Available online at **www.ijmrhs.com**

ISSN No: 2319-5886

International Journal of Medical Research & Health Sciences, 2016, 5, 8:346-355

Older people's experiences involving the decision to transition to an aged care home

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ABSTRACT

The decision to relocate to an aged care home can is important change in older adults live but little attention has been paid to their experiences of this decision. The study explored older people's experiences involving the decision to transition to an aged care home. Data were obtained via semi-structured interviews with 17 participants, which were content analyzed. Results: Transition motives, ambiguity, participation in decision making and decision making meaning were four themes extracted through data analysis. Conclusions: In the main, the decision to transition to an aged care home had been made without the older person's participation. In addition, due to inadequate information about aged care home services, participants experienced a great deal of ambiguity in the decision-making process. Moreover, transition into aged care homes had different meaning for the participants. The findings suggest that far greater emphasis must be placed on having older people involved in the decision to move into residential aged care, providing them with more information about service offerings and making psychological support accessible to them prior to and following transition to the home.

Key words: aged care homes, decision making, Iran, older people, qualitative research

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INTRODUCTION

One of the greatest global social changes is population ageing.[1] According to the latest reports, Iran's older population was around 6.3 million in 2012 [2] and is expected to reach more than 10.5 million in 2025.[3] Older people are vulnerable to physical frailty and require a combination of family and other forms of support to continue living in the community.[4] WHO has reported that the number of older people who are no longer able to look after themselves in developed countries will quadruple by 2050 and many of them will require long-term care for assistance with activities of daily living.[5]

When the older person is no longer able to care for themselves or be cared for by their family, an alternative form of care can be provided by aged care homes when available.[5] Most Iranian families believe transition to aged care home is due to lack of sense and apathy. So living in an aged care home is a stigma for the older person and their family in Iranian culture.[6] This stigma arises from the deep-rooted culture of family cohesion and belonging, which is outlined in the Koran: "If one of them [parents] or both of them reached their old age while staying with you, do not utter a word of disrespect such as "Oh" nor irritate them, but address them in terms of respect and kindness and be humble out of compassion and pray".[7] Despite the religious believes and cultural values of Iran it has become necessary for some families to make use of aged care homes in recent years.[8] There are no available national data on aged care home use in Iran, but according to some studies approximately 10 percent of older Iranian people live in aged care homes.[9]

Since information on aged care home use in Iran is very limited and based on estimates, the international literature was reviewed to gain an appreciation of the issues for older people and their families with the move to aged care homes. It was found that in many countries and cultures greater use of aged care homes has coincided with changing social structures and family systems,[5] similar to what has occurred in Iran.[10] Given the important role of social and cultural structures in shaping life transitions,[11] having relevant information about aged care service offerings would be helpful for potential residents and their families. The literature reports that transition to an aged care home is perhaps the most important relocation affecting an older person.[12] The decision to relocate to an aged care home can cause the older person and their family a great amount of tension and fear,[13] and ongoing stress.[14]

Providing older people with an opportunity to talk about their involvement in the decision to transition to an aged care home can often help them adjust to the transition process [15] and may help them to adapt more readily to the changed living situation.[12, 16, 17] For many older people, however, the transition decision is mostly made by family members following hospitalization of the older person. In this situation the decision on discharge destination needs to be made quickly and under stressful conditions, if the older person is unable to have ongoing care from their family.[18]

There are numerous studies in the literature that have explored different aspects of decision making for older peoples' transition into an aged care home,[19-21] but little attention has been paid to older people's own experiences of this decision.[20] Research in Iran identifies the stigma of moving to an aged care home for older people and their families,[6] but there is no available literature on older Iranian people's experiences of moving to an aged care home, nor on the impact of the decision-making process for them. The study, therefore, aimed to identify older Iranian people's experiences involving the decision to transition to an aged care home.

MATERIALS AND METHODS

Setting

This exploratory study was conducted in four aged care homes in East Azerbaijan Province and four aged care homes in Ardabil province located in North West Iran. The capacity of these homes ranged from 30 to 120 persons. One home was for men only; four homes were for women only, and in three other homes men and women resided separately. All Iranian aged care homes are administered by the private sector under the supervision of State Welfare Organizations.

Participants

Purposive sampling was used to recruit 17 older people with permanent residence (P1 to P17) from eight aged care homes which agreed to allow residents to participate in the study. The participants were recruited if they were: older than 60 years; had sufficient cognitive and communication ability to respond meaningfully to interviews; able to communicate in Persian or Azeri; and able to give informed consent to discuss the decision-making which occurred in their transition to the aged care home. Participants were, therefore, recruited on the basis of being sufficiently 'mentally lucid' to give informed consent to being interviewed and providing meaningful answers to the researcher. The recruitment process was assisted by staff caregivers, who advised the researcher (author VP) which of their residents over 60 years of age were able to converse freely with staff and others. As well, since it was intended to recruit residents with many varied experiences of marital, economic, social, and educational status, the staff caregivers were able to assist with the convenience sampling procedure, drawing on their knowledge of the residents' past lives. Maximum variation purposive sampling was performed in terms of selecting residents with

good communication ability, and differentiated by gender, age, education, financial status and physical abilities. Sample size was limited by the researcher's capacity to undertake all interviews within an 11-month time period.

Data collection

Data were collected by means of in-depth semi-structured interviews from Jan 2015 to November 2015. This interview technique is helpful in obtaining rich and deep information from vulnerable research participants [22] because of its flexibility of approach and potential to probe participant responses, in order to gain more meaningful insight to individual experiences and perspectives.[23] Interviews were carried out by the researcher (author VP) in a quiet and private place (the resident's bedroom, or an empty room) where participants felt comfortable. Interviews began with questions such as "How was the decision made to transition to the aged care home?" and "What factors gave rise to your transition to the aged care home?" Depending on the answers give to these two questions and the residents' perceptions of the decision to move to the aged care home, other questions were then posed, such as "What did you do to get information on the aged care home?" and "Can you give an example?"

Analysis of the data following each interview guided subsequent interview questions. The researcher took field notes during the interviews to support and give context to the data being recorded. All of the interviews were audio recorded and subsequently transcribed into Persian and were annotated with reference to the hand-written field notes, which recorded all nonverbal communications such as pauses in the conversation, incidences where the participants expressed emotional distress, such as feeling choked and crying, as well as incidences of showing happiness through smiling and being animated. Some of the participants' direct statements were translated into English to be used in reporting their responses for this manuscript. The initial 17 interviews took between 25 to 66 minutes (average 37.45 minutes). Second interviews, lasting 15 to 55 minutes (average 33 minutes), were conducted with three older people residents to clarify, confirm and extend the previous interview findings. Data were considered to be saturated after 18 interviews with 15 residents; when no additional resident experiences were expressed during the interviews. Two further interviews were held to confirm data saturation and when no new category of response arose to interview questions.

Data analysis

Data were analyzed by means of conventional content analysis, commencing with the first interview and continuing as further interviews were conducted. This approach to qualitative data analysis was considered useful since no literature was available on the decision-making experiences of older Iranian people in transitioning to an aged care home. Since these data were novel, content analysis allowed data codes and categories, and subsequently themes, to be derived inductively from the data.[24]

The transcribed interviews were read many times by the researchers to obtain a general understanding of participant responses to each questions posed. MAXQDA 2010 software was used to organizing these data,[25] in which the unit of analysis was the whole interview. Words, sentences and paragraphs were considered as meaningful units and condensed to core concepts. The condensed semantic units were abstracted and labeled by using codes. The codes were grouped into data categories and then into common themes and sub-themes on the basis of similarities and differences. The themes that emerged which were more abstract and conceptual, were treated as expressions of hidden content in the data.[26]

Methodological Rigor

To increase the study's methodological rigor, Lincoln and Guba's (1985) research criteria were applied.[27] Research credibility was increased through the continuous presence of the researcher in the research setting, constant and long involvement with the data, simultaneous data collection and analysis, checking preliminary analyses and findings with participants in second interviews, and in discussion among the research team. Transferability was enhanced by means of employing purposive sampling for selecting participants with maximum variation. Dependability was reinforced by involving more than one researcher in data analysis while one of the researchers collected and analysed the data, study supervisors discussed, checked and reviewed emerging meanings. To increase confirmability, the researcher recorded and reported the stages and procedures in order to allow other researchers to replicate the study

Ethical considerations

This study was reviewed and approved by the research ethics committee of the author's research institution (No.5.4.8213). All participants were provided with verbal and written information about the goal of the study, the

necessity of recording their personal interview and how their personal identities and their data would be protected. All participants were informed about voluntary participation and consent to participate in the study, knowing their right to withdraw at any time. When the researcher was confident that the participant was fully aware of their rights as a research participant, their informed consent was obtained from them in writing.

RESULTS

All the study participants were Muslim. Eleven (64%) of the residents were men, 12 (70%) were divorced or widowed, and 11 (64%) were illiterate; the mean age of the residents was 68.93 (ranging from 62-91). The average length of stay in aged care homes was 11 months (ranging from 1-48 months). All of the participants lived in public rooms with other residents. The participants' common experiences in the decision to transition to aged care homes were classified into four themes: transition motives, ambiguity, participation in decision making and decision-making meaning.

Transition motives

Resident participants had experienced significant changes in their physical condition and financial situation prior to making the transition to an aged care home. These changes had been the catalyst for their decision to move into an aged care home. This theme consists of two sub-themes: "caring motive" and "financial motive".

Caring motive

The majority of participants lived alone before transitioning to an aged care home. In the aftermath of a physical crisis such as having a fall, or experiencing progressive chronic disease, the older person often needed extensive physical care. Two participants had been looked after by their family members, but with the older person's increasing care needs, their families were no longer able to look after them and decided to send them to an aged care home. Three participants, although living with their families, considered that they had not received adequate care from the family and either the older person, or their family, looked for a place to get better care.

"I stayed at my daughter's home before,… but she could no longer look after me… then she decided to bring me here (P7)".

"I just thought I should leave, so I'd receive care. No one looked after me there (home) … I didn't know how aged care home was. I thought whatever it is; they would look after me after all (P1)".

Financial motive

Financial hardship was the primary or secondary motive of 16 residents when deciding to move into an aged care home. Four of the participants had become homeless because of bankruptcy and had been looking for a shelter to live, before they decided to live in an aged care home.

"My wife left me, because I was bankrupt, and I lost my properties and became all alone by myself. When I had no income or a place to live, I came here (P17)".

Ambiguity

Many of the participants experienced ambiguity in the decision to move to an aged care home, mainly because of an information deficit on services that might be available to them and how they would experience life following the transition to an aged care home. None of participants had adequate information on aged care homes and living conditions prior to their transition, and in some cases they were not even aware of the existence of these homes. In other cases, the participant's knowledge was limited to issues with living in an aged care home that had been gleaned from the mass media like television and radio. In the majority of cases the main media message about aged care homes in Iran was the loneliness of older people living in them.

"I just heard it. I had seen in TV. Once the TV showed a reporter interviewing a woman. She said I have kids, but they don't come to my visit. And I cried my eyes out then (P6)".

Lack of authentic information sources and little knowledge of living in aged care homes had caused fear and resistance to the transition for participants who were involved in the decision-making process. As ambiguity in

decision-making increased, participants experienced more tension and concern both during the decision making process and upon transition to the aged care home.

"I was scared. What would they do to me here? Who would serve lunch? What would they do to me? (P2)".

Participation in decision making
This theme focuses on how some participants were involved in the decision to transition to an aged care home and the factors which affected their involvement in the decision-making process. The participant's involvement in the decision making process varied to a great extent, identified at three levels: independent, participatory and non-participatory.

Four participants who independently decided to move to an aged care home made the decision because of their deteriorating physical-caring or financial conditions.

"It's been a while since I'm ill … it's not ok for me to stay with my children ... Because I wanted my respect and dignity untouched, I told my son to take me to an aged care home (P6)".

In participatory decision making, family members had suggested that the transition into an aged care home would be best for two of the participants, but only with their consent.

"My husband told me so. And I agreed with him. I said if there is such place, it's ok, take me there (P1)".

In non-participatory decision making, the process of decision making had been made by family members, or government organizations, with the older person being left out of the decision-making experience. The participants in this group could be further divided into three groups. The first were participants who had been aware that their families had made the transition decision, and they had reluctantly agreed with the decision. This kind of passive agreement had caused feelings of rejection and their former burden on family members. The second group included participants who had been aware of their family's role in enforcing a decision to transition to an aged care home. These people had subsequently experienced severe psychological distress such as depression and feelings of family rejection.

The third participant group had not been conscious during their transition to an aged care home. After recovery following a hospital admission and prior to being informed about the nature of living in an aged care home, they had perceived that an aged care home would be like a hospital. Since these participants had been satisfied with services at the hospital and expected the same level of service in the aged care home, they experienced severe psychological reactions when they became aware of permanent residency in the aged care home since the level and type of care was quite different to expectations. Some had attempted to escape from the aged care home, while others quarreled with other residents and disturbing the order of the home. In addition, one resident of this group had attempted suicide three weeks after the interview.

"My brother said that he would take me to an aged *care home [pauses] … I said I didn't want to over and over, but he said I had no other choice … I became upset and a month after my arrival here, I had a stroke (P4)".*

"I became ill in the home and I was hospitalized about 12 days … my daughters didn't tell me at all. I suddenly realized that they dropped and left me here … When I was new here, they said to me that we are bringing you here to be well again and then we'll take you home … but they didn't take me out of here when I became well (P12)".

To a great extent, the participant's physical condition and their financial situation before transitioning to the aged care home influenced the nature and extent of their participation in the decision making process. The more the person's physical care and financial needs, and the less available the person's resources such as having a family caregiver, aged care insurance and sufficient finances, the less the older person had participated in the decision-making process.

"Because I had lost all my money and because of my lung problems, I couldn't work and I had to accept my family's decision and come here (P15)".

Those who had fully participated in the decision making process had come prepared for the transition and were more able to adapt to living in the aged care home.

"I could more easily adapt to being here, because myself decide come here (P8)".

Decision making meaning
Given the unique condition and situation of each participant before transitioning the aged care home, and the different ways that the transition decisions had been made for/by them, the meanings derived from the decision process are classified into four sub-themes: stigma, rejection, surrender, and relief of suffering.

Stigma
The participant's statements showed that even who were involved in the decision-making, the stigma of living in an aged care home had made them avoided this decision for as long as possible. In the majority of cases, the participants perceived that the transition was a social and cultural stigma and a social embarrassment. It was deteriorating physical and financial conditions that had forced them to overcome the stigma and make the decision to relocate to an aged care home. Because of their embarrassment they even avoided meeting with their friends. Existence of such stigma in Iranian culture had also made family members reluctant to include the older person in the decision making process and to not disclose the real nature of the transition to their family member even after the transition had occurred.

"I always thought about the fact that it is a blot to stay here … because I have daughter and son, … If I died here, this would disgrace them among relatives (P14)".

"when someone goes to their house to visit me, my children lie and say I am at Mrs. so-and-so' or my other child's house; the aged care home is not mentioned at all (P13)".

"I'm embarrassed to be seen in this situation… I'm really sad [crying] (P10)".

"Coming to here destroyed people's personalities, aged care home is not fit for persons who is healthy (P8)".

Rejection
A feeling of being rejected was experienced by 13 of the participants. This feeling was even more severe in those who had been living in their own home in the community and had not received adequate physical care support from their family members.

"When my kids said they wanted to take me to an aged care home, I felt dead inside, I felt loneliness … I saw myself alone (P11)".

"Today older people have no value in the society; As soon as I got sick my kids dropped and left me here and each of them went looking for their life (P6)".

Surrender
In most cases, participants with high physical care needs which family members were unable to provide for, were more willing to surrender to the transition decision. This was more likely for those participants who were initially unaware that the transition had occurred. Consequently, they were unable to resist the transition and were more resigned to surrendering to the unexpected change in events.

"I was sick and my kids looked after me. When my children told me about aged care home I felt that I have no other choice… I had to resignation to their request (P17)".

"I surrender to life situations with entrance to aged care home [crying] and I haven't hope to improvement (P14)".
Relief of suffering

Four participants, who had been homeless prior to their transition to the aged care home and had experienced numerous personal and financial losses in their life, considered that the move to an aged care home was the only

way of surviving. They considered that by living in the aged care home, they would at least get rid of their problems and receive adequate care and a secure place to live.

"Coming here (aged care home) saved me from death. Like I was reborn … before I came here, I had no hope in tomorrow (P15)".

DISCUSSION

The purpose of this study was to explore Iranian older people's experiences of the decision making to transition to an aged care home, since there was no published literature on these experiences. To the authors' knowledge, this study is among the first which explores this life-changing experience in older age in the context of Iranian culture. The study findings are original and contribute to the literature on this important research, practice and policy topic.

One finding that is of relevance to aged care policy and practice is that these older Iranian people experienced increased physical-care needs which were unable to be met by their families, as well as financial issues, which motivate their move to an aged care home. These findings concur with the results of studies conducted in other nations and cultures, and highlight the increased care and support needs of older people that must be met by either families or community support services to keep them living in their own homes, or in their family's home.[28-30] As well, the findings reflect the international literature in regard to the older person's struggle to maintain household chores [29] and the general inability of families to give adequate level of care to older people.[31, 32]

One important finding was the ambiguity felt by most of the study participants to both the decision making process and the resulting move to the aged care home. When planning the transition to an aged care home, having adequate information and sufficient time are critical factors in this life-changing decision.[16, 17] The majority of participants in this study had inadequate information about what aged care living would entail and were fully aware of the associated stigma. This was the main reason for their sense of ambiguity and feelings of stress regarding their transition to the aged care home. Other researchers have similarly found that anxiety is one of the most common outcomes for people who are considering making the transition to residential aged care.[33] For some participants, their knowledge of the real situation was minimal in the sense that they were not provided with information about their transfer to the aged care home by family members, and this strongly influenced their feelings of ambiguity or distress about the forced situation.

Non-participation in the decision making process was among the main experiences which gave rise to negative emotional reactions including frustration, desperation, sorrow, confusion, loneliness and homesickness, impatience, feeling of emptiness, being forgotten, being confined. Research emphasize time and again that taking an active part in the decision to transition to an aged care home is essential for older people of many different cultures.[30, 34] While differences will undoubtedly occur in decision-making processes for older people in different cultures, there is a common feeling of stigma in the necessity to transition to residential aged care. The common view still remains that living in an aged care home is the purvey of other people who are highly disabled and/or cognitively impaired.[6, 35] Such beliefs give rise to feelings of dependence, dysfunction and abandonment when the need to move into aged care is realized.[14] Forced entry to an aged care home can also cause reduced mental health,[36] and increased mortality.[37] Non-participation in deciding to move to an aged care home, similarly, created negative emotional reactions in study participants. The extent to which older people are able to exercise control over the decision to move from their home in the community to an aged care home has emerged as an important determinant of their relocation experience.[14, 17]

Another important study finding was the different meanings attributed to the transition decision by different participants. The stigma of living in an aged care home, the feeling of rejection and the surrender to the situation, were among the negative meanings of the transition decision for 15 of the 17 participants. High appreciation of family support within the social and cultural structure of Iranian society has led to negative views of aged care homes within Iranian society. This negative view is so influential, that the decisions to move to an aged care home by the older person themselves, and/or by their family was very difficult. It was only two of the older people who had no family to call on, and were very poor and homeless, who were able to accept the transition more easily. However, negative preconceptions about the move to an aged care home were predominant and reflective of Iranian cultural views.

Feelings of rejection among aged care residents is an important issue, and indicates an urgent need to provide aged care residents with ongoing psychological support to ease their transition to the new living situation. The importance of understanding and addressing preconceptions in older people's adaptation to the aged care home is underscored in international research.[38, 39] Unfortunately, many of these preconceptions are realized upon entry to residential aged care, where new residents feel isolated from family and vulnerable to the systems that require efficiencies over more personalized care approaches.[40, 41]

Feelings of isolation and despair arising from unwanted and compulsory decision making by most of participants also led them to surrender to the situation. A sense of surrendering to the change in lifestyle was most notable in participants with physical and financial difficulties. This created feelings of powerlessness, a finding reported in the literature for this population group.[8, 42] The difference between findings of this study and those of other studies is in the feeling of surrender such that all of participants had ultimately surrendered themselves to the situation and had been forced either internally or externally to decide to live in aged care homes. This difference might be attributed to the different structure of Iranian aged care homes, or to the lack of social support for older people in Iran, such that if family support is not available, the older person will be forced to transition to an aged care home or a shelter.

However, it must be acknowledged, that for some of the participants the transition to an aged care home meant a relief to their suffering, and a new life of care and support that they had not hitherto experienced when they became physically unwell and/or financially deprived. Evaluating their sources and needs, these participants had decided to live in aged care homes to relieve their suffering and avoid conflicts with their families. Other studies have also found that some older people regard aged care homes as shelters,[43] and moving into them when unwell and dependent as a way to relieve the burden on family, and to avoid conflict within the family.[28, 39]

While this study is among the first of studies exploring Iranian older people's experiences of decision making to transition to aged care homes, thereby providing important information for Iranian aged care policy makers, service providers, potential residents and families, it has a number of methodological limitations. Since the study was restricted to interviewing a very small number of older people, the findings cannot be generalized to all residents of aged care homes in Iran, and cannot be considered to reflect the experiences of all older Iranian people who make the transition to an aged care home. Moreover, this research was carried out in two provinces of Iran and therefore, it cannot be generalized to represent other parts of the Middle East.

CONCLUSION

Findings from this small qualitative study show that the decision to transition to an aged care home is complicated for older Iranian people. High physical-care needs, along with financial problems, pave the way for transition considerations. Based on older people's financial and social resources and needs, the process of making a decision to transition to an aged care home creates different meaning for individuals. These meanings can include feelings of stigma, rejection and surrender, as well as feelings of relief of suffering. It is suggested that there are many barriers to an effective transition to an aged care home in Iran which can be overcome to some extend through having access to relevant information about aged care home services for both the older person and their family.

Having better information on how the aged care home can support the older person's physical, emotional and social needs, can reduce some of the ambiguity the older person might feel about the necessity to accept these services. However, where the older people is not able to be involved in the decision to transition to an aged care home, or are forced to reluctantly accept the family's decision for their transition, the stigma surrounding aged care homes will persist in Iran. Such stigma will inevitably cause despondency and other negative emotions in aged care residents, as they feel abandoned by families and marginalized by Iranian society.

Another important way to break down such barriers is for aged care homes to support increased in social contact residents' families, to facilitate a better understanding and correct negative preconceptions about aged care homes. Providing more information to older people on transitioning to aged care homes, encouraging older people to become more active in the decision making process and providing psychological counseling before and following transition to the home, may also help to ease the transition process.

Acknowledgement
This article is part of the PhD dissertation in nursing submitted to nursing and midwifery of Tabriz University of Medical Sciences and was supported by the research deputy of Tabriz University of Medical Sciences (Grant number 5.55.6388). The authors would like to thank all the study participants as well as authorities of the State Welfare Organization in East Azarbayjan and Ardabil provinces.

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