Informal Caregivers' Perception of Barriers for Cognitive Health Promotion Activities for Older Adults in Galle District

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ABSTRACT

Health promotion activities to improve cognition have shown a significant impact on the prevention of cognitive decline in elderly people. Limited studies are available on the caregivers' perceptions of barriers to health promotion interventions to improve the cognitive health of older adults. A qualitative descriptive explorative study was conducted with the participation of 17 caregivers. Data were collected through focus group discussions, and all the sessions were audio recorded and transcribed verbatim. The thematic analysis was used for data analysis. The mean age ±SD of the participants was 40.24±4.7 years and 9 participants out of 17 were female. Five themes were identified based on discussions with caregivers. These themes were; lack of awareness of cognitive decline and preventive interventions, the physical discomfort of older people, lack of financial independence, resource deficiency, and intransigent behavior. The findings revealed that the majority of caregivers do not have an appropriate understanding of cognitive health promotion interventions. Therefore, a well-structured, culturally sensitive, and person-centered intervention programme would be beneficial to introduce cognitive health promotion activities for older adults and caregivers.

1. INTRODUCTION

Population ageing is a universal phenomenon, and with ageing older people are at a higher risk of cognitive decline (Murman, 2015). The global prevalence of dementia is increasing, and it has been estimated that 35.6 million people are living with dementia globally, and this number is projected to double every 20 years (Ojo & Brooke, 2015). In dementia, there is a decline in cognition which is needed to perform everyday tasks from simple to complex. Cognitive decline diminishes the well-being of older adults, and it can increase caregiver burden (O'Shea & O'Reilly, 2000; Michalowsky, Kaczynski &Hoffmann, 2019). As there is no cure for dementia, the functional and cognitive decline can be delayed using cognitive health promotion interventions. Hence, cognitive health promotion interventions for older people are particularly important for their cognitive well-being. Cognitive health interventions consist of regular exercise programmes, cognitive activities, spiritual activities, leisure time activities, and proper nutrition. In a country like Sri Lanka, informal caregivers play a vital role in the care of older people, since a majority of older adults live with their family members. Therefore, the implementation of those activities may be performed by caregivers in the community. Analysis of barriers or motivations which will be helped to change behaviours is essential. In Sri Lankan settings, cognitive health promotion interventions for older people have not been implemented so far either in community living or institutionalized settings. Therefore, the aim of this study was to explore the informal caregivers' perception of barriers to performing cognitive health promotion interventions for older adults in non-institutionalized settings in the Galle District.

2. MATERIALS AND METHODS

2.1. Study Design

This was a qualitative descriptive explorative study.

2.2. Study Setting and Sample

This study was conducted in Galle district with a sample of caregivers who provide care for older people above 60 years. A purposive sample of informal caregivers who provided regular care or assistance to their family members was included to maximize the diversity among participants based on characteristics, such as gender, marital status, educational status, and illnesses.

2.3. Data Collection

To collect data, focus group discussions (FGDs) were conducted using pre-tested, interview guides. The discussions were used to explore the perceptions of caregivers on the performance of cognitive health promotion interventions in non-institutionalized settings. It was allowed to talk with each other and to generate ideas freely. Four FGDs (n=4-5 in each) were carried out, with each session lasting for 45- 90 minutes, until data saturation was achieved. The discussions were conducted in a comfortable environment in healthcare institutions in close proximity to the participants. All sessions were facilitated by the same moderator who is the principal investigator (TS), while a note taker recorded all non-verbal and verbal expressions. All sessions were audio recorded and transcribed verbatim in order to ensure the process is trustworthy, the research satisfied credibility, transferability, dependability, and confirmability criteria throughout the study. During each interview, the researcher observed the participant's behaviours and mannerisms and wrote notes in a field diary. These field notes were incorporated into the data analysis. All the interviews were transcribed verbatim by the researcher to help with immersion in the data. Transcripts were translated into English and discussed with the research team. Collectively, these measures assisted with establishing credibility of this study. During data analysis, a code-book was prepared and the decisions made during analysis were recorded in a notebook; these

strategies assisted with establishing confirmability. Dependability was demonstrated by the researcher documenting detailed information.

2.4. Data Analysis

The thematic analyzing approach (Braun & Clarke, 2006) was used for data analysis. Two investigators (TS and PN) checked all transcripts individually for errors by reading them and listening to the audio recordings simultaneously. After being familiarised with the transcripts and audio-recorded interviews, data were categorized into themes manually.

2.5 Ethical Clearance

Ethical clearance for the study was obtained from the Ethics Review Committee, Faculty of Allied Health Sciences, University of Ruhuna, Sri Lanka (Ref. No: 35.09.2021.). Written informed consent was obtained from all eligible caregivers before participation. The confidentiality and anonymity of the participants were protected.

3. RESULTS

A total of 17 family members participated in FGDs. The mean age ±SD of the participants was 39.94±4.7 years. Of 9 participants were female. More than half of the participants (60%) were educated up to Advanced Level (A/L). The average monthly income of the majority (68%) of the participants ranged between LKR 50000.00-100000.00. All participants who attended the discussions reported that they felt comfortable and relaxed during the discussion.

Table 1-Participant characteristics

Participant	Age	Gender	Education level	Relationship with the patient
P1	34	Female	Up to the advanced level (A/L)	Daughter
P2	32	Female	Upto the ordinary level (O/L)	Daughter in law
P3	38	Female	Up to the advanced level (A/L)	Daughter
P4	42	Male	Upto the ordinary level (O/L)	Son
P5	44	Male	Up to the advanced level (A/L)	Son
P6	41	Female	Up to the advanced level (A/L)	Siblings
P7	39	Male	Up to the advanced level (A/L)	Son
P8	37	Female	Upto the ordinary level (O/L)	Daughter
P9	40	Female	up to the advanced level (A/L)	Daughter
P10	43	Male	Upto the ordinary level (O/L)	Son
P11	42	Male	Upto the ordinary level (O/L)	Son
P12	44	Female	Up to the advanced level (A/L)	Daughter in law
P13	41	Female	Upto the ordinary level (O/L)	Daughter
P14	39	Male	Up to the advanced level (A/L)	Son in law
P15	40	Female	Upto the ordinary level (O/L)	Daughter
P16	41	Male	Up to the advanced level (A/L)	Son in law
P17	42	Male	Up to the advanced level (A/L)	Son

In this qualitative study, we found five themes based on discussions with caregivers. These themes were lack of awareness about cognitive decline and preventive interventions, physical discomforts of older people, lack of financial independence, resource deficiency, and intransigent behaviors.

3.1 Theme 1: Lack of Awareness about Cognitive Decline and Preventive Interventions

Most caregivers highlighted that they do not have sufficient consciousness or knowledge especially related to the cognition changes with the aging process and the available methods that can be used to attenuate the progression of cognitive decline. They mentioned that nobody taught them about cognitive impairment and preventive interventions. Some of them mentioned that they had not even heard about cognitive exercises that would help to enhance elders' cognitive abilities.

In the words of family members, *"What? cognitive exercises. I knew about physical exercises, but tell you frankly I would not have an idea about cognitive exercises. I gave good nutrient food to my parents but I didn't encourage them to engage in physical activities since I didn't know its' benefits that much".*

3.2. Theme 2: Physical Discomforts of Older People

In general, the majority of caregivers highlighted the physical discomforts of their family members. Mainly, they emphasised that their family members were not willing to engage in physical activities. Further, they explained that they were reluctant to go outside to visit their friends or religious places without anybody due to common physical discomforts, such as back pain, leg pain, hearing, and vision difficulties.

One participant stated *"My mother is in alone once we go to work. Therefore, I asked her to visit her friends and have a chat with them or at least go to the temple. Though I encouraged and provided money and all the facilities for her to engage in such kind of activities that she loved to do previously, she told me that she couldn't go anywhere else since she had severe leg pains and back pains*."

3.3. Themes 3: Lack of Financial Indepen dence

Another concern expressed by caregivers was a lack of financial independence. Fifteen caregivers out of eighteen expressed unavailability of any pension or retirement plans for their parents. Therefore, they expressed that they have to fulfil their family needs as well as their parents' needs. Thus, some caregivers felt that it was particularly difficult to provide nutritious food to their parents since food prices were considerably high in the Sri Lankan market. Further, they mentioned that they struggled to balance their children's needs along with their parents' medical needs. Hence, they stated that they were helpless even though they had the willingness to give a better life to their parents, they couldn't afford money to do that due to high family demands.

One caregiver noted *"I loved to give a comfortable life to my parents. Therefore, I would like to give support to my parents to be involved in such kind of programme. But unfortunately, I am the breadwinner of my family. In addition to my parents, I have two small mouths to feed. I need to find money for their tuition classes as well. Though sometimes my parents requested some money to go on pilgrimage or elderly society activities, I couldn't give money due to financial constraints. If there were any system in Sri Lanka to give some allowance or any retirement plan for my parents, that matter would not occur."*

3.4. Theme 4: Resource Deficiency

Human and material resources are essential to conducting any programme. However, the majority of caregivers indicated that they did not have sufficient human or material resources to

promote cognitive health of their family members. Mainly, they mentioned that they did not have dedicated family members to provide care to their elders. Some of their siblings had moved from the city or the country. Therefore, they have to take responsibility for their elders. Despite these activities, they had to look after their children and themselves. Further, they emphasised the importance of the government's involvement in implementing these programmes through social care workers.

One family member stated *"I am the only person in Sri Lanka now. I live with my husband's family members. My parents live alone and like to enjoy their life by meeting their friends and being involved in ceremonies in temples frequently, but they don't have the physical capability to do these activities as well cook for themselves. Further, they couldn't engage in regular physical activities since no assistance to them. If there were any place that I could keep them safely and help them to have proper nutrients and help to enhance their cognitive health, it would be better."*

3.5 Theme 5: Intransigent Behaviours

Caregivers stated that it was hard to change their elders' behaviors. They mentioned if they would ask their elders to have food enriched with high nutrient values or engage in physical activities, they would strongly refuse to do these activities due to their life principles. Caregivers stated that elders were inflexible and that they did not have any interest in changing their behaviors.

One caregiver stated *"I am pretty sure my parents will not agree to adhere to any intervention. One day, I asked my mother to add eggs or chicken to her diet to enhance her physical health. Then she told me why I had to add them. I have stopped them for ages. It is okay for me to die, but I will not add these things to my diet."*

4. DISCUSSION

This qualitative descriptive exploratory study was carried out to explore informal caregivers' perception of barriers to performing cognitive health promotion interventions in non-institutionalized settings in the Galle District. From our semi-structured focus group discussions with caregivers, five barriers were identified. They were a lack of awareness of cognitive decline and preventive interventions, physical discomforts of older people, lack of financial independence, resource deficiency, and intransigent behaviours.

Cognitive health promotion interventions are essential to reduce the future risk of cognitive decline among older adults. However, awareness is of utmost importance to begin any interventions. In the present study, caregivers highlighted their unawareness of health promotion interventions, especially regarding cognitive exercises. However, cognitive and creative activities such as doing puzzles, playing chess, memory flops, playing brain function games, and reading books may reduce the risk of dementia by 50% (Tsai & Shen, 2022). Thus, it is essential to enhance awareness regarding lifestyle interventions.

Though engaging in physical activity at least 150 minutes per week may be effective in preventing dementia and neurological damage (Quinn & Morgan, 2017), in Sri Lanka it seems that it is not common among the adult population due to physical disabilities, and caregivers also have not provided that much of a motivation to them. On the other hand, many religious beliefs and spiritual well-being interventions have directly affected dementia prevention, they have moved away from these activities due to some physical barriers. Therefore, it should be considered when introducing intervention programmes.

Caregivers have identified a lack of financial independence of them as a huge barrier to

implementing cognitive promoting intervention in Sri Lanka. This matter will be enhanced with the current economic crisis in Sri Lanka. Surprisingly, developed countries have also experienced difficulties in maintaining social and financial security schemes for older adults (Binstock, 2010). However, Asia has attempted to strengthen family support by giving various incentive schemes for the family members. Though the Sri Lankan government also provides an incentive for older adults in low-income families, it is not enough at least to buy their regular drugs due to current financial constraints. Therefore, the promotion of health practices especially for those who are in late adulthood is essential to adopt a healthy lifestyle which would help them to keep healthy. The life course approach will be the most suitable key to overcoming this matter in the future.

In the present study, caregivers have reported human and physical resource deficiency as one of the major themes. Social health and social support may reduce the incidence of dementia (Orgeta et al., 2019). Though it is reported that older adults living with family members may have rather good social care (Liang et al., 2020), it has changed in Sri Lanka nowadays due to various scenarios, such as increased migration. Therefore, government involvement is vital in achieving the success of the interventions. A Mediterranean diet which consists of fruits and vegetables, cereals, nuts, olive oil, seeds, fish, poultry, and dairy products, is considered to slow cognitive decline and prevent dementia (Morris et al., 2015). However, some Sri Lankan adults are inflexible and do not like to change their behaviors. In our study, caregivers reflected on the complexity of changing behaviours of older people.

5. CONCLUSION/S

The findings revealed that a majority of caregivers do not have an appropriate understanding of cognitive health and its promotion. Further, financial constraints should be a huge matter to introduce a lifestyle intervention programme and intransigent behaviors should be a matter to enhance adherence to the programme. A life course approach should be used to enhance the functional ability of elders and a well-structured, culturally sensitive, and person-centered intervention programme would be beneficial to introduce for older adults and caregivers.

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