



# BMJ Open Barriers to home care for older adults from perspectives of Iranian informal caregivers: a qualitative study

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## ABSTRACT

**Objective** A longer life expectancy increases the number of older adults who require long-term care. The presence of a caregiver at home prevents the placement of older adults in care facilities. Identifying the caregivers' viewpoints around the care clarifies key factors in providing quality care. This study aimed to assess barriers to home care from the perspective of Iranian informal caregivers of older adults.

**Design** This was a qualitative study with content analysis. Semistructured interviews were conducted via telephone in Persian with informal caregivers of older adults using open-ended questions.

**Setting** Social and health organisations in southern Tehran, Iran.

**Participants** Seventeen informal caregivers were selected on purpose. Participants were eligible to participate in the study if they were 18 years or older, and had at least 1 month of care experience for a minimum of 6 hours per week.

**Results** Barriers to home care for older adults from informal caregivers' points of view were categorised into three domains: (1) Individual barriers include the physical, mental and social burden of care as well as personal characteristics of the caregiver; (2) interpersonal barriers include psychobehavioural characteristics of the older adult and misbehaviour of people around the caregiver and (3) care system barriers include inefficient institutional/organisational infrastructure, moral issues and inefficiency in public policy.

**Conclusions** Our study showed multiple individual, interpersonal and care system barriers to home care for older adults. Specific contextual challenges among Iranian caregivers, such as their attitudes and beliefs, as well as a lack of social and healthcare support for families, hindered the quality of care.

**Trial registration number** IRCT20201012048999N1

## INTRODUCTION

It is estimated that the number of older adults will be more than double over the next three decades and might reach 1.5 billion by 2050.<sup>1</sup> Longer life expectancy leads to an increase in the number of people who need long-term care,<sup>2</sup> and the presence of a caregiver at home prevents or delays the transfer to care facilities.<sup>3,4</sup> In low-income and middle-income

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We recruited the participants via different social and health organisations in order to have a diverse study population.
- ⇒ We did not limit our study to a specific group of older adults' caregivers to achieve a broader and more comprehensive view.
- ⇒ Due to the COVID-19 condition, we were unable to conduct focus groups and face-to-face interviews.
- ⇒ We did not interview caregivers who had hearing impairments or spoke languages other than Persian.

countries, most of the care provided to chronically ill or disabled people is carried out by informal caregivers (spouses, children, neighbours or friends),<sup>5</sup> who are responsible for taking care of another person's daily physical, emotional and financial needs due to their age, sickness or disability, without receiving any salary.<sup>6</sup> In addition to economic issues, strong emotional ties between traditional family members, social norms and religious beliefs are the main factors that keep older adults at home for as long as possible. Also, most aged people in these countries prefer to be cared for by their family members until the end of their lives.

Like other eastern nations, Iranian society is family-centred, with traditional attitudes regarding elderly family members preserved. According to this culture, caring for older adults is almost an obligation and tradition; and most Iranians are eager to support and care for their older adults at home. Although the rate of placing elderly people in nursing homes has grown in recent years, it has not yet become the norm in Iran.<sup>7,8</sup> Given that Iranian culture and religious beliefs emphasise paying respect to and honouring elderly people, many Iranian families prefer to assume the caregiver position in their own homes to avoid violating the sense of sacred obligation towards other family members or relatives.<sup>7,9</sup> While the role of informal

caregivers is so important in responding to the healthcare needs of older adults, the needs of informal caregivers themselves have not received enough attention in the healthcare system.

Iran's health system consists of public and private medical universities, as well as primary, secondary and tertiary care settings throughout the country. The Primary Healthcare Network is Iran's largest healthcare network, providing access to primary healthcare even in the most rural areas. According to the structure of the PHN system in Iran, every 1200 people in the village receive health and treatment services from a multipurpose healthcare provider named Behvarz at the Health House, which serves as the initial point of contact for people. In addition, there are centres providing comprehensive rural and urban health services in large villages and cities, which have about 10 health workers, including doctors and trained staff to cover more complex health problems. These local centres are supervised by the provincial health centres and universities of medical sciences.<sup>10 11</sup> The 'Integrated and Comprehensive Elderly Care' programme is one of the programmes implemented in PHN centres since 2017.<sup>12</sup>

Despite having a strong PHN system and the existence of a national programme, there has been no approach to identifying and registering informal family caregivers in Iran's health system, nor is there enough information about the quantity and quality of home care provided by informal family caregivers.<sup>13 14</sup> The COVID-19 pandemic potentially postponed the development and implementation of the national programme.<sup>11 15</sup>

Identifying the needs of caregivers clarifies various key factors in providing quality care and can be considered as a guide for planning effective interventions to promote it.<sup>16</sup> Furthermore, current health programmes focused on individual older adults' lifestyle changes and paid less attention to environmental context, whereas ecological-social models see individuals as part of a system and pay attention to interactions between individuals and their environment. These models show five levels of impact: intrapersonal factors; interpersonal factors and primary groups; institutional factors; community factors and public policy. Sustained health improvement is effective when at least two of these factors are simultaneously targeted when planning interventions.<sup>17</sup> This study was conducted to investigate barriers to effective care from the perspectives of informal caregivers with respect to different ecological levels of impact.

## METHODS

### Approach, setting and sampling strategy

We used a qualitative conventional content analysis method using semistructured telephone interviews. The method is described in detail using the Standards for Reporting Qualitative Research Checklist.<sup>18</sup>

Participants were selected purposefully from the south area of Tehran. This area consists of four urban and two

rural areas. The South Tehran Health Centre provides healthcare services in the district to approximately 80 000 people over the age of 60.<sup>19</sup> We also received assistance from two social service departments in the south of Tehran (Health Department of Tehran Municipality, and Tehran and Rey Welfare Organisation) to identify and recruit a variety of informal caregivers.

Informal caregivers of dependent older adults who aged 60 years or older, could not do activities of daily living alone, and in need of care were invited by telephone to take part in the study. The inclusion criteria included those aged 18 years and older and having informal care experience for a minimum of 6 hours per week for at least 1 month. Participants who could not speak Persian were excluded.

To carry out the interviews, the first author (FR), who is a Ph.D. candidate and well trained in conducting qualitative studies and deep interviews, explained the purpose of the study to the participants and obtained their written informed consent through WhatsApp or in-person contacts. All participants were assured of privacy and confidentiality.

### Data collection

Data were collected from January to April 2021. To consider the diversity of participants, we enlisted the four organisations mentioned above to invite caregivers. In addition, a blueprint of the following factors was provided: demographic information including the type of caregiver (primary or non-primary), age, gender, literacy level, marital status, relationship with older adults, occupational status, having an alternative caregiver or not, duration of weekly care time, care history and residence status (living with the older adults or living apart).

Telephone semistructured interviews were recorded after getting permission. In addition, important points were noted by FR. Every interview began with the main question, 'What barriers make care more difficult?' and continued with other probing questions (online supplemental file 1).

Each interview took approximately 30 min on average. Immediately after each interview, the content of the audio file was transcribed verbatim into a Word file and sent to the interviewees to verify the text. Data collection continued until data saturation. After 15 interviews, the data were saturated, but two more interviews were performed to confirm the saturation.

### Data analysis

The first author was primarily responsible for entering transcripts into the MAXQDA 2018 for qualitative inductive analysis. Data were extracted and coded by careful and multiple listening to the audio file of each interview and comparing it with the text, as well as taking field notes. During the analysis, the tone of voice, silence and pauses of the interviewees were noticed.

The interviewer listened to the participants in a friendly and non-judgemental manner while engaging deeply and

continuously with them and devoting sufficient time to data collection and analysis. During the interviews and data coding, research objectives were constantly reviewed to prevent deviation. In order to make sure that the study results do not emerge from previous hypotheses and researchers' views, the participants took part in endorsing the findings. For the validity and reliability of this research study, we used the Guba and Lincoln criteria.<sup>20</sup> ES and MF were reviewed and modified the coding to enhance the trustworthiness and credibility of the data analysis. The researchers also sought the opinions of experts in older adults' care to increase accuracy and authenticity. To protect the security of the process, the anonymity of the participants was maintained at all stages. For data reliability over time and in different situations, a few days after processing the initial coding, the codes were reread and compared with the original codes. In order to increase the generalisability of the results, informal caregivers with different demographic characteristics were interviewed, and the interviews were not limited to caregivers who were caring for older adults in specific groups, such as those with dementia.

### Patient and public involvement

Patients and/or the public were not involved in this research.

## RESULTS

Seventeen semistructured interviews were held with 17 informal caregivers (14 primary caregivers and 3 non-primary caregivers) who cared for older adults in the south of Tehran. The primary caregivers were those who were primarily responsible for caring for older adults, while the non-primary caregivers were those who were assisting primary caregivers.

The number of older adults under care was 19. Eleven caregivers cared for one elderly person and four of them cared for two elderly people. There were 12 females and 7 male older adults with a mean age of  $80.63 \pm 10.96$  years.

The least time duration of care was 6 hours per week and the most time was more than 50 hours per week. On average, participants provided care for 9 hours per week. The history of care varied from 3 months to 20 years, and the average was 5 years. Eight caregivers lived in the same home with the elderly. Other characteristics of the caregivers are shown in [table 1](#).

Barriers to home care for older adults were categorised into three main barriers: individual barriers posed by the caregivers; interpersonal barriers and barriers due to the care system ([table 2](#)).

### Individual barriers

The findings of our study indicated that individual factors were crucial in older adults' home care. The burden of care per se, as a negative consequence of care, could itself act as a barrier to successful care, along with the personal characteristics of the caregivers. Four subcategories

**Table 1** Characteristics of the participant caregivers

Age (year)	
Mean±SD	51.8±11.27
Range	25–78
Gender	
Male	4
Female	13
Literacy level	
Bachelor and above	4
Diploma	7
Primary school	5
Illiterate	1
Marital status	
Married	10
Single	4
Widowed/divorced	3
Relationship with older adults	
Child	14
Daughter-in-law	2
Spouse	1
Occupational status	
Housewives	8
Public work—part time	2
Public work—full time	2
Self-employed	2
Retired	2
Unemployed	1
Source of participation selection	
South Tehran Health Centre	11
Tehran Municipality	1
Tehran and Rey Welfare organisations	2
Other caregivers	3

embracing physical, mental, social burden of care and personal characteristics of the caregiver were placed in the main category of individual barriers.

### Physical burden of care

Physical injuries experienced by caregivers were expressed in the form of suffering or worsening of various pains and diseases, inadequate rest time and physical fatigue, especially in the case that the older adults could not move by themselves. In this regard, participant No. 12 (primary caregiver/female/daughter) stated:

I had problems with my lumbar disc and a neck disc for ten years ... When I take her to the bathroom, I get a neck ache and headache for a few days ... This disc is hitting my neck to my head, and this headache never stops even with medicine.

**Table 2** Barriers to home care for older adults from the perspectives of informal caregivers, Tehran, Iran

No	Category	Subcategories
1	Individual barriers	Physical burden of care
		Mental burden of care
		Social burden of care
		Personal characteristics of the caregiver
2	Interpersonal barriers	Psychobehavioural characteristics of the older adult
		Misbehaving of people around the caregiver
3	Care system barriers	Inefficient institutional/organisational infrastructure
		Moral issues
		Public policy inefficiency

### Mental burden of care

Participants referred to the emotional trauma they had experienced, most of which was in the form of anxiety about existing or potential problems or accidents. They felt anxious as a result of difficult and harmful conditions and the need for immediate care. Feeling guilty for prioritising care tasks over other life items, discomfort from observing the elderly's suffering or boredom, anger from the accumulation of various life issues, and feelings of embarrassment from some elderly behaviours or words were among the items that created a psychological care burden for caregivers. Participants also reported that they had to change their lifestyle, which made them experience stress and pressure due to a feeling of captivity, which meant that they had to limit their time spent on personal chores, communicating with others, and leisure time. Participant No. 10 (primary caregiver/female/daughter) stated:

My biggest concern is that sometimes there are situations where we cannot go to her house ... Now we are all afraid that if she falls and her bones break again, worse problems will occur.

### Social burden of care

The term 'social burden' refers to the caregiver's relationships with other family members, friends and coworkers deteriorating as a result of caregiving.

The elderly's objection to the expenses that the caregivers incurred for the needs of their family members and their misbehaviour with the family members of the caregiver, as well as being forced to be absent from work for the sake of care, had negative effects on the caregiver's healthy relationships with others. Participant No. 17 (primary caregiver/ male/son) stated that:

When I want to take leave from work to take care of my mother, my manager and colleagues say: You always make the same excuse. They think I'm lying ...

### Personal characteristics of the caregiver

Being employed, experiencing physical illness, experiencing financial limitations, old age, gender and not having an alternative caregiver were the most obvious hindering characteristics of the caregivers. The participants emphasised some other challenges such as the inability to leave work due to the need for income, the distance of the workplace from the older adult's residence, long working hours and work shift. Participant No. 12 stated:

I have only one brother who is at work from morning till night, if he doesn't go to work he can't pay the rent of his house. He is married and has to manage his own life....

There were inhibiting attitudes and beliefs among the participants that hindered quality care at home. The participants refused to receive help from others. They believed that there were no alternative caregivers available. In this context, not accepting a stranger as a caregiver in the family, incompatibility of the older adults with home nurses and distrust of care by others were mentioned.

### Interpersonal barriers

These barriers included the type, history and quality of communication between the older adults and their caregivers. Moreover, it included communication with the closest social circle of the individual, such as family members, friends and colleagues. This category entailed two subcategories including psycho-behavioural characteristics of the older adults and misbehaving of people around the caregiver.

### Psychobehavioural characteristics of the older adult

Participants explained personality traits, response states of the elderly, and their cognitive disorders as challenges. According to participants, the elderly's loneliness feelings made care more difficult because they expected someone to always be by their side. Participant No. 10 explained that:

My mother does not like to be alone at all. She likes to always have someone with her... always! not sometimes or just for 1 hour.

In addition, caregivers highlighted mental problems that older people experienced during the coronavirus epidemic, such as nervousness, feeling tired and imprisoned, more sadness and depression, excuses due to reduced elderly relationships, and being forced to stay at home. Participant No. 5 (primary caregiver/female/daughter) stated that:

My dad cried a lot when we wanted to leave his home ... sometimes he got very nervous and made a lot of



excuses like: I am tired of how long I will stay in this prison. because we haven't let him out since last year (due to the Corona pandemic).

Caregivers reported destructive ageing behaviours like restlessness, repeated requests, over-reliance on others, childish behaviour, stubbornness and obsession with the caregiver-elderly relationship, all of which had a negative impact on the quality of care provided.

#### Misbehaving of people around the caregiver

Disrespectful services provided by the healthcare providers, verbal harassment of the relatives, and not taking the problems and diseases of the elderly seriously were mentioned as negative feedback by the caregivers. Participant No. 3 (primary caregiver/male/son) believed that:

My family members and relatives, who are not responsible for the care and don't know the hardiness of caring, criticize everything I do ... they make meaningless and useless suggestions.

#### Care system barriers

This category included physical, social and policy issues of the care system. Three subcategories have emerged as the care system barriers: inefficient institutional/organisational infrastructure, moral issues and public policy inefficiency.

##### Inefficient Institutional/organisational infrastructure

This subcategory focuses on the rules, regulations and structures of social and healthcare centres. In response to the research question, participants' quotations indicated dissatisfaction with the quantity and quality of services provided by the related organisations. Participant No. 12 denoted:

We request a doctor to visit at home, but they (referring to the employees of the social service organization) do not respond ... They would not even give us a second hand ... We wanted a way bed ... We asked for a traffic limitations license for our car to take them to the doctor... Even though the family had three members with disabilities and all the documents were prepared. Finally, they are not doing the only thing they could do.

As stated by the participants, some other important issues were: non-reimbursement of care costs due to inadequate insurance coverage, lack of adequate training of family caregivers on elderly care, and lack of access to officials. Some participants stated that organisations had no plan to assist caregivers with modifying and adapting elderly's homes. According to the participants, the lack of remote services, and the high expenditure of time and money on visiting the doctor made the care conditions more difficult.

##### Moral issues

The obligatory payment before receiving health services, irresponsibility and dishonesty of service providers were

mentioned in this regard. Irresponsibility was expressed in the form of lacking compassion and commitment, procrastination and lack of work conscience. Participant No. 11 (primary caregiver/female/daughter) said of healthcare providers being sent home by an organisation to visit her elderly father:

... Because the doctors who come to our home receive their money late from the organization, they do not have a sense of responsibility.

##### Public policy inefficiency

The constant increase in health costs and instability of living costs, problems related to production, import and distribution of medications (quality, quantity and availability), and low pensions of the elderly were some of the challenges encountered by the caregivers. Inadequate support of the government for the care of the elderly was another issue, which was expressed as the lack of special financial facilities for the elderly, insufficient budget for the care centres and neglecting the caregivers in national planning. The caregivers said that the social support staff was not familiar with the needs of the caregivers due to the fact that the staff did not visit the homes and it was difficult to access senior officials. Participant No. 13 (non-primary caregiver/female/daughter) explained that:

Earlier, when we were in good condition, the costs were not very high, hence, we paid for a physiotherapist to visit him at home, but nowadays, we cannot! It is not affordable.

In addition, the participants pointed to the need to establish appropriate employment policies such as flexible or shorter working hours, paid leave and early retirement without loss of benefits.

## DISCUSSION

In this qualitative study, we conducted semistructured interviews via telephone with 17 Iranian informal caregivers of older adults to investigate barriers to home care from their perspectives. Barriers were categorised into three domains: individual, interpersonal and care system barriers. Clarifying caregivers' challenges in family, organisational and community contexts can lead to a greater understanding of their needs.

The physical burden of care was a challenge for the informal caregivers in our study. They talked about musculoskeletal pain and lack of sleep. Other studies have reported that informal care was perceived as a heavy burden,<sup>21</sup> was significantly related to poor physical health<sup>22</sup> and could be associated with pain and sleep disorders.<sup>23</sup> Our participants also felt trapped by too many tasks to do for the older adults; so that they could not leave them alone to care for their personal and social relationships. They also experienced anxiety and anger, felt guilty and were ashamed of the older adults' behaviours. Caregiving is known as an inevitable situation that causes negative

feelings.<sup>3 24 25</sup> Caring for older adults means always being on call, especially at night, which affects the caregiver's daily life, creates a feeling of pain,<sup>3</sup> and causes stress, adjustment disorders, depression and anxiety.<sup>23</sup>

Caregivers in our study stated that caregiving ruined their relationships with others. They explained that caregiving made them feel stuck between being a good caregiver and being a good parent, spouse or colleague. It was hard for them to maintain a balance between their responsibilities to care for the older adults and other daily chores. They complained about pressure due to conflicting demands or norms, that is known as 'sociological ambivalence', which is applied in a specific position, role or social relationship, such as relationships with other family members.<sup>26</sup>

In our study, some caregivers were forced to leave their jobs, and others lost their financial benefits due to limited work hours; and/or were concerned about high rates of absenteeism from work. Complete or partial deprivation of the labour market due to care has negative effects on caregivers' incomes; shortens their work duration and experience, and reduces their public pensions.<sup>3 27</sup> Furthermore, being employed limits taking on the caregivers' role. Studies show that people who have full-time jobs are less likely to give care to older adults than people who work part time or non-workers.<sup>24 27 28</sup> Caregivers' outdoor activities face them to duality and interference of roles<sup>29</sup> and limit their possibility to care for older adults.<sup>28</sup> Protective employment policies can both reduce the negative effects of employment on care,<sup>29</sup> and affect the dimensions of the caregivers' lives. These supportive work policies that acknowledge caregivers' efforts and facilitate work-life balance are not given much attention in Iranian workplaces.

Informal caregivers in our study refused to receive help from other formal/informal caregivers due to a range of reasons, such as distrust of strangers or the inconvenience of the older adults with home nurses. Also, they had the feeling that no one could take care of their older adult better than they could, and this persuaded them to take on the main responsibility. Female caregivers found men incapable of carrying out the tasks of daily care; however, they needed help in handling some issues, such as moving the elderly person around, which required physical strength. This looks to be a cultural issue in Iran that caring is mainly a feminine role; and men are less involved in caregiving based on perceived traditional gender roles. In our study, we could only interview one spouse as a caregiver because most of them were too ill to take care of their elderly spouses; moreover, culturally, it seemed to be a responsibility for the children or daughters-in-law to care for the older adults. There were also some other contextual issues, such as the religious perspective on caregiving that made some caregivers count caregiving as a divine test, so they solely asked for help. In addition to the statement above, non-married women had to take on the role of caregiving more than their married siblings. These reasons were the frequently cited ones for why the

caregivers did not use the help of alternative caregivers. Other reasons mentioned in previous studies were that asking for help could interrupt other people's plans and lead to receiving negative comments, admitting weakness and being unable to deal with situations on one's own.<sup>30</sup>

Regarding interpersonal factors, the most stated challenge was the older adults' cognitive and mental status that were exacerbating during the COVID-19 epidemic. Older adults' mental health issues are among the factors that complicate the care process and influence quality of care.<sup>25 31</sup> Mental issues related to the epidemic (fear of infection, feelings of confinement and limitation) were also reported by older adults' caregivers in other studies.<sup>32 33</sup> It seems that promoting mental health literacy among the older adults' caregivers to identify symptoms and know how to deal with them is worthwhile.

Regarding care system barriers, our participants complained about the low-quality of health and social services. In Iran, services such as psychoemotional support, financial assistance or insurance for older adults are insufficient.<sup>25 28 29 34</sup> Caregivers face complex and costly challenges that no single public or non-public organisation can address alone. Care systems should promote collaboration among professionals, services, sectors and families to design supportive interventions for informal caregivers.

In our study, some caregivers talked about morality issues among some home healthcare providers. Studies on the moral aspects of home healthcare are limited in Iran.<sup>35</sup> A systematic review have reported ethical challenges in home caregiving including resource allocations and priority settings, end-of-life and palliative care, autonomy and self-determination, truth-telling and information disclosure, and balancing the professional role.<sup>36</sup>

Informal care is not integrated into Iran's health system. Most of the caregivers in our study were unfamiliar with the limited community-level facilities provided to them that they could claim or use as informal caregivers. Lack of training opportunities on how to care for informal caregivers leaves them unskilled and incompetent to provide mutual communication, and build trust among families who need the service. Registering informal caregivers in the health/social system could give the system an opportunity of informing them about potential resources and support services related to older adults' care.

Our study showed that the caregivers faced several individual, interpersonal, and care system barriers to care. Assessing the needs of caregivers is a prelude to successful planning and implementation. According to the findings, it seems that health systems should encourage caregivers to take care of their mental and physical health; while taking care of their older adults. Training coping strategies, providing opportunities for social interaction, expressing feelings and emotions through peer support groups, and providing hotlines can all be beneficial.

Moreover, structured peer support groups for caregivers have not been provided in Iran; however, evidence has shown that interacting with peers and professionals

in support groups has many benefits, including feeling understood because of shared experiences, receiving positive feedback, reducing isolation and being able to access information that is difficult to find elsewhere.<sup>37</sup> Moreover, the establishment of more available and affordable long-term/daycare, and supportive institutions to provide different types of services is another change that should be considered.

For future studies, the viewpoints of the decision-makers and policymakers should be identified to obtain a broader perspective on the issue. It is also important to pay attention to the care needs of certain groups of caregivers with different backgrounds to obtain more specific challenges. It is also suggested to consider the positive and negative aspects of care together in order to plan appropriate health interventions.

### Limitations of the study

This study had some limitations. Telephone interviews limited the role of researchers to observe the facial expressions and gestures of the interviewees. It was also not possible to interview caregivers who had speech and hearing impairments or spoke a language other than Persian. In addition, since the informal caregivers are not registered in any formal system in Iran, and due to the COVID-19 pandemic that made it hard to recruit the participants, we did not limit the selection of participants based on literacy, income level and housing status. Due to the need for lengthy interviews, we did not report positive aspects of caregiving. We could only interview one spouse as a caregiver. So, the results of the study can mostly be applied to children and/or daughters-in-law as informal caregivers.

### CONCLUSIONS

Our study showed that there are multiple individual, interpersonal and care system barriers to home care for older adults from informal caregivers' viewpoints. Specific contextual challenges among Iranian caregivers, including their attitudes and beliefs, hindered receiving quality care at home. Moreover, the social and healthcare support to families with older adults is insufficient; and there is no clear pathway for the families to reflect their needs and feedback. Reducing these barriers can help to maintain the health of caregivers and, consequently, older adults who often have multiple and complex demands.

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