão

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ABSTRACT

Since dementia is a progressive terminal clinical syndrome with no cure, the life of persons with dementia (PwD) can be adversely affected. Due to limited access to healthcare and lack of awareness in Pakistan, a majority of older adults do not get screened for dementia. The objective of the current study was to examine the problems and the Quality of Life (QoL) of underprivileged older adults with undiagnosed mild dementia in the Pakistani context. Using purposive sampling and case study unstructured interviews, 3 participants with apparent symptoms of dementia aged above 75 years (2 female and 1 male participant verified as persons with dementia by 8 researchers) from a low-income group in Lahore, Pakistan were observed and interviewed. Some dementia caregivers inevitably intervened as unintended/incidental participants. Thematic analysis of interviews with persons with dementia in Lahore, Pakistan revealed sense of loss and alienation as one of the dominant themes. This research has implications for dementia caregiver education, dementia friendly places, healthcare registration, family therapy, accessible social support groups, social security organization for elderly, need for neuropsychologists, and dementia awareness in Pakistan.

Keywords: Gender, early-stage/mild dementia, Pakistan, Lahore, older, low-income group, quality of life (QoL), qualitative study.

RESUMO

Visto que a demência é uma síndrome clínica terminal progressiva sem cura, a vida de pessoas com demência (PcD) pode ser afetada adversamente. Devido ao acesso limitado aos cuidados de saúde e à falta de informação no Paquistão, a maioria dos adultos mais velhos não faz o rastreio de demência. O objetivo do presente estudo foi examinar os problemas e a qualidade de vida (QV) de idosos carentes com demência leve não diagnosticada no contexto do Paquistão. Usando amostragem intencional e desenho de estudo de caso, 3 participantes com sintomas aparentes (verificados por 8 pesquisadores) de demência de um grupo de baixa renda em Lahore, Paquistão, foram observados e entrevistados. A análise temática revelou o sentido de perda e alienação como um dos temas dominantes. As implicações são discutidas.

Palavras-chave: Gênero, demência em estágio inicial/leve, Paquistão, Lahore, grupo mais velho, de baixa renda, qualidade de vida (QL), estudo qualitativo.

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Introduction

Each year, 4.6 million cases are added to the existing cases of dementia. Overall, 11.3% years of life are spent in disability due to dementia. There are around 8 million older adults diagnosed with dementia in Pakistan and the figure is predicted to rise to 27 million by 2050 for population aged over 65 years (Ahmad et al., 2013). About 0.2 million persons with dementia (PwD) currently have Alzheimer's type of dementia in Pakistan with increased life expectancy. Dementia is a global health priority (Zaidi et al., 2018). Dementia is likely to increase from 2 to 6 % in the next 30 years among individuals over 65 years of age, which means that health care costs will also increase in Pakistan in terms of patient and caregiver arrangements and health care facilities (Thaver & Ahmad, 2018).

Dementia is a general term for a clinical syndrome characterized by a decline in cognitive ability, severe enough to interfere with daily life. Alzheimer's disease is the most common type of dementia, which involves memory loss (Alzheimer's Association, 2019). Dementia results from a range of neurodegenerative diseases or other causes, which lead to declining memory and multiple cognitive deficits, progressive, and irreversible brain damage, and an eventual death. Dementia reduces a person's ability to communicate and perform various tasks with time. Gradual changes occur during earlier stages, while supervision is needed during moderate stages. During advanced dementia, PwD are completely dependent upon the caregivers (Alzheimer's Association, 2019). Dementia is not widely recognized as a clinical syndrome among medical professionals and the general public of Pakistan (Khan, 2014). People avoid seeking help for PwD due to stigmatization of dementia, inaccurate beliefs about dementia or a general trend of misinterpreting dementia as normal advancing age related mental decline (Giebel et al., 2019; Zaidi et al., 2018).

Being alive is not the goal of life, but good quality of life (QoL) is pertinent for psychosocial adjustment particularly for older adults who are becoming dependent on others with advancing age (Levasseur et al., 2009). The current research focused on QoL of older adults with dementia. QoL refers to the state of happiness and contentment, the source of which can vary across individuals (Fayers & Machin, 2013). Due to development of medicine and technology, there has been an increase in the older population throughout the world. However, the QoL of senior citizens has declined. Therefore, older people experienced physical and cognitive decline (Ma & Chan, 2020).

According to Christiansen (Christiansen et al., 2019), the QoL of PwD is compromised due to increased dependency to perform routine tasks, provision of informal care and the sense of pain and loneliness. Poor orientation, greater physical dependency, administration of anxiolytics, and depression has been related to poorer QoL in PwD (González-Salvador et al., 2000). Dementia reduces the ability of the PwD to perform daily activities, which can cause depression in PwD (Sengupta & Benjamin, 2015). In addition to depression, poor physical health, neuropsychiatric symptoms, and lower levels of caregiver's wellbeing have been related to a poor QoL in PwD (Martyr et al., 2020). Distress has been related to decreased QoL in PwD (Häusler, et al., 2016). Dementia has been associated with disturbing symptoms such as hallucinations, anxiety, and depression in addition to cognitive decline (Dawood, 2016). In Sun et al. (2018), the ability to engage in daily activities and consequently the QoL of PwD was adversely affected due to poor cognitive functioning. The QoL in PwD with Lewy bodies (DLB) is worse than QoL in PwD with Alzheimer's disease due to delusions, apathy, and reduced independence in carrying out routine activities (Lee et al., 2018).

However, QoL does not necessarily decrease as dementia progresses. Improving the mood and cognition of PwD can help in improving the QoL of PwD (Hoe et al., 2009). A study (González-Salvador et al., 2000) has shown that QoL of PwD is better at residences where facility of assisted living is available as compared to residences with skilled nurses. Social, emotional, psychological support along with meaningful participation in various activities can increase the QoL in Alzheimer's dementia. Health education of family members, social engagement with the family, efforts to maintain the dignity of PwD, good quality diet, rest, exercise, and reduction in accidents can also improve the QoL of PwD with Alzheimer's disease (Yi & Jiaying, 2018).

In Pakistan, religiosity has been related to life satisfaction for people aged above sixty years (Gull & Dawood, 2013). People are generally not aware that PwD have no religious obligations. Thus conforming to religious obligations becomes a distress for PwD, and the QoL is compromised in terms of the ability to fulfil the religious rituals such as 'salat' (Willis et al., 2020). The social support system for the older people in urban Lahore is deteriorating with the increase in nuclear family system and it is having a negative impact on their levels of disability (Ahmad, 2011). The social support system is mainly characterised by patriarchy (Bhopal, 2019). Therefore, the male gender PwD might be adversely affected by patriarchal breadwinning expectations (Janssens, 1997). Family support affected the health of the older people in the rural Gujrat (Shoaib et al., 2011). A study (Ilyas et al., 2020) on different regions of the Punjab province showed that family support affected spirituality and spirituality positively affected self-esteem and ego-integrity of older individuals. Self-esteem and ego integrity impacted the physical and the physiological well being of Pakistanis aged 61 years and above.

Lack of knowledge, poverty, and poor state laws are some of the determinants of poor QoL of older individuals in Pakistan (Vertejee & Karamali, 2014). QoL of PwD is also compromised due to stigma related to dementia in Pakistan (Zaidi et al., 2018). The term 'dementia' has been stigmatised. Due to lack of awareness, the family caregivers are ashamed of the behaviours of PwD. Sending a loved one PwD to care homes is stigmatised as equivalent to abandonment and family neglect (Zaidi et al., 2018).

Since caregivers are likely to report lower QoL as compared to the subjective reports of the PwD according to Sands et al. (2004), the current research focused on the subjective self-reports of PwD instead of subjective reports of caregivers of PwD to get a clue to the state of older persons with dementia (PwD) in Pakistan from their subjective perspectives. However, the scope of QoL covered in the current research was limited to the self-reported subjective verbal descriptions of PwD and the observation of PwD's home environment consisting of informal/family dementia caregivers. Currently, very few studies (e.g. Khan, 2014; Zaidi et al., 2018) with a psychological focus on dementia have been conducted in Pakistan. The ethical approval was made keeping in view that the current study was significant in terms of the focus on dementia in Lahore, Pakistan.

Aim

The aim was to understand the effect of undiagnosed early-stage/mild dementia on self reported QoL of elderly Pakistani PwD with observable symptoms of dementia belonging to low-income group.

Research Question

1 - How does undiagnosed early-stage/mild dementia affect self reported QoL of older Pakistani PwD with observable symptoms of dementia belonging to low-income group?

Method

Statement of Ethics

This study received ethical approval from the ethics committee of Applied Psychology Department of a well-known university in Lahore. The ethics committee included PhD qualified ethics experts who had an autonomous review of the ethics application. There was no affiliation, financial or conflicts of interests involved in this research. There were no risks to the safety and security of the participants and the researchers. All researchers had read the APA ethical guidelines for research. The researchers were aware of conducting research with vulnerable individuals. The purpose and expectations of the impact of the current study and the ethics application was explained to the dementia caregivers and the participant PwD in their native language. A copy of letter of introduction with contact detail of the principal researcher, information sheet, and informed consent form was provided to the participant PwD and their caregivers to keep. The PwD and their caregivers consented to interview participation. The researchers were also mindful of processual consent. The participants were free to withdraw their data or quit participating in this study at any stage of data collection without any implications. The participants and their caregivers did not consent to be photographed or their interview to be video-recorded. Therefore, according to their processual consent only audio recording was permitted and made. The data was destroyed from the phones after transferring it to principal author's secure device. The participants and their caregivers were ensured that the data in the publication would be in a de-identified form. The participants did not belong to unique cultural and religious background. No other individuals were involved in translating the responses of the participants other than the researchers of this study. The ethical principles of interviewing were followed.

Participants

PwD were the main participants in the current study, but given that PwD have limited capacity for informed consent, low cognitive processing and are depending on their caregivers for cognitive, emotional, social, and practical support, the caregivers unavoidably and unsolicitedly intervened during the interview and served as a communication bridge between the interviewers and PwD interviewees at some points. PwD were interviewed in the presence of and with the permission of their primary caregivers. The caregivers' informed consent had to be obtained and they were also debriefed at the end of the interview. However, the caregivers were not the direct research participants for the interview. The caregivers were aged between 17 to 40 years.

Following was the inclusion criteria:

1 - The participants must be Pakistani older individuals/senior citizens with observable early stage/ mild symptoms of dementia, such as 'forgetting' and 'change in personality and behaviours' from Lahore.

2 - The participants must belong to a low-income group.

3 - The participants with dementia (PwD) should be able to converse with the interviewer.

4 - The dementia symptoms must be witnessed through interview and observations of PwD by 8 researchers.

Due to lack of awareness about dementia in Pakistan, it was very difficult to get clinically diagnosed cases of dementia specifically in a low-income group. Most of the caregivers were not willing to provide access to the PwD. Finally, three participants were found from the researchers' social circle, a neighborhood whereby the neighbors and primary informal/family caregivers identified the PwD. The participants might have been remotely related to some of the researchers because it was very difficult to find participants who were completely unrelated to the researchers. With the sensitivity of this research involving a mental health stigma, generally unrelated people were hesitant to disclose information.

Purposive sampling was used. The sample included two women participants and one man.

The first case was a male participant with a reported age of 75 years, who had not received any formal schooling. He was a retired skilled worker, an electrician. He forgot certain things but he appeared quite aware of his surroundings and his memory problem. His long-term memory was intact.

The second case was an old female participant who did not report her age. She appeared to have anosognosia because she was unable to recognize any problem with her memory (her caregiver, her daughter-in-law reported that her mother-in-law, the participant often forgets names and her statements).

The third case was a female participant who reported her age as above 100 years. The third participant apparently had some insight of her forgetting problem, was overexcited to take the interview, but reported certain deviant behaviours such as 'talking to her feet'.

Research Design

A case study design was used. The PwD were interviewed with questions related to dementia, their routine life, and profession but at the same time they were allowed to express their own perspectives or express any ideas that randomly came to their mind to assess PwD's QoL. Thematic analyses based on unstructured interview were used to analyse the PwD's responses to understand PwD's daily functioning in terms of PwD's QoL.

Quality Assurance

The current study met the quality criteria of credibility and dependability through member-checking of transcripts (via audio recordings, participants and their caregivers) and the self analyses of 9 researchers. Method triangulation was used through the use of interview and observation during the interview by at least 3 researchers.

Tools of Data Collection

Unstructured interview and observation of PwD's behaviours, dementia caregivers' reactions, and the home environment during the interview were the tools used.

Procedure

The project on dementia was introduced in the researchers' social circles, and different departments of a well-known university in Lahore after ethical approval. Eight researchers together went in a group for data collection. The interview took place in a familiar environment for both the researchers and the participants. The interview schedule was adapted according to the situation, i.e. the characteristics of the participants', their caregivers' and their settings. The interviews were recorded and transcribed with the permission of PwD and/or their family/informal dementia caregivers.

Interviews with PwD lasted 15 to 30 minutes in the presence of caregivers. All dementia caregivers were debriefed at the end of the interviews.

The concept of dementia was explained to the informal dementia caregivers in 'those terms', as it is known among the uneducated individuals in Pakistan. The concept was explained as a memory loss health problem, 'the problem of forgetting' that accompanies changes in personality and behaviour.

The male PwD responded in Urdu while the female participants responded in Punjabi. The author translated the transcripts from Urdu and Punjabi to English and analyzed them for different patterns and themes. Two PwD appeared aware of their forgetting symptoms and how their QoL had been consequently affected. One of the female PwD was unable to recognize her problem but she was able to provide answers to the interview questions (in this case informed consent was obtained from her caregivers).

The dementia caregivers were informed of the counseling services at Alzheimer's Pakistan and Fountain House in case if the PwD were distressed due to the research interview and needed support and counseling.

Sensitive personal issues such as grief, trauma, depression, and loneliness arose during the interview but the participants explained their feelings and thoughts in a fluent and comfortable way. The interview questions focused on QoL in terms of symptoms of forgetting and difficulty in routine functioning. The participants were very responsive and cooperative.

Results

Thematic analyses of interviews with PwD were used to analyse the results. A total of 9 researchers worked on the analyses of this project. Therefore, the self-analyses of the researchers are also given with the case summaries below. The theme of *'forgetting'* was the major theme in the self-analyses of all the researchers. They understood dementia in terms of *'forgetting to eat', 'forgetting to take medicine', 'forgetting the way', 'being confused and disoriented in time and space', 'forgetting the routine tasks', 'forgetting the names', 'forgetting their talk' and 'forgetting almost everything'.*

Case # 1: Male participant

Researchers 1, 2, 3, 4, 5, and 9 resonated with the theme that socioeconomic status contributed towards QoL. Researchers 1, 2, 3, 5, 6, 7, and 9 agreed with the participant's perspective that tension and anxiety affected the QoL of older PwD. All 9 researchers had a consensus that forgetting affects the QoL due to increased social dependency. Some of the researchers resonated with the problems of the participant about their home country. The participant expressed a certain level of dependency upon others but overall the participant seemed grateful towards life and daily functioning and his life appeared manageable with social support at his then existing stage of dementia.

Case # 2: Female participant

The themes of death and disease emerged from participant's conversation but her consciousness also seemed to fluctuate. Overall, the female participant appeared satisfied with the income sources and her independent living. She proudly reported that her daughter had three sons. The participant was confident and was not upset with her cognitive decline and poor reasoning abilities. She appeared comfortable in depending on her sons for her living. Even though there was an element of increased dependency on others, the female participant defied her situation and thus appeared quite contented with her current setup. The participant was limited to her house with rarely any visitors but she seemed ignorant of her memory issues and appeared overall adjusted to her environment at her then existing stage of dementia.

Case # 3: Female participant

The female old participant attributed most of the things to the creator and the prophet of her religion. The participant mixed factual information with imaginary information in her conversation. One of the researchers resonated with this case because the researcher's late mother with DLB used to say things such as '*The saints are coming and going*'. The female participant overestimated the number of her children as being 14. She did not seem to follow the questions. She did not remember her age, reported forgetting names, the time of prayers, the number of head bows to the ground during the prayer which she attributed to her age. She also reported talking to her late husband in the spiritual world. The participant indicated a severe sense of alienation through her report about 'talking to her feet'. The participant reported that she never went outside her house. All researchers related to dementia in terms of 'social isolation'. One of the researchers was a caregiver for her late mother with DLB. She could resonate with the participant's feelings of grief, insecurities, and paranoid beliefs. Nevertheless, with limited evidence, it was difficult to assess whether such beliefs were paranoid beliefs, a reflection of past abuse or an actual current elder abuse happening in the family.

Overall, this participant's dementia seemed to have progressed in terms of fluctuating consciousness, paranoia, and cognitive decline with clearly compromised QoL. She seemed to reside in her imaginary religious and spiritual world. She seemed to be socially deserted and deprived. She also expressed feelings of persecution by unknown individuals.

Self analyses: Researchers' perception about dementia

According to Researcher 1, dementia is a complex disease, which requires challenging differential diagnosis. Researcher 1's mother had DLB. The researcher subjectively felt that her mother could have a better QoL if the researcher as a caregiver was aware of symptoms, and had dealt with dementia before or during its onset. The subjective reports of her mother with DLB varied according to her fluctuating consciousness and the antipsychotic medication that she was taking. Researcher 1 believed that awareness about dementia could have helped her as a caregiver to improve the QoL in terms of increased socialisation and autonomy in leading day-to-day life without any medications. The life that her late mother with dementia spent still traumatizes the caregiver researcher even after several years of her mother's death.

Researcher 2, as a mere observer of older PwD believed that PwD's QoL is adversely affected due to their age, low social support from the family, and their low socioeconomic status. Researcher 2 believed that older PwD have difficulty in completing their tasks, finding their way, taking medicines on time and so forth. Researchers 2 and 3 believed that QoL of PwD in terms of daily functioning and social relationships were affected by dementia due to impaired memory. Researcher 3 also believed that older PwD face problems because their caregivers have lack of awareness of dementia and due to their low socioeconomic status. According to Researcher 4, older PwD have restricted autonomy with respect to leaving home and returning to their residence and forgetting affected the QoL of older PwD. Researcher 4 stated that improving family relations could improve the QoL of PwD. Researcher 5 also believed that forgetting was the most important symptom in the lives of older PwD that affected their daily routine and social functioning and the demographic factor of low socioeconomic status exacerbated it.

Researcher 6 also held the same belief that older PwD face difficulties in their social and independent lives due to the main symptom of forgetting. Researcher 7 believed that older PwD repeat certain behaviours and become disoriented due to dementia and thus they need social support of their families to overcome their confusion. Researcher 7 also opined that PwD's physical health declined because they often forgot to have meals and PwD frequently became upset or anxious. Researcher 8 believed that due to lack of awareness of dementia, families do not consider dementia to be a BIG problem. Therefore, the caregiver families are unable to perceive the needs and problems of older PwD. Researcher 8 believed that family cooperation can be beneficial for older PwD. Researcher 9 believed that older PwD lead difficult lives due to memory issues. They are unable to complete their tasks and their interpersonal relations are affected. Positive family involvement, and increase in socioeconomic status can alleviate their situation and enhance their QoL.

Table 1 showing QoL of 3 elder/older/senior Pakistani citizens with dementia belonging to a low-income group

Case #1	Main theme	Sub-theme	Sub-theme components	Example quotes
Male participant	Relationship of poverty/ affluence and power politics and age with sickness/ health	Struggles of life	Poverty, education and sickness	"My parents sent me to school but I did not study"-line number 6 "…Even if there is a very highly educated person here, his mind is of another sort. Second is that one more thing I would like to tell you, that always a person who is well off in life, neither will he be sick- always poor people get the diseases, poor people…"- line number 53 "…, I left the cloth shop and learned the skill of electrician. I learned that work till 1962 and 1963. After this I started my own work. Then I became an employee in the Telephone department."- line number 8
			Migration and leg pulling by fellow Pakistanis	"I joined a program in Saudi Arabia"-line number 14 "My brothers there Pakistani brothers were a danger for me."- line number 27 "Because they could not bear it that our nation should progress."- line number 29 "A Bangladeshi will bring a Bangladeshi not anyone else but a Pakistani cuts a Pakistani (leg pulling; i.e. not supporting people from one's own nationality or race but going out of the way to hire foreigners) and will bring a foreigner. This is the goodness/virtue we have."- line number 31 "…In our country when someone gets caught, all others start cutting him off.. that he is the one…(responsible)."- line number 31
			Home country tensions	"Most of the men, not only me, many men face the situation of tension, the mental tension that exists in our country. Not in the foreign countries. This is in our country. There is a lot of control (ajara daree). The earning reduces. Worries increase. The man gets tense. Thinks about how to manage house expenses. The conditions of the country here are as such."-line number 22 "…we suffered a loss of 4 crore and we could take a stand on it. We could not stabilise…. On top of it my son who used to work there died"….long pause…..''after that we……at that time I did not do any work…"- line number 23

	Heroic acts and efforts	"…you will see me in one thing that is as supervisor in the telephone department, who is usually a B.Sc graduate. I was illiterate but I used to do all sorts of work. Not only electric work of the telephone but I did all sorts of work…..I went to Saudia Arabia and there I worked as a technician."- line number 27 "…they went to the market and bought something for 15 and when I went I bought the same thing for 9."-line number 31 "…The person who had signed an agreement of 15 days with me did not return. I worked for a month and he came after one month. He looked at me with an angry look….. with him he had an engineer. ….he said to the Philipino this is the record of the entire month. Then the person who held the complaint ….that….. Mirag…Miraj Deen, he said what is this? He said there was no other man. He did all the work on his own the entire month. He instead of 15 more days had an agreement of 3 years with me and along with it he promoted me. He said we know that you are a technician but we will change your designation to maintenance technician. Then they made me a general technician for the time I stayed there, till 71…till 91…."- line number 31
Forgetting	Awareness of the forgetting symptom and consequences of forgetting on daily functioning	"I did not have it (forgetting) first. Now, I have had this problem for around 15-20 years. This causes a lot of problem. I am telling about this problem first. I forgot. I am thinking that what was I talking to you about."-line number 20 "I ……….pause………when I was a supervisor in the telephone department , I had all the telephone numbers retained in my mind. I also orally remembered all the telephone numbers of Lahore, I went to a foreign country, …..I went to a foreign country, I just told you, when a person is cut off from something, he forgets"-line number 25 "I have forgotten many things in it. I would not have told you 100 percent of it. Many of the things I would have forgotten and many of the things I might have mentioned in excess. I mean that in everyday life, I place money somewhere and then I forget where I kept it. And if there is no money, there is nothing to forget. I forget to say my namaz (prayer), I am not saying my namaz nor…."- line number 37 "No. I forget everything. Betay (son/child) namaz is a routine. It should not be forgotten. I gave two sajday (head bows on floor) but I had to do it three times. I forgot and started namaz all over again. I am talking to you now. Suddenly my attention diverted, the entire map from my mind was lost. Now I will start over again whatever I say.- line number 39 "…I live at home, and the names are of the house children. But one thing I will tell you, I do not know the names of my paternal grandchildren."- line number 42 "I forget, I call one 'Puppoo' and another something else. I do not take their names."- line number 44 "No, at the moment since the problem began, I do not go anywhere alone."- line number 46 "…The switch was broken. I boasted off to the family members that I will change the switch even though they do not let me work because my hands tremble. I cannot see. ….. pause… I opened it. Near me was my paternal grandchild. I changed the switch. Then, I did not understand where to connect the wires. I have forgotten…"- line number 53 "…I forget the maths…."- line number 53 "This often happens. When I was coming to you, a girl child called on the telephone. I said ok beta I am coming. I got up from this time, I have to take sugar medicine …..after the breakfast….I had not taken the medicine….now I got up and I remembered that sugar medicine……then my wife gave me the medicine and I came….. pause……this often happens, these forgettings."- line number 55

		Physical and social dependency	Presence of social support	"…I have a son"……..pause………He goes to work in the morning and returns in the evening. Whatever he earns he brings it to me"………..pause…….- line number 23 "…In the past few days, I was very ill and I could not walk."- line number 47 "I have problem with my knees and my back which is known as chuk."- line number 49 "I did not carry weight. I could not walk. I used to get out of the house and sit on the ramp. When a motor cyclist passed by, I used to wave him and request him to take me to the masjid. This is how I completed my journey."- line number 51 "…I am used to purchasing the vegetables. I go every Sunday to the Mundey (Sunday market) and take my grandchild with me. I cannot go alone. We park the motorcycle. I give him the money I have and tell him that this is the money I have. He says okay. Then I say, you have to take care about how much money I give to whom. I take the bodyguard with me. I do not go alone."- line number 53 "Dada abbu (paternal grandfather) please tell us…this dada abbu you have to put it here. This you have removed from here."- line number 53 "……then my wife gave me the medicine and I came…..pause……this often happens, these forgettings."- line number 55
		Family education	Mixed feelings of regret and pride	"I am telling you that my parents tried a lot to get me educated but I did not get educated. My elder brother was a chartered accountant, but he is not alive now. His elder son is a CA. They got educated. My elder son passed his FA. We got him to the shop-keeping business. The younger one passed matric and he also joined his brother in shop keeping. I returned from abroad and joined them both at the shop…… pause …… Now Masha'Allah (God willed) I try that my paternal grandchildren get educated."- line number 61 "My father was a reader and writer in a newspaper."- line number 63 "…. He was in the nawaiwaqt (newspaper) and after this there was a press in Lahore, he was there……then he started managing a shop." Line number 65
		Aging	Attribution of age to memory loss	"Beta (child/son) in this age whomever I have talked to, has talked in the same way."- line number 53
Case #2				
Female participant	Denial of having an ailment- and contradictory statements	Early events	Birth, brought up, migration, marriage, death, ailment and unsettlement	"I was around 2 to 2 and a half years old when my mother left me. After this there was no mention of my birth date. My disease does not leave me. I cannot get rid of it."- line number 6 "Look I am not in my conscious awareness since I was born. I was around 2 and half years old when I my mother passed away. Sometimes at one sister and sometimes at other sister's house… Those poor ones have brought me up. I am not in my own self. I do not know about myself (where I am)."- line number 8 "Wedding when I was saved. When people came to Pakistan. When they came from Hindustan to Pakistan. At that time they got me married with the will of my parents. I did not feel good anywhere Since then (relocation from India to Pakistan), we did not get settled, sometimes here and sometimes there."- line number 10 "My husband died a long time ago."- line number 12 "Many years ago and my sister about ten years ago."-line number 14

		Current family setup	Progeny and expense management	“Masha’Allah (as God willed) I have 2 sons and 1 daughter. They both are here.”-line number 16 “All maasha Allah (as God willed) are married. My daughter Masha’Allah has all three sons.”- line number 18 “My sons are here. One son has taken a house here. My house was the lower portion. These days all three offspring go according to their own will. They are married. They do as they will. Wherever they live, the house is mine.”-line number 20 “My expenses? My husband left his pension in my name with his own hands.”- line number 22 “Look, the same amount that is written, the amount which they pay me. We do not count this or that…”- line number 24 “When I am the only one here- who else is here? I cook and eat”-line number 26
		Adjustment with the forgetting problem through dependency and limited social life	Denial of the forgetting problem	“I do not take/buy anything that I forget.”- line number 28 “..The thing which is there, I never forget….neither I go out nor I bring anything. Never.”-line number 30 “No, No….the food (curry) is delivered by my daughter sometimes, and sometimes I feel like cooking myself and I cook it myself. If she feels, she sends some food that she has cooked.”-line number 32 Interviewer: “Do you face difficulty in recognising people? I mean if you have met someone before, and when you meet again you are unable to recognise that person’s name?”- line number 33 “I never went to anyone’s house- how do I know?”-line number 34 “Yes, I remember the names of all my grand children.”-line number 36 “One is named Ikraam, one is named Islam, one is Adnan, these types of names they have poor ones.”-line number 38 “…I forget the name so this is my daughter in law.”-line number 42 “Never said nor ever heard. We keep quiet.”-line number 44 “No, no, I remember their names.”- line number 50 “No, I do not forget. I do not call. They come and go by themselves. I have my own concerns. Why should I need to call anyone? They are near me, downstairs. I am here upstairs. They go and come by themselves.”- line number 52 “I have a son. He is her husband.”-line number 54
Case #3				
Female participant	Age and forgetting, extreme sense of loss and alienation from others, overwhelming religiosity, and living in an imaginary world	Religiosity	Attribution to God	“God has kept me busy”- line number 4 “My expenses are borne by Allah”-line number 22 “Everything is given by Allah and man is also engaged by Him (Almighty God)”- line number 24

	Religiosity	Over occupied devotedness to God, prophet and the religion Islam	"Man is made of mud and has to return to mud. I have bathed in kalmia (verses) and marriage with kalima, and read my funeral prayer with kalima, and bury me with kalima. My Allah is one and only and Prophet Muhammad (PBUH) is my witnesss. Make it easy angels, the person is a muslim. With kalima is my friendship and Quran is my belief. And grave is my destination." - line number 20 "…I bathed with the kalima…. go, go, go…."- line number 38 "…I bathed with kalima"- line number 40 "With kalima, I bathe, and with kalima I read my nikah (marriage), and with kalima say my funeral prayer and with kalima bury me…."- line number 66
	Religiosity	Vague and strange spirituality and concepts about healing	"Those who have engaged me, they say something that you should not take any 'huddia' (some sort of payment/charity)"- line number 60 "If you come for 'dum' (spiritual healing), and you do not have huddia (charity), if you have then you can get the dum (spiritual healing)"- line number 62 "Those have engaged me of whom I read"- line number 64
	Memory loss	Unsure of the date of events and her number of progeny	"He went … went around above the age of 100 years child!"- line number 10 "He he… also went more than 100 years ago"- line number 12 "7 daughters and 7 sons". Line number 14
	Memory loss	Forgot her age, names of her children and grandchildren, time of prayers, steps of the salat ritual, attributed forgetting to age	"….Momina…..Fatiha….." line number 32 "Leave 3, I bow 7, 7 times"- line number 38 "Ameen, Yaseen, Bashir… I forgot son"- line number 40 "I already told you, that I do not know the answer."- line number 48 "I cannot recall it naaa…." Line number 52 "Beta, I am aged above 100 years going now"- line number 68
	Grief, loss, and loneliness	Imaginary talk to her late husband	"I ask my husband if you come, so sit here…but he does not answer… he says… Allah has not ordered (allowed him to speak)… to sit near you… pray for us. To the same God we have to return."- line number 28 "The splendid company, which was given; now one has to go…" –line number 18
	Social isolation	Talking to the feet	"Look at this. The leg is straightened, shoe taken off and done like this, and come here near me. You do not talk to me…? You do not talk to me? I talk to it (my feet) … come and sit and I will talk. It (feet) will damn talk to me….?" Line number 38
	Social isolation	Did not go outside the house	-
	Persecution complex	Beaten by some unknown individuals	"Those who have engaged me. They beat me. They beat a lot. One should ask these children. They (girls) will tell you." (Paternal grand daughter: may be beaten, we do not know that)- line number 58

Discussion

The purpose of the current study was to present a case by case explanation of problems in life in terms of lived experiences, and QoL of 3 older/senior Pakistani individuals with symptoms of undiagnosed mild dementia belonging to a low income group in Lahore from their interviews. A major theme and the sub-themes were identified in a hierarchy (see Table 1). Overall the 3 participants had apparently reconciled with their current circumstances and did not blatantly complain about their lives. However, *'the sense of social dependency and loneliness'* was apparent in all three cases in agreement with Christiansen et al. (2019). Hence the QoL of these individuals was limited to the provision of services of their household members. Belonging to a low-income group might be one of the reasons for dependency on family members, which echoes the role of poverty in QoL as suggested in Vertejee and Karamali (2014).

A general pattern also revealed a gender difference, which corresponded to the cultural norm of patriarchy (Bhopal, 2019). The male participant had financial concerns throughout his life. He seemed to be affected by lack of education in his life. He was able to maintain his social life through social dependency on passersby, his wife and his grandchildren. The male participant was still in touch with his profession as he *'worked with wires'* at home. On the other hand, the female participants did not express any financial concern nor did they express any regret about being uneducated. There were *'others'* in their lives, who were managing everything. González-Salvador et al. (2000) have demonstrated the role of assisted living on QoL.

Female PwD's social lives were limited to the boundaries of their home as in a typical patriarchal system. One of the participants expressed pride about her daughter having three sons. According to Ilyas et al. (2020), family support affects self-esteem and ego-integrity and self-esteem and ego-integrity are related to PwD's wellbeing. Therefore, the female participants exhibited extensive social dependency because they *'never moved out'* contrary to the male participant who did move out and had some degree of autonomy in his life. Both genders appeared overall satisfied with their lives (Sands et al., 2004). Looking at the gender differences from an opposite angle, contrary to the male participant, the female participants had no financial or social worries. The patriarchal system was a buffer for both genders with PwD.

Nevertheless, all three participants had decreased autonomy and more social dependency (Christiansen et al., 2019). PwD, Case # 1 had retained his sense of self, had a good relationship with his caregivers, which included his son, his wife, and his grand children, and had good mental health. However, mild dementia symptoms had reduced his autonomy and thus affected his everyday schedule (Sun et al., 2018). Case # 2 had also retained a rather strong sense of self as an autonomous individual *'owning a house', 'cooking for herself when she wished'*, and *'having pension of her husband'*. The relationship of Case # 2 with her caregivers was not clear due to her contradictory statements. However, she did seem cared for when she said that she often received food from her daughter. Conforming to the patriarchal system, her everyday schedule seemed unaffected. She appeared to have good mental health. Her daughter in law as an unintended participant also reported that the participant was in a good state except that *'she often forgot names and her statements.'* Case # 3, female participant seemed to have a distorted sense of self when she associated herself to her husband or *'talked to her feet*'. She was pessimistic about life and mentally prepared to embrace death. Sense of pain (Christiansen et al., 2019), depression (González-Salvador et al., 2000), and distress (Häusler, et al., 2016) have been associated with a poor QoL in PwD. Therefore, she had a strong sense of future self rather than the present self. Since she seemed less in touch with reality, her schedule might have been changed with dementia. She was more oriented towards her religious rituals. Religiosity has been related to life satisfaction among the elderly in Pakistan (Gull & Dawood, 2013). Case # 3 expressed confidence in her caregivers but a reciprocal relationship was not expressed (e.g. she said, *'ask my grandchild, she will tell you who beat me'*. The grandchild did not know the answer). She seemed depressed, alienated, and confined to her own world. Case # 3, female participant seemed to be preoccupied with her grief due to limited social life. Martyr et al. (2020) have also shown poor QoL in

PwD due to depression. Case # 3, female participant experienced the delusions/hallucinations of being beaten by some unknown individuals, which was not verified by her household members. Dawood (2016) has shown the co-existence of dementia with depression, anxiety, and hallucinations. Impaired daily functioning and depression have been identified as themes from the QoL of PwD in a past study (Bruvik, et al., 2012).

All 3 participants living within a joint family system, appeared settled in their lives specifically Case # 2, probably due to the availability of assisted living and family care at their own residences (González-Salvador et al., 2000; Shoaib et al., 2011). However, Case # 3, was a very old lady and did not seem to experience any pleasure in her present life. In case # 3, maybe physical and cognitive deterioration was a consequence of age (Ma & Chan, 2020).

Conclusion

Using unstructured case study interviews with 3 PwD, this research explored the effect of undiagnosed Pakistani early-stage/mild dementia on self-reported QoL of older PwD with observable symptoms of dementia belonging to low-income group.

Two PwD seemed to be quite satisfied with their QoL; specifically the male participant still had a certain level of autonomy in terms of going out of the house. However, the third participant who was older than the other two PwD and apparently at a stage of dementia whereby the observable symptoms were quite pronounced, did not seem to have a good QoL.

This research has shown that despite the availability of informal dementia caregivers' social support in a joint family system, the QoL of PwD is compromised with nature of undiagnosed mild dementia, gender, and age of PwD.

Implications

Overall, the current study has shown gaps in QoL of the three cases (e.g. social dependency, stigma), which could have been filled in through education of the entire family of caregivers about meaningful involvement in life, health and safety (Zhao & Zhao, 2018) in reducing the social stigma of dementia. **Family therapy** should be proactively applied in educating and training of family caregivers of PwD. During family therapy, information such as the use of certain affordable objects such as a badge with name and address pinned to the backside of the PwD might be provided.

In line with Phinney, et al.(2007), the Pakistani senior/older PwD reflected a need for a positive view of life, of feeling useful and needed, alleviating depression, having a sense of increased autonomy and reduced pain of loneliness, staying mentally and physically active, being connected to family, friends and community.

This research revealed that true meaningfulness in terms of autonomy is missing from the lives of older adults with undiagnosed mild dementia who belonged to low socioeconomic income group in Pakistan. This research has several important implications for Asian societies including Pakistan.

The need for **dementia friends campaign** is absolutely necessary to fight the stigma associated with dementia and raise awareness of the needs of PwD and the way in which their lives could be made more meaningful with complete autonomy. **Accessible social support groups** similar to Dementia and Delirium Support Lahore (Facebook) need to be introduced in every town of the city.

Dementia friendly spaces might be introduced through massive awareness to dementia caregivers. Such steps might help PwD in regaining a sense of purpose and be re-integrated into society. The overexcitement to talk in one of the participants reflects an underlying need for social attention. Talking about places and recalling pleasant memories can improve the QoL of older PwD.

Dependency in advancing age can reduce QoL of PwD (Levasseur et al., 2009). Therefore, there is also a **need for smart technology that PwD** could rely on in uncertain times of confusion and forgetfulness. Gadgets that could help one to trace back home address, and gadgets that prevent unnecessary wandering out of the house could be useful in keeping older adults (particularly in case of male PwD) safe.

There was no indication as to how the observable paranoia is being dealt with in Case # 3. There was no way to assess whether the condition was that of paranoia or real violence. Pakistan needs **social security organisations** to ensure safety of older adults with PwD.

The healthcare system in Pakistan needs to increase proactive accessibility to households to screen for and provide assessment and care to older adults with PwD. A **health care mandatory registration** system needs to be introduced to ensure equal access to healthcare in Pakistan. Reaching the low-income groups and catering to their needs should be the **priority of the government** because it is the underprivileged and disadvantaged older adults who are unable to go abroad for assessment and treatment.

In addition to such organisations, the medical professionals need to have **dementia studies incorporated into their curriculum** (Khan, 2014). The practice of clinical neuropsychology is rare in Pakistan. People are not aware of such terminologies and concepts. Given that diagnosed dementia is on the rise (Ahmad et al., 2013), **experts in clinical neuropsychology** are indispensible and have a lot of scope for practice in Pakistan.

This is the **first research to highlight the aspect of gender in QoL** among PwD (undiagnosed) from a low-income group in a patriarchal society whereby financial management is major concern for the male gender. Although the clinicians might consider ‘undiagnosed dementia’ unreliable, this study brings the unique perspective, plight and voices of ‘undiagnosed PwD with early-stage dementia from a low-income group’ and their caregivers.

Professionals might benefit from this study by understanding that there is a need for expertise, skills, knowledge, awareness, and institutions, which could enhance the QoL of PwD. This research might also help politicians and policy makers consider or revise policies surrounding proactive diagnosis and access to healthcare for PwD. This research provided an insight into different cases with symptoms of undiagnosed mild dementia (the symptoms were verified by 8 dementia researchers), among individuals belonging to a low-income group in Lahore, Pakistan.

Limitations

The results of this research based on only three cases cannot be generalized to elderly PwD belonging to low-income group in Lahore or to Pakistani senior citizens. It was a hard task to recruit PwD participants due to the stigma of the disease and confusion surrounding it. Due to time constraints, case studies more than three could not be obtained. It was difficult to conduct lengthy in-depth interviews with PwD in one session. In the home environment, it was not possible to exclude informal dementia caregivers from being present with PwD or avoid dementia caregivers’ interruption during the interview. The nature of dementia slightly varied across participants but the researchers could not determine or operationalize the exact stage and type of undiagnosed mild dementia.

Future Research

In future, sample size of PwD should be increased to at least 20 participants. The participants should be recruited from memory clinics, hospitals, and mental health institutions. Keeping in view the short attention span of PwD, in future, short interviews of about 10 minutes should be completed in several sessions. The PwD should be interviewed in privacy in the presence of a healthcare provider in a hospital while dementia caregivers should be interviewed separately.

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