

## Manuscript File

### Title

The psychological and economic impacts of caregiving on family carers for people with probable dementia in rural South India.

### Abstract

Informal carers play a vital role in the care and well-being of older people with dementia. This article examines the psychological and economic impacts caregiving has on carers of people with suspected dementia and the mechanisms by which they cope with challenges. A mixed-method design was adopted. A baseline survey of 123 older people was undertaken in a resource-poor setting in Kerala, India, using Addenbrooke's Cognitive Examination – Malayalam Version (ACE-m) to identify those with probable dementia. This was followed by in-depth interviews with ten carers of those identified as having cognitive impairment. The data were later transcribed and thematically analysed using N-Vivo to identify main concepts and themes. Analysis of the in-depth interviews with carers revealed that dementia was often interpreted as a 'second childhood', but that this conceptualisation aided carers to cope better. Anger and irritation were the commonly expressed psychological reactions which got accentuated by lack of reciprocation of emotion on the part of care recipient. Government support through social security measures and medical care, along with traditional social practises, helped carers to tide over care expenses. These support systems lessened the psychological and economic impacts of caring. Misconstruction of the disease nature, for example by considering it a normal part of ageing, also seem inadvertently to have helped in coping with care requirements, although this comes at a cost of lower than optimal healthcare access for older people with cognitive impairment.

**Keywords:** Caregiving, Informal Carers, Mixed methods

## **Main Text**

### **Introduction**

Psychological issues among carers, along with financial demands of caring, make dementia a challenging condition, especially for family caregivers who form the main pillar of caregiving among older people living with dementia (PLWD). This is particularly the case in many Asian countries where informal carers provide care with very little support from formal sources and in resource-poor contexts (Lambert et al. 2017; Prince and 10/66 Dementia Research Group 2004; L. Ritchie et al. 2020; Srivastava et al. 2016).

In a resource-poor setting, a debilitating illness like dementia can destabilise a family which might already be under financial pressure. This might manifest as either an increase in stress or other psychological issues among caregivers, which in turn could affect the quality of life (QOL) of the care recipient (Kasper et al. 2015). A worsening QOL can lead to a vicious cycle, where the older population becomes more dependent, demanding more care and financial support. This in turn worsens the carer stress causing further deterioration of QOL of the care recipient (Gupta et al. 2009; McIntyre et al. 2006; R. Schulz and Beach 1999; Wachholz and Damiance 2021). Studies conducted in Indonesia found that as the care burden intensified and care networks diminished, the provision of care by the primary family carers declined in quality (Schröder-Butterfill and Fithry 2014; Van Eeuwijk 2006).

It has been noted that in developing countries dementia often remains undetected in the community (Balouch et al. 2021; Shim et al. 2021) and is often mistaken as part of normal ageing (Chen et al. 2013). This could have an adverse impact on caregivers, as they might not be cognisant of the presence of a disease condition, thereby failing to pursue any medical support (Johnston et al. 2020). Early identification and initiation of drug and non-drug interventions have shown to have benefits, such as behavioural stabilisation, delayed cognitive decline and dependence (Gauthier 2005; Robinson et al. 2015). This would have

a positive effect on carer stress, providing them with time to adjust and plan for future care, incorporating care recipients' wishes.

There is a dearth of evidence assessing disease-specific economic and psychological impacts of caring for PLWD on caregivers belonging to lower socio-economic statuses, especially from the Indian sub-continent. This article attempts to throw light onto the psychological and economic challenges faced by caregivers of PLWD in a low-income rural South Indian community. A mixed-method approach involving both quantitative and qualitative methods was adopted to address the research question: What are the economic and psychological impacts caregiving has on carers of those with probable dementia belonging to the lower economic strata of South Indian society? The main objectives were to study the psychological impact of the role as caregiver and the burdens that might come with it; and to understand the various costs that arise from caregiving in terms of, for example, medical care of the patient, inability of carer to go for work, and adjustments made to other family needs, such as children's education.

### **Materials and Methods**

The study area chosen was a village (the smallest administrative region in India) which has a population of nearly 12,000 and is situated in the central part of Kerala, a southern state of India. This village has multiple poor colony settlements, with an average population of nearly 500 each. In these settlements almost all households are engaged in small-scale income-generating activities, such as quarry work or agricultural labour. Majority of the households are joint families, where two or three generations are related patrilineally. They follow a patriarchal system where men hold the primary power and predominate in political and social roles. The property and family titles are inherited through the male lineage. This allows many to have their family members as their immediate neighbours, since people prefer to build houses on their inherited ancestral properties. The youngest son in the family

is mainly responsible for the welfare of the older parents, and the caring obligations are usually delivered by the women in the household who are either the wife or daughter-in-law.

The village represents the service area of the medical school where the first author is employed, providing services such as local area clinics, home visits and health education. Besides, there is an area doctor who is overall in charge of all medical activities in the village. The existence of these services helped in developing a close rapport with the people in the households studied.

A sampling frame of those with dementia was not available from this region, therefore making it difficult to identify their carers. For this reason, a baseline survey was conducted in two randomly selected colony settlements – ‘Kurunth’ and ‘Purunth’.<sup>1</sup> The objective was to assess the level of cognition among the elderly population aged 60 years and above using Addenbrooke’s Cognitive Examination - Malayalam version (ACE-m). ACE-m is a widely used screening tool initially developed by the Medical Research Council Cognition and Brain Sciences Unit at Cambridge University, UK (Noone 2015). It covers five cognitive domains, which include attention and orientation, memory, language, verbal fluency and visuo-spatial skills, using various tasks such as memorising a fictional address and a clock drawing test to mark a particular time. Each individual interview takes approximately 20 minutes to complete and the maximum attainable score is 100 with the minimum being zero. It has been successfully translated into many languages, with cultural and linguistic modifications; the Malayalam (official language of Kerala) version is one among them (Mathuranath et al. 2004; Sheehan 2012). Since ACE-m is a screening tool, rather than a diagnostic examination, those with low ACE-m score were considered to have *probable* dementia. Since the prime objective of this part of the study was to identify carers of PLWD, all who were aged 60 years and above in the selected colonies were screened. Those with poor scores were subsequently labelled as having *probable* dementia and were informed about the results soon after the interview. They were further referred to the local area doctor for

further follow-up and care. A sample size was not calculated since everyone aged 60 years and above was included, after obtaining a list of older people from the *panchayat* (village council) office. Those who were living in care homes and those who had availed a paid care service, like hiring a maid or home nurse, were excluded on the assumption that those belonging to low-income strata would not be able to afford such services. Each of the listed households was approached and the objective and methodology explained verbally and by providing an information sheet to each participant. For those with poor cognition, maximum effort was made to make the information as accessible as possible, paying attention to non-verbal clues. Where older people were unable to give informed consent, proxy consent was taken from the immediate caregiver using a consultee information sheet and declaration form. Eventually, 123 participants were surveyed, 53 (43.1%) from 'Kurunth' and 70 (56.9%) from 'Purunth'. Being a medical doctor, the first author has the technical skill to administer questionnaires like ACE-m, thereby improving the reliability of the findings.

Once the survey was completed, participants' ACE-m score was calculated, and a list of the twenty older people with the lowest ACE-m score was made. From this list of 20, immediate carers of 10 were selected for qualitative in-depth interviews using a semi-structured interview guide to study the economic, social and psychological burdens they faced. For the in-depth interviews, a sample of 10 was considered appropriate, as this number was not too small for information to be missed and not so large to risk informational redundancy (J. Ritchie et al. 2014). The final sample was selected using typical case sampling after revisiting all 20 older people with the lowest ACE-m scores. This helped to categorise them according to their care dependency. Carers of those who were completely or partially bed bound, who required greater support in activities of daily living were given priority. This is because providing care for them was considered more challenging than providing care for those who were more independent with their day-to-day activities. For those older people who could communicate, the immediate carer was identified by the older

person. Those who could not communicate due to debilitating conditions, for them immediate carer was the one who primarily did, or helped in doing, the daily tasks which included activities of daily living such as dressing, bathing, toileting. Their identity was also counter-checked with local volunteers and the carers themselves before finalising him/her as the main carer.

The interview guide had open, non-leading as well as probing questions that would encourage participants to generate descriptions of their social world, by exploring their experiences and opinions (J. Ritchie et al. 2014; Rubin and Rubin 2012). The first author conducted all interviews. She had the flexibility to take the lead from participants and incorporate emerging themes into later interviews, while not straying from the objectives. Although the relationship between the interviewer and interviewee was imbalanced due to steep differences in educational and economic status, this did not appear to affect the richness of data collected. This may be due to the strong ties the first author shares with these communities through the services provided via her medical school. It helped in building a trust atmosphere which put participants at ease and made the interviews more interactive.

Since the study involved a face-to-face survey and further follow up, the initial data on participants was not anonymous. However, the data were anonymised at the point of transcription (e.g. using pseudonyms, blurring other identifying details). It was difficult to ensure privacy while conducting qualitative interviews as carers preferred having care recipients within their sight. This might have cautioned carers from being candid while stating their difficulties.

The survey data were entered using Epi Info version 7, a free data entry software, and analysed using SPSS Statistics version 24, a software package for statistical analysis. The mean ACE-m score of survey participants was calculated (Daniel 2005). For the qualitative part of the study, all audio-recorded in-depth interviews were transcribed and the transcripts

entered into NVivo version 11, a qualitative data analysis computer software (Bazeley and Jackson 2013). A thematic analysis approach was chosen to move from descriptive to more abstract themes. It started with familiarisation and subsequent indexing and categorisation of data. After that abstraction helped to identify more analytic concepts, such as emotional reciprocity, and interrogate them for patterns of meaning.

## **Results**

The first part of this section presents the findings of the quantitative study which screened the cognition level of community dwelling older people using ACE-m. In the second part themes identified from the qualitative study are presented. The main emphasis in this article is on the qualitative findings, as the quantitative study was undertaken mainly to identify the participants for qualitative study.

### **Survey findings**

Among the 123 survey participants, nearly two thirds were women. The mean age of the participants was 71.6 years, with women being older when compared to men (72.3 and 70.4, respectively). Those who were aged less than 80 years were very confident of their age, and able to quote their year of birth. For those who were among the older old, especially those aged more than 85 years, age could only be approximately established, for example by asking what life course stage they were in at the time of notable events. Such respondents could neither state their exact age, nor show any document indicating their actual age. We had 8 participants whose age was likely to be more than 85 years. The baseline demographic characteristics of the participants are given in **Table [1]**.

**Table 1:** Demographic Characteristics of Survey Participants

| <b>Demographic characteristics</b> |             | <b>Number (%)</b> |
|------------------------------------|-------------|-------------------|
| <b>Place</b>                       | Kurunth     | 53 (43.1)         |
|                                    | Purunth     | 70 (56.9)         |
| <b>Age category</b>                | < 80 years  | 99 (80.5)         |
|                                    | >= 80 years | 24 (19.5)         |
| <b>Gender</b>                      | Male        | 44 (35.8)         |
|                                    | Female      | 79 (64.2)         |



### **Presence of Poor Cognition**

The primary objective of the survey was to identify those with poor cognition or having *probable* dementia. ACE-m has the following subcategories: attention, memory, fluency, language and visuo-spatial ability. The maximum attainable score is 100, and for each subcategory the maximum attainable scores are 18, 26, 14, 26 and 16 respectively. The mean score obtained by survey participants for the ACE-m was 41.86 (ACE-m $\pm$ 3.8) which was less than half of the maximum obtainable score. In **Table [2]** the overall mean ACE-m score obtained in the study along with the overall mean scores obtained for its subcategories are given. Within each subcategory, the scores obtained were much lower than the maximum attainable scores. The most poorly scored categories were memory (recalling three simple words said earlier, memorising a fictional address and recalling historically known facts) and fluency (saying words starting with a particular letter and names of animals), where the scores were less than a third of the maximum attainable scores.

**Table 2:** Overall Mean Score ( $\pm$  confidence interval) of ACE-m and its Components

| <b>Variable</b> | <b>Maximum attainable Score</b> | <b>Overall mean (Confidence Interval)</b> |
|-----------------|---------------------------------|---|
| ACE-m           | 100                             | 41.86 (38.06 – 45.66)                     |
| Attention       | 18                              | 9.83 (8.88 – 10.78)                       |
| Memory          | 26                              | 7.33 (6.24 – 8.42)                        |
| Fluency         | 14                              | 3.33 (2.87 - 3.79)                        |
| Language        | 26                              | 13.87(12.67 – 15.07)                      |
| Visuo-spatial   | 16                              | 7.46 (6.77 - 8.15)                        |

The educational level among this older population is low, and our data show a statistically significant positive relationship between years of education and ACE-m scores, indicating that performance on the test is partly related to education.<sup>ii</sup> The results should therefore be

treated with caution as an indicator of probably dementia at the population level. However, we feel that as a tool to identify those with poorest cognition, the test served the purposes of this study.

Once the ACE-m score was calculated, twenty participants with the lowest scores were identified. Among them, ten were selected for the qualitative interview, as explained in the methodology section.

### **Qualitative Data Analysis Findings**

Qualitative in-depth interviews were carried out among ten consenting carers of which seven were women and three were men. All carers were also household members, which had two or three generations of kin related through the maternal or paternal line. The baseline characteristics of carers are summarised in **Table [3]**.

**Table 3:** Baseline Characteristics of Carers interviewed

| Person         | Sex    | Age in years | Care recipient's age group | Carers comorbidities | Carer's marital status | Household size | Occupation  | Relationship with the care recipient | Other members in the household (relationship with respect to care recipient) |
|----------------|--------|--------------|----------------------------|----------------------|------------------------|----------------|-------------|--------------------------------------|--|
| <b>Aka</b>     | Female | 34           | 60 – 69                    | Absent               | Married                | 6              | Working     | Daughter-in-law                      | Husband, son, daughter-in-law and two grandchildren                          |
| <b>Ani</b>     | Female | 65           | >= 90                      | Present              | Widow                  | 4              | Working     | Daughter-in-law                      | Daughter-in-law, grand daughter-in-law and great grandson                    |
| <b>Bhasi</b>   | Male   | 66           | 60 – 69                    | Present              | Married                | 5              | Not Working | Husband                              | Husband, Sister and two grandchildren  |
| <b>Karanan</b> | Male   | 64           | >= 90                      | Present              | Married                | 3              | Not Working | Son                                  | Son and daughter-in-law  |
| <b>Lalu</b>    | Female | 60           | 80 – 89                    | Present              | Married                | 6              | Working     | Daughter-in-law                      | Son, daughter-in-law, grandson, grand daughter-in-law and great grandson     |
| <b>Mary</b>    | Female | 50           | 80 – 89                    | Present              | Married                | 4              | Not Working | Daughter                             | Daughter, son-in-law and grandson  |
| <b>Indhu</b>   | Female | 65           | >= 90                      | Present              | Married                | 3              | Not Working | Daughter-in-law                      | Son and daughter-in-law  |
| <b>Savita</b>  | Female | 75           | 80 – 89                    | Present              | Married                | 6              | Not Working | Wife                                 | Wife, elder son, daughter-in-law, grandson and younger son                   |
| <b>Sheela</b>  | Female | 46           | 70 – 79                    | Absent               | Married                | 5              | Working     | Daughter-in-law                      | Wife, son, daughter-in-law and granddaughter                                 |
| <b>Maran</b>   | Male   | 85           | 80 – 89                    | Present              | Married                | 2              | Not Working | Husband                              | Husband  |

### ***Psychological aspects of caring***

Caring evoked different types of emotional reactions among caregivers. Here we present three reactions that were echoed in the study. First were the instinctive emotional reactions that carers expressed when they had to face a particular behaviour pattern or response from the care recipient. The second type of reaction was mainly guided by the emotional attachment carers had with care recipients before the onset of disease. Lastly, we also highlight how considering ageing as a second childhood helped carers cope with care recipients' behaviour.

#### ***Instinctive feelings while caring***

An emotion that was often noticed among carers was anger. According to Aka, "*when [carers] are caught up with many things, definitely [they will] get irritated*" especially with care recipients' repetitive behaviour. "*Overwhelming! [...] I am doing everything for her, but she fights with me,*" was the response from another carer. The carer's irritation with the care recipient's inability to reciprocate appropriately was palpable in the interview.

Many a times carers were expecting only an acknowledgement and not necessarily physical support from other family members. When this was not forthcoming, carers expressed irritation. Ani was frustrated with her sister-in law as she "*never asks about her mother's whereabouts.*" This led on to harsher comments, as in "*I will not inform them even if mom passes away.*" Meanwhile Aka was relieved by the moral support from her young school-age children. "*They know the condition at home. They will manage their own things.*" It was clear that other family issues also had a bearing on the carer's mood. Karanan had to single-handedly manage his mother's well-being along with other household activities because "*[my] wife is not quite well. She is very slow and she cannot multi-task. [...] Sometimes I get very angry. I have even told my wife to leave me and go.*" Maran was the only participant who was living alone with his wife (care recipient) and hence was forced to do all household chores

by himself; this is not a common practice in a patriarchal society. I could sense his irritation when he said *“I will have to do everything by myself. [...] cooking, washing cloths; I don’t have any help.”*

The three men carers expressed low mood, and all had different reasons for it. Karanan’s concern was *“[mother] may die anytime”*, while Bhasi was upset with inappropriate language used by the care recipient. He was teary-eyed while talking about it and said *“I know I have to forgive and need to bear it all.”* His mannerisms suggested that he was invoking virtues like forgiveness as a coping mechanism. In a patriarchal culture where caregivers are mainly women, it must be particularly difficult for Bhasi to embrace his new role which would explain his displeasure. Maran was sad because of his seemingly non-supportive children. He was crying while saying *“Our children will not take care of us.”* However, in a later part of the interview he mentioned that when his wife fell ill *“my grandson who was living nearby was the one who took her for treatment [...] to a nearby private hospital. My grandson and children helped in paying the bill.”* This was an indication that children were in fact involved in taking care of their mother, but not to the extent that was expected. It is possible that Maran’s children do not share a good relationship with their father; throughout the interview he was less forthcoming about his children and their whereabouts, but often mentioned his grandson who was living nearby.

By contrast with the male carers, two (of the seven) women carers showed a positively nonchalant attitude towards all difficulties involved in caring. One among them was already reeling under many other issues, which included the damage she suffered in the 2018 Kerala deluge. Caring for her mother-in-law was just one among her many challenges. Her attitude was *“But what’s the point in sitting around idly. We have to somehow move forward. [...] There are only few things that I can do with my capacity.”* She showed a certain amount of willpower and courage in the face of adversity and was talking as if she got things

under control. However, she was mindful of people's opinion as she continued by saying, *"Those who want to judge, let them. I really do not care"*. Perhaps she had faced some harsh comments regarding caregiving, but throughout my interactions she came across as someone who was doing her best despite the harsh circumstances. The other participant, Lalu, took care of her cognitively impaired mother-in-law with a certain amount of ease. We realised that her awareness about the nature of her care recipient's illness, including the forgetfulness, prevented her from getting too affected by her mother-in-law's behaviour. *"She will [accuse me]. But soon would forget what she had said. [if reminded] she would respond, Me?! Did I talk like that?"*

The most commonly reflected psychological reaction was anger and irritation. This was situational, it developed from a lack of acknowledgment and other problems the carers faced, but was seemingly short-lived. Men conveyed a sense of melancholy whereas women exhibited a stoic attitude.

#### **Emotional reciprocity towards care recipient**

We noticed that most carers developed a close emotional association with their care recipient, so much so that they would not prefer someone else taking over the care role from them. As Karanan said, *"I am not happy with the way my wife and sister take care of her. [...] I am very attached to my mother."* Besides, two of the carers, who were daughter-in-laws, felt that they should reciprocate care as they had been looked *"after like their [own] daughter[s]"*. Lalu, when she was younger, never had to do any of the family's washing. *"She [the mother-in-law] used to never allow me to. That was her level of care."* The feelings carers expressed were *"responsibility"* and their *"turn of duty"*. According to Sheela *"My in laws practically raised [my children] while I was working. So [I am] very close to them."*

Interestingly, Maran and Bhasi, who were taking care of their spouses, did not express such sentiments. During the interview, their facial expressions did not hide the

displeasure they had in fulfilling care needs of their spouses - as though they did not have any other choice but to empathise with their sufferings. This different response from that of children or children-in-law suggests that the way that caring is experienced depends to some extent on the nature and quality of the relationship between carer and care recipient before the onset of the disease. Where carers had been strongly supported by the care recipient in the past, they displayed a high current level of emotional attachment with the care recipients and bore the caring with greater ease.

### **Ageing as second childhood**

Participants were seeing cognitive and behavioural changes in the relatives they were caring for as part of ageing. This was captured in general statements like: *"It's all part of ageing/life. Do not take it to heart."* Many accounts suggested that carers were not blaming care recipients for their behaviour but understood their *"helpless[ness] [and] childishness;* understood that *"it's not intentional, it's all part of [their] disease and age."* Mary had this to say about older people: *"When people become old, they are like children. Imagine taking a child to the shop. He/ [she] would want a toffee and would cry for that. These older people also have a similar mind set."* Our evidence suggests that the interpretation of the older care recipients' behaviour as a 'second childhood' and the acceptance of it as part of ageing helped caregivers to adjust to and cope with the difficulties they faced while caring for their relatives with probable dementia. According to Indhu *"sometimes [her mother-in-law] passes urine on the cot itself. [...] we [do] make her sit in the toilet like how we train a baby. She is just like a child. [...] We use this thin cotton cloth for her, as an under garment. We made a special cot wired with a plastic material. So the urine will fall on the floor which we can clean easily."* The ease with which Indhu explained the arrangements and the relaxed look on the face of her mother-in-law who was sitting alongside her during the interview, created the impression that what might

have appeared as trouble or difficulty to an outsider was more like normality for the carer and her charge.

### ***Economic aspects of caring***

In our data collection we tried to get an understanding of the expenses involved with caring, which included expenses directly related to disease and treatment, expenses with respect to loss of labour of the carer and the other losses with respect to inability to participate in social activities. We noticed a general apathy towards old age-related ailments, which indirectly appear to have lessened the costs involved with medical treatment as part of the care for older family members. This is also highlighted in this section.

### **Cost of caring**

Most direct expenditure associated with caring was on medications which care recipients were taking for disease conditions other than cognitive impairment, such as diabetes. Sheela said *“their medication cost [for diabetes, hypertension and stroke] per month itself will be around ₹6000 [68£] for which I will pay from my salaries.”* Families were earning enough to meet their day-to-day requirements, without much savings. Nobody talked of having any major debts due to treatment. In case of an emergency, Ani said *“[I] managed [medical expenses] by keeping a gold bangle in a pawn broker’s shop in exchange for money. [I also] borrow from neighbours or other family members which I will return gradually.”* However, it was noticed that carers generally opted only for those medical treatments for care recipients which they could reasonably afford, without having to go into debt. Sheela told us that *“[care recipient] needed an open heart surgery. But [the family] could not afford the cost. [...] So finally decided not to opt for surgery, but to manage medically; and to make him as comfortable as possible.”* Considering care recipients’ poor cognition, their acquiescence was expected. There were many medical facilities available, especially government-run facilities, which made some of the medical expenses less expensive. Most carers *“buy medicines from the*



*[government] medical college itself. [Some] things are free there. [...] In case of any emergency admissions [we have] government [insurance] card. So that will cover a part of hospital bill."* Money was also spent on things such as diapers, which were "very costly. [...] Its ₹540 [6£] for 10 diapers". Ani said she had "to spend around ₹3000 [33£]-₹ 4000 [44£] for diapers itself [per month]. She [mother-in-law] passes urine 5 to 6 times a day and most of the time she does not realise. [...] It is difficult to clean her all the time, especially because I am also not well." In most cases diapers were used to reduce the burden on carers as their use meant less changing, cleaning and washing of clothes.

There were hardly any routine hospital visits by care recipients, mainly because of the robust palliative home care services provided by government-run primary health care centres. This helped in bringing down the direct and indirect costs of care as it cut out transportation costs and time investment. "Palliative care nurse from the PHC [for bedridden elderly population] will change the nose tube, urine tube; also help with medicines."

The government of Kerala has initiated various social pension schemes, such as an old age pension, agricultural labourer pension, and widow pension. All ten care recipients were beneficiaries of one of these pensions, providing them with nearly ₹1200 (14£) a month. The majority of care recipients were either living with, or near the families of their male children. As Aka summed it up, "the responsibility of taking care of [an older parent] is with the son." Only one person's carer happened to be her daughter. Her elder son became a catholic priest, and she chose to live with her daughter instead of her younger son. There were five carers who were currently working. But they were involved in locally-available jobs, like being a house-maid, a nurse in the nearby hospital or running their own small business, like a petty shop or duck farming. Labour migration has not really started to affect this community. "[I] come in between to check on [care-recipient], to give food," said Ani. Older spouses who were caretakers were sometimes given a mobile phone by their children. Then

*"[the children] keep calling on an hourly basis to check on the care-recipient."* This meant that working carers really did not have to sacrifice their occupation to take care of their older family members. Many of the carers were old themselves, and thus neither currently working nor looking for any employment opportunities. In addition to being able to combine their job with the caring responsibilities, many of the carers referred to the proximity of others who could help to keep an eye on the care recipient: As Karanan said, *"My relatives are living nearby."* Nevertheless, the impact on social life was felt by many carers. According to Ani: *"I do not go for any functions nowadays. Occasionally during holidays my daughter will come. When she is around, I could go. [...] Last month I missed 2 weddings."*

#### **Passivity towards old age ailments and less spending**

We saw a general passivity or fatalism towards old age illnesses. This passivity contributed to keeping the cost of care low, as we noticed that many families did not pursue treatment for older family members indefinitely. According to Aka, *"They gave us injections saying [the back problem] was due to nerve damage [...]. So, we left it."* Aka is taking care of her mother-in-law, whose spouse is alive, and the elderly couple have three other living children. Interestingly, even Aka's father-in-law, who was at the house when the interview was conducted, did not specifically ask anything about further treatment, which was rather unusual. In a typical Indian scenario, when people realise that someone is a doctor, they will surely ask one or two medical questions. But in this case, everybody appeared to be content with the medical care received by the care recipient. Cognitive deficit was perceived as a condition with no cure. As Indhu said *"things are not going to change at the end of it. [...] She is 80 years now. Is it not expected? Who will walk behind all this check-up?"* There seemed to be a general consensus that occurrence of cognitive impairment was an expected event in old age. As a result nobody seemed to pay much heed to it, nor did carers appear remorseful about not probing it further.

Overall, we found that participants did not feel overly burdened economically by caring, nor did they perceive costs of caring to be high. Treatment modalities were decided upon judiciously, keeping in mind the families' delicate financial status. Public support systems certainly seemed to ease financial burdens on families. The community was following the traditional patrilineal joint family system, and the responsibility of older parents went to male children and their wives. Even the issue of migration has not much affected this community, thereby ensuring the proximity of children to actually follow these traditions.

## **Discussion**

This article is an attempt to understand the psychological and economic impacts of providing informal care for those with *probable* dementia in a resource-poor setting in rural South India. In this section we discuss our findings, highlight their contributions to the existing literature and emphasise the policy implications arising from our results. As is commonly recognised, qualitative studies do not seek to arrive at generalizable knowledge, and the study site was certainly unusual even for the wider Indian context, because Kerala has a more advanced ageing profile. However, the findings can be expected to resonate with other similar resource-poor settings in southern India.

A common psychological reaction by carers was anger/irritation. It was often a situational reaction to care recipient's inappropriate words or adamant behaviour, and did not appear to persist. Literature has found a negative association between care recipient's behavioural disturbances and quality of carer's relationship with them (de Vugt et al. 2003; Lawrence et al. 1998; Pattanayak et al. 2010). In this article, although carers did not mention it explicitly, their tone often suggested that behavioural issues were a source of stress. This chimes with studies highlighting the role played by behavioural disturbances in developing carer stress (Alzheimer's Association 2018a, 2018b; Richard Schulz and Sherwood 2008; Sinha et al. 2017). The carers in our study appeared baffled not by cognitive impairment as

such, but by their charges' adamant nature and repetitive behaviour. An early study also found this, stating that cognitive impairment itself had no influence on reported stress on carers, but that carers could not tolerate its behavioural manifestations (Greene et al. 1982). Studies have also stated that these behavioural manifestations could deteriorate the carer-recipient relationship as they diminished joint activities and sharing experiences (de Vugt et al. 2003; Keating and Eales 2017; Landes et al. 2001). It has also been found that carers could cope better with disruptive behaviour, as this left room for interaction, than with behaviour which did not involve reciprocation (de Vugt et al. 2003; Ugargol and Bailey 2018). We presume that in our study this possibility to reciprocate in some form by the carers, when their care-recipients displayed adamant or repetitive behaviours was what enabled them to cope and move forward without taking the behaviour by the older family member personally.

A lot of the literature has found the physical and time-consuming aspects of caring to cause stress and burden on informal carers (Lambert et al. 2017; Lindt et al. 2020). However, in our study stress and dissatisfaction seemed to arise from the lack of acknowledgement of carers' contributions by other family members. A similar issue was identified by Board on Health Care (2016), where a common source of conflict was the failure to appreciate the pressure on carers. Further studies have found that encouragement and acknowledgement were equally important as assistance from family members (Li and Sprague 2002; Ugargol and Bailey 2018). Previous research also stated that those carers who had conflict-less family relations prior to their family member being diagnosed with dementia experienced less of a sense of burden, whereas conflictual relationships were more likely to give rise to depression in the caregivers (Deimling et al. 2001; Heru and Ryan 2006). In the present study those women participants who had developed a close emotional bond with their care recipients reported a sense of reciprocating the warmth and attention they had received from their care-recipient while they were still cognitively sound. These women did not on the whole find their caring responsibilities burdensome. Men carers, by

contrast, were melancholic and preoccupied. They presented their caring more like an altruistic gesture, rather than as reciprocity. This might stem from their patriarchal culture where caring is usually considered a woman's task. In the current study, women who were caught in multiple roles other than caring displayed a stoic nature (compare Emmatty et al. 2006). By contrast, the literature suggests a different picture regarding gender differences in caregiving. A few studies found no gender differences in psychological reactions among carers (Gerson 2002; Pöysti et al. 2012; Vitaliano et al. 2003). Other studies found that women showed more signs of burden and psychiatric morbidities, like depression and anxiety (Pattanayak et al. 2010; Sharma et al. 2016; Yee and Schulz 2000). The current study findings could of course be atypical because there were only three male carers in the interview sample of ten.

Caring is often expensive, causing direct and indirect financial burdens on families. Through our study interviews, we tried to understand how the identified costs were experienced in this particular setting. What we found was an arrangement which was fairly well-adjusted to the economic needs of caring. No one brought up expenses as a cause of stress. Carers decided upon treatment modalities by judiciously weighing their own financial status and possible treatment outcomes. When there was a dire need for money they turned to friends and family for support, and their requests were usually addressed positively. Such loans are an accepted norm in the region, and the money thus borrowed does not have any interest rates attached and can be returned leisurely without having to follow a fixed timeline. Other locally-followed practices include pawning of gold jewellery, often for small amounts which would be reclaimed later by paying an additional interest. The proximity of government hospitals also helped in taking financial pressure off carers. Apart from this, initiatives like regular monthly free home visits by nurses, social security pensions and free material supports, like wheel-chairs or air beds, minimised the impact of direct costs of caring.

As is the case in many parts of India, the study population has a traditional joint family system in which people from different generations live together even after marriage. Being patrilineal, the community entrusts male children to be primarily in charge of older parents, although most hands-on care is provided by daughters-in-law. The existing literature tends to emphasise social developments that undermine intergenerational support arrangements, for example due to declining fertility and rising migration, both internal and international, as these contribute to smaller and more dispersed families (Pradhan 2011; Ugargol and Bailey 2018). Likewise, greater non-domestic work participation by women is seen as disrupting traditional roles (Eapen and Kodoth 2003). However, in our study the issue of migration has hardly arisen due to the local population's poor educational status. People are involved in local jobs and manage to fit physical caring into their daily schedule. The houses are closely spaced, and most neighbours are family members. This means families are not isolated, and a helping hand, at least for supervision, is always available (contrast Pattanayak et al., 2010). While there is an undeniable indirect cost of caring, its impact is often diluted as there are many people involved. Although they did not explicitly talk about hobbies and other activities, it appeared that family carers were not completely cut off from the activities around them, as has been observed for family carers for people with dementia in the West (Vasileiou et al. 2017; Victor et al. 2021). A family support could always be found if the carer had to be away to attend an unavoidable matter. Our findings thus resonate with an earlier study of burden among carers of people with dementia in India, which also found that the presence of relatives living nearby helped to share the caring responsibilities and thus reduce the perceived burden (Emmatty et al. 2006). It was notable that we encountered no discourse about the 'bad family' or declining family solidarity due to 'Westernisation' and urbanisation, as is sometimes reported for India (Cohen 1998).

Although most of our findings point towards strong coping strategies around caring for older people with suspected dementia, there were also less positive findings. Chief

among them was the fact that cognitive impairment was not recognised as a medical condition and often got dismissed as a 'second childhood'. This chimed with the data published by (Alzheimer's Australia Vic 2008) that in various cultures dementia was often perceived as 'second childhood'. On the whole, the literature rightly problematises discourse and behavioural patterns which liken people with dementia to children, as the resultant infantilisation and disempowerment denies the personhood of the older person with dementia and can hasten their 'social death' (Higgs and Gilleard 2016; Hockey and James 1993; Kitwood 1997). However, a recent ethnographic study of spousal caring for people with dementia found that by re-casting the relationship in parent-child terms, the interdependent and familial aspects of the bond were preserved (Seaman 2020). We would argue that in our study, although the normalisation of dementia impeded engagement with healthcare services, the metaphor of 'second childhood' helped with making sense of behavioural changes and growing dependency and enabled care and support to be provided within a pre-existing, largely positive frame.

The government of Kerala had come a long way in implementing social security and health insurance schemes which cover older people (Information Kerala Mission 2022; KSSM 2022a, 2022b). Also, it is commendable that government medical schools and primary health centers are providing palliative services to people. Such interest from the government ensures mainstreaming of old age issues. An evaluation conducted on the decentralisation of the health care system showed that by responding effectively to public needs, both the quality and reach of service delivery had improved (Abimbola et al. 2019; John 2012). The community where the study was conducted was unusual because traditional patterns of sociality and mutual support remained strong, and migration has not yet affected the availability of informal carers. But Kerala on the whole is facing challenges like dwindling household size, migration and increasing non-domestic workforce participation by women (Census Commissioner 2011; Eapen and Kodoth 2003; Pradhan

2011). Soon having an older person at home to take care of will mean an additional burden on already dwindling numbers of family members. It is therefore important to pre-emptively start support programmes specifically targeting people with cognitive impairments, as dependency among them can be long-lasting and increasing in intensity. The grass-root-level health providers and local leaders should be taught about dementia so that they can educate people about its care demands. This will enable it being recognised as a disease rather than being disregarded as a normal part of ageing or a 'second childhood'. In this study it was found that lack of acknowledgement from family members was one of the major sources of conflict experienced by carers. This could also be addressed through health education and community awareness programmes.

It is important to streamline the referral system so that those with suspected dementia can get further evaluated in a government medical school. Studies have shown that treatment with drugs will delay clinical decline and reduce mortality risk (Casey et al. 2010; Xu et al. 2021). Further it has been found that the use of these drugs among community dwelling patients with moderate to severe dementia were quite cost-effective with respect to outcomes measured in terms of improvement in cognitive and functional impairment and health-related quality of life (Howard et al. 2015; Knapp et al. 2017). This is beneficial not just for the person with dementia but also for informal carers by delaying behavioural issues and physical dependence. The existing social security schemes should be expanded to include the carers of PLWD to compensate for direct and indirect costs associated with caring. There is also a need for more research to develop projection models to understand the demand for formal care in the future, depending on expected variations in informal care provision. This will give the Indian government a clear direction on how fast and by how much they need to intervene to expand and support existing care delivery systems.

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<sup>i</sup> The study (quantitative and qualitative parts) received ethical approval from the University of Southampton, United Kingdom (ERGO41772) and local institutional review board clearance from Pushpagiri Institute of Medical Sciences and Research Centre, Thiruvalla, Kerala, India (IRB ref: 16/2018).

<sup>ii</sup> Mean education in the population of older people surveyed was only 5.07 years (CI +/- 0.58), with only 15 participants having more than 9 years of education. The Pearson correlation coefficient between education and cognition was 0.601 ( $p < 0.001$ , adjusted  $R^2$  0.356), suggesting a moderate positive relationship between education and cognition. Simple linear regression analysis between education and ACE-m found a beta regression value of 3.98 ( $t$ , 7.556;  $p$  value,  $< 0.001$ ), indicating that for every unit increase in education, the ACE-m score increased almost four-fold.