Barriers to and factors facilitating empowerment in elderly with COPD

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Abstract

Background: Empowerment of elderly people with chronic obstructive pulmonary disease (COPD) can increase their quality of life and feeling of well-being. However, few researches focused on the obstacles and factors facilitating empowerment in elderly people with COPD; and an adequate determining of these factors need an in-depth understanding of the meaning of these factors which influences empowerment. The objective of this study was to explore the barriers to and factors facilitating empowerment in elderly people with COPD.

Methods: This study was conducted with a qualitative approach using content analysis. Twenty-four participants were selected based on purposeful sampling. Data were collected through conducting in-depth semistructured interviews and making filed notes. Data analysis was performed according to the proposed steps by Granhym & Lund man (2004).

Results: The potential to empower the elderly with COPD was influenced by mediating factors; the nature of aging, the difficult nature of COPD, fear and hopelessness, the cultural values and beliefs, poor formal support systems and poor economic status were found to be the barriers; and incentive, trust to health care providers, the educable status of the elderly and increased experience were found to be facilitating factors.

Conclusion: It seems that empowerment of the elderly with COPD was affected by many factors which mainly rooted in social factors, health care systems and personal resources.

Keywords: Empowerment, COPD, Elderly People, Barriers, Facilitating Factors.

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Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a major and increasing global health problem with an enormous expenditure of indirect/direct health care costs (1). COPD prevalence rates increase with age, such that they are highest among those 65 years of age and older (64.2 %) (2). Chronic Obstructive Pulmonary Disease is a major cause of chronic morbidity globally; and currently it is the fifth leading cause of mortality (3). Predominant symptoms of COPD include fatigue and restrictions in daily living (4). These limitations increase the elderly’s’ dependence on other people, and deteriorate their quality of life (5, 6).

In today's world, people with chronic conditions such as COPD are expected to maintain their own health and do their own daily activities and improve their quality of life. Empowerment of older adults with COPD is a cornerstone for increasing commitment, self-management, improving efficacy and quality of life (7), which could reduce disability and health care costs (8). The empowerment process has been fo-
cused on one's ability to knowingly participate in health care decision-making and is associated with awareness of one's developmental strengths and abilities, self-esteem, well-being and self-capacity (9).

There are different conditions that affect empowerment in the elderly with COPD. For example, Sohanpal (2012) concluded that ‘a desire to learn about social benefits of meeting others with COPD’, and being too ill or not feeling ill enough’ are common reasons for the patients’ interest to learn about empowering interventions (10). Robinson showed that 30% of elderly patients with COPD had no knowledge about COPD conditions and its management (11).

It seems that most of the factors affecting the empowerment process are rooted in contextual factors, especially social ones (12). Although most studies on empowering the elderly were conducted in other fields of chronic diseases in developed countries, little is known about elders with COPD in Iran. Mohammadi narrating Golshan (2011) has reported that the prevalence of COPD in the Iranian population is approximately the same as in Western countries (13). In Iran, the highest frequency of COPD is reported in the age group of 65-74 years (8). It is estimated that 8.23% of Iranian people are elderly (14), and their growing number along with the increase of such chronic diseases as COPD could be a challenge to the country’s health care system. In Iran, like most other developing countries, chronic conditions care is provided based on medical models. However, based on the social and economic costs of the aging population, the health care system needs to change its approach to the chronic model of care that focuses on empowerment.

Understanding the barriers and facilitating factors for empowerment in the elderly with COPD may help the health care providers to plan effective interventions and improve the quality of life of the elderly patients with COPD. Considering the consequences of empowerment (e.g., self-efficacy, well-being) and bearing in mind that lack of clarification and true understanding of the factors influencing the empowerment process may affect care, this study was conducted to explore the factors influencing empowerment in Iranian elderly with COPD from the perspective of the elders with COPD, their family caregiver, and the professional team members.

Methods

Study Design

The overall aim of this study calls for a qualitative approach that encompasses a basic understanding of human interaction and social processes. Data analysis was done according to the proposed steps by Granhym & Lundman (2004) (15). Qualitative content analysis was used for the interpretation of the content of the text data; and through the process of regular classification, implicit and explicit themes or patterns in the text could be identified (16). This method concentrates on life experiences, interpretations and concepts to which patients have been exposed (17). This study presents the results of conceptual ordering produced by constant comparison analysis. The aim of conceptual ordering is to develop categories in terms of their properties and dimensions by the process of content analysis. Conceptual ordering is classifying events and objects along various explicitly stated dimensions, without necessarily relating the classifications to each other or developing an overarching explanatory scheme (18).

This paper was a part of a larger study that explored the process of empowerment in the elderly with COPD. Conventional content analysis was used to address the aim of the current study.

Sample and Setting

Considering that empowerment is an interactional phenomenon (12), therefore, older people with COPD, their family caregivers and the health care providers were interviewed. The participants were recruited from an educational hospital which was operating under the supervision of the Na-
From the National Research Institute of Tuberculosis and Lung Diseases (NRITLD) in Tehran and from two district hospitals in the northern Iran. We used criterion-based sampling technique (19). Four criteria were used to select the participants: (i) be 60 years of age or older; (ii) have the ability and interest to explain experiences, (iii) have a minimum of 5 year experience of patient care with COPD (for health care providers); (iv) be a family caregiver to an elderly relative with COPD (for family caregivers).

**Ethical Considerations**

This study was approved by the Research Ethics Committee of Social Welfare and Rehabilitation Sciences University in Iran. The participants were informed about the study verbally and were assured of the confidentiality and anonymity of the data. We made it clear to the participants that they could withdraw from the study at any time. Written informed consent was obtained from the participants before the interviews.

**Data Collection Procedure**

Data were collected by conducting in-depth semi-structured interviews and making filed notes. The main participants (the elders with COPD) could invite a support person to attend in the interview sessions with them and they could stop the interview if they became breathless or did not want to continue. The data were collected from March 2012 to February 2014. The places for the interviews were chosen by the participants to ensure the most convenient environment; accordingly, the participants were interviewed at their home (n= 8), at the hospital (n= 8), in the rehabilitation clinic (n= 4) or at their workplace (n= 4). The interviews lasted 30-100 minutes based on the participants’ tolerance and interests. The semi-structured interview began with an open question based on the main question of the study. The initial questions were broadly focused to encourage the participants to speak freely and recount their personal experiences with regards to the objective of the study such as: 'How do you become empowered? What are the challenges for you in the empowering process?' Then, according to the participants’ answers, coding and analyzing the interviews, more complementary questions were asked from them.

**Data Analysis**

This paper reports a part of the findings of a grounded theory study; then "constant comparative method" was applied as a data analysis procedure. The analysis stages included transcribing the interviews, reading an re-reading the interviews, finding meaning units, coding, condensing, abstracting, identifying contents that addressed a specific topic in the interview, and identifying emerging codes, categories and themes. In the first step, each transcript was read many times to familiarize the researcher with the data (immersion); in the second step, meaning units with reference to the participants’ experiences were identified from the transcribed data; in the third step, the meaning units were condensed. In the fourth step, the interpretation of the underlying meaning was expressed in terms of codes; and in the fifth step, the codes were analyzed and labeled. After reading the analysis as a whole, all the authors discussed and compared the findings until consensus was reached. In the sixth and last step, themes were developed, expressing the main latent content of the text. When all the data had been coded and the categories were condensed, each category was assessed to determine the saturation of data (15).

**Trustworthiness**

To ensure the accuracy, reliability and scientific accuracy of the qualitative data, we addressed the criteria of credibility, dependability or accountability, transferability and confirmability (20). To increase the reliability of the data, the researcher was involved with the data over the two year duration of the study. Interview texts and a list of categories were revised by other research colleagues with experience in qualitative research. In addition, through the
process of member checks, initial coding of the interviews was reviewed by the interviewees to confirm the accuracy of the codes. Three faculty members who were familiar with qualitative research reviewed the codes and agreed on the interpretations. To audit the study, the researcher accurately recorded and reported the stages of the study.

Results
Participants were 24 persons; of whom, 15 (62%) were older people with COPD, and 4 (17%) were family caregivers with the experience of living with the patients: Kinship of family caregivers is as follows: wife (1 person), daughters (3 persons) and 5 (21%) health care providers with a minimum of 5 years working experience with COPD patients (1 head nurse, 1 nurse, 1 physiotherapist, 1 infectious specialist and 1 pulmonologist).

The participants’ descriptions resulted in the following subcategories and categories: The nature of aging (lacking the physical ability, co-morbidities, forgetfulness); the difficult nature of COPD (confronting a difficult disease, complexity of the treatment); poor economic status, poor formal support systems (insufficient social support systems, deteriorated health care system, little attention to client-centered care), fear and hopelessness and cultural values and beliefs were the barriers, and incentive, trust to health care providers, increased experience and the educable status of the elderly were the facilitating factors in elderly empowerment (Table 1).

1. The Nature of Aging
Based on the experiences of the participants, lacking physical ability, co-morbidities, and amnesia had a negative impact on the process of empowerment so that a professional team member (Participant 18, nurse 2) said, "We have a lot of problems with them. They have amnesia too, and some of them are dependent to others."

1.1. Lacking Physical Ability: The informants said that their physical strength have been decreased due to aging and the disabling nature of the disease. In this regard, an elderly participant (Participant 8, a 78-year-old woman) said, “Now that I’m older, I don’t have the strength; I gasp when I take two steps. I have to sit down to catch my breath and walk again and I have a back pain as well.”

Another elderly participant (Participant 2, an 82-year-old man) spoke about the disabling complications of the disease, "When I walk even two steps, I become short of breath. Even for going to the bathroom, I need to stop and rest two or three times."

1.2. Co-morbidities: There are other

| Categories | subcategories |
|------------|---------------|
| The nature of aging | Lacking the physical ability, Co-morbidities, Forgetfulness |
| The difficult nature of COPD | Confronting a difficult disease, the Complexity of treatment |
| Bad economical status | Economical status, insurance status, poverty, economical support by social organizations |
| Fear and Hopelessness | Fear, hopelessness |
| The cultural values and beliefs | Individual beliefs, Cultural beliefs |
| Poor formal support systems | Insufficient social support systems: No Supportive Association, Authorities hypothryroidism in creating a healthy community, Centralized support sources |
| Incentive, Trust to health care providers, Increased experience | Deteriorated health care system: Health system routine-centered, medical dominant approach in health systems, the old approach to chronic disease management, empowerment/ an unclear concept, not acceptable team-working, drug shortages in the market, lack of equipment, and small budget, Little attention to client-centered care: Poor communication, Partially view of the patient, Negatively viewpoint of the elderly patient |
| The Educable status of the elderly | The status of cognition, The educational status, Awareness |
common disorders such as osteoarthritis, low back pain, leg pain and cor-pulmonary disease, which exacerbate disability in the elderly. They (Participant 7, a 74-year-old woman) said, "Our comorbid diseases cause negative impacts on doing the recommended breathing exercises."

In this regard, a chiropractor (Participant 17, a Chiropractor) said, "Co-morbidity is high and I reckon that every elder with COPD has some form of presence of one or more disorders. These disorders are barriers to the outcomes of our work."

1.3. Forgetfulness: Forgetfulness causes many problems in the elderly education. This statement was repeated by most participants. For example, an old man (Participant 10, a 76-year-old man) said, "I am sure that I won’t need to be hospitalized if I listen to their advices carefully, but I am old and forgetful; and besides, my body is weak so I cannot apply their instructions."

2. The Difficult Nature of COPD
COPD is a chronic condition, and unsuccessful care and treatment may turn it to a progressive disease. The second concern in the process of empowerment deals with how to balance one’s approach to a disease that confronts the professional team members with their medical professional limits, that is, the limits for the curing process with the elder’s existential deterioration at all stages.

The most common and most distressing physical symptoms were breathlessness and fatigue, anxiety and social isolation: one participant (Participation 13, a 75-year-old woman) said, 'If I go walking in the street, I become short of breath. I am not working anymore…I don’t sleep well either."

They were not able to move around easily and had to be cautious whenever they wanted to do some hard work. To describe the debilitating nature of the disease, one of the elderly participants compared his condition to that of a runner (Participant10, a 76-year-old man), "I feel like a person who has run for 3 km and is gasping now though I am always resting."

2.1. Confronting a Difficult Disease: COPD is a chronic condition with many difficulties. One infectious specialist noted (Participant 23, an infectious specialist), “These patients fall in to the category of severe patients, and you won’t know how to help them despite all the existing medications. Neither oxygen, nor steroid therapy-sometimes nothing- for these patients can be done."

2.2. The Complexity of the Treatment: Another often mentioned dimension of this disease dealt with the complexity of treatment. Another infectious specialist (Participant 23) said, ‘We use the maximum therapy, but it still gets worse bit by bit. It is like you prescribe one drug after the other, but the condition of the patients worsens and they have difficulty breathing.”

The failure of smoking cessation was considered as the main obstacle for the prevention of exacerbations. An infectious specialist (Participant 23) noted, “Sometimes I find the opportunity for a whole hour to talk to the patient and I spend a lot of time and energy to encourage him/her to quit smoking. Although they agree to stop smoking, they just continue doing it.”

3. Fear and Hopelessness
Participants talked about having less control over distressing symptoms such as breathlessness and indicated an overwhelming sense of hopelessness. They were worried about their unpredictable future. They mentioned that they did not know what will happen to them in the future. One participant (Participant 13, a 75-year-old woman) said, “We have to accept it and try to cope with it.” Another participant (Participant 10, a 76-year-old man) expressed his feelings about the deterioration of his health, “Now I just have to put up with it, now that I’ve got it never gets any better.”

4. Cultural Values and Beliefs
Individual or cultural beliefs can also be two factors that influence the empowerment of the elders with COPD. The influ-
ing factors that affect empowerment include behaviors, beliefs, attitudes and values.

One participant (Participant1, a 72-year-old man) said, “I had to postpone my follow up care, because of my brothers’ funeral. Considering our traditions I had to attend …."

5. Poor Formal Support Systems

5.1. Deteriorated Health Care System: The existing defects consisted of a routine-centered health care system, medical dominant approach in health systems, old approach to chronic disease management, empowerment/ an unclear concept, unacceptable team-work, drug shortage in the market, lack of medical equipment and low budget. Moreover, lack of funds and planning, fundamental defects in treatment management and falling behind from the world's successful health care systems were among the problems in our health care system.

In relation to attitudes about empowerment, a participant (Participant 4, a 60-year old man) stated, "Neither the doctors nor the nurses accept "empowering" as a duty. They feel ‘empowerment training’ is an extra responsibility."

Another participant (Participant 16, a pulmonologist) said, "There are still patients that are not aware of their disease. Currently, in Iran, the possibility of elderly self-management of chronic diseases does not exist."

In relation to the existing problems in the health care system, a participant (Participant 15, nurse 1) said, “... Sometimes there are more than 35 patients in the ward, with only 2 nurses taking care of them. Well, how much time does a nurse have to train them? Sometimes there are two critically ill patients. In the case of more manpower, a nurse can work with peace of mind and train the patients.”

5.2. Little Attention to a Client-Centered Care: Most participants mentioned some problems in the healthcare system such as offensive behavior, poor communication, lack of respect for the elderly and devoting no time to speak to an elderly patient.

In this regard, a participant (Participant 2, a 78-year-old man) said, "You know, they (the professional team members) do not talk to the patients."

Another participant who was a professional team member declared that the nurses do not communicate with the patients and their families.

5.3. Insufficient Social Support Systems: The participants complained about the insufficient social support system. The patients need to be supported economically and socially by the government. They demanded special facilities in insurance support, health care programs, and.... In addition, regarding the participants’ experiences, absence of Associations for COPD patients was another problem of the participants. One of the participants (Participant 6, a family caregiver) said, “There is an Association for diabetes mellitus patients. I think that COPD is just as important, but there is no supportive association for COPD patients in Iran.”

The evidence showed that the health insurance companies nearly never cover the costs for rehabilitation programs, medication costs and cure costs. One participant (Participant 16, pulmonologist) said, "That is a daily conflict to fight insurance companies, because they won’t cover rehabilitation programs. Moreover they don’t cover many of treatment services, medication costs, and...."

6. Poor Economic Status

Poor economic status was considered by the participants as one of the main obstacles against empowerment which is affected by the high cost of treatment, medication supply and expensive medical equipments such as oxygen-generating machine and Bi PAP. A daughter of an elderly participant (Participant 14, a family caregiver) said, "We couldn’t buy the oxygen-generating machine which the doctor told us to buy many years ago; to be honest, we couldn’t afford it."
In some cases, the participants did not follow the recommended diet due to their poor economic status. For example: one participant (Participant 8, a 78-year-old woman) said, "This year, I did not get vaccinated. I caught a cold a few times and was hospitalized two times. Every vaccine costs 20 thousand Tomans; how can I afford to buy it?"

In addition to the possibility of solving therapeutic problems with money, less dependence on children and the possibility of independence have been mentioned to be as the other advantages of having a good economic status by the participants. One participant (Participant 3, a man 86 years) mentioned, ‘If I had an income and could afford my costs, I didn’t have to feel like a burden and be embarrassed in front of my children.”

7. Incentive

When the participants had the incentive to participate in the treatment and care plans, the ability to cope improved. In this regard, an elderly man highlighted the role of incentive in the process of empowerment. He (Participant 4, a 60-year-old man) said, "Any individual must be self-seeking. If an old person doesn’t want to become self-seeking, even being literate does not help. Literacy without having an incentive for becoming self-seeking is not of any use."

A physiotherapist (Participant 17, a Chiropractor), based on her experiences, highlighted the important role of incentive in pulmonary rehabilitation programs and follow-up of the elderly: "Usually the ones that come to us have the will, but their success depends on their incentives."

8. Trust to Health Care Providers

Trusting the healthcare staff, especially trusting the physician was important to the elders’ process of empowerment. It was based on the belief that the elder was receiving adequate care. The experience of continuity in health care created a feeling of security and trust, as did the experience of co-ordination of treatment and needs. Trust in the staff’s competence, especially in the physician was indispensable. Honest information about the elders’ medical condition was essential to their trust in the staff. In addition, the elderly with COPD and their families stated that training provided by the health professionals would improve the awareness of the elderly about COPD, extend their thought processes and help them develop appropriate attitudes towards COPD.

One participant (Participant 7, a woman 74 years) said, "Well, my physician told me to use one of these things (masks) when I go out, so I use it whenever I go out, particularly in the winter."

9. The Educable Status of the Elderly

Those participants who were more informed had a better chance of knowing what to do and how to do it. This is partially reflective of the educational status, cognitive function and awareness. One nurse (Participant 15, nurse 1) mentioned, "Younger people do very well. They quickly learn what we teach them, but the elderly do not."

Also, misunderstanding led to a perception of COPD being both reversible. One participant "(Participant 11, a man 76 years) said, “because of shortness of breath due to my asthma I am not working anymore.”

10. Increased Experience

Some participants stated that they felt more experienced than before and compared to young people. An old patient (Participant 12, a 73-year-old man) said, “Because of many problematic situations in the past we, as elders, are well experienced and others can ask for our help to solve their problems.”

Reflecting on past events and gaining experience based on cognition, knowledge and reflecting on them and evaluating the results, helps the elders with COPD to convert to experienced individuals who can find the best solutions to control their life and disease and even help others by giving
Discussion

It appears that there are factors that facilitate or hinder the process of empowerment in Iranian elders with COPD. As people age, their self-care ability may be weakened by one or more functional limitations. This is particularly important for those Iranian elders with a disabling disease, whose caregivers demonstrate respect by performing those self-care activities the elders could not perform for themselves. Doing the normal tasks was simply impossible for the elders because they needed all their energy to breathe. Lack of energy resulted in their having to sacrifice activities they wanted to participate in, limiting their sense of freedom and social interaction. This is consistent with the findings of other researchers who have also found that aging, degree of disability and co-morbidities cause excess problems for the elders (21, 22). In addition, the nature of COPD means that control is forever in flux; for example, an acute exacerbation could temporarily shift the elder from a controlled phase to an uncontrolled phase.

According to the nature of the disease, it was for these people to lack physical ability, to be forced to forgo activities and to be forced to accept being dependent on others and on various assistive devices. The combination of breathing difficulties and a lack of energy curbed daily activities.

Similar to the findings of other studies, the participants of our study spoke about the difficult nature of the disease (4, 23, 24). Earlier researchers have described the physical limitations associated with COPD, which can also be seen in our study (5, 21, 22). Participants described their struggles to handle their daily life and how difficult it was to forgo participation in activities and relationships and accept their dependence on others. This result is harmonious with that of other researchers that found COPD and its associated symptoms, along with perceptions of having no energy, being forced to forgo activities and experiencing meaninglessness (25, 26). In a study conducted by Ferreira et al. (2002) it was revealed that independence in ADL is related to the degree of airflow limitation, health status and mood (27).

The cultural values and beliefs were the next obstacles to the empowerment process, and these findings were consistent with those of other studies. For example, beliefs and cultural values prevented the patients with diabetes mellitus from adhering to treatment regimen (28).

The common and distressing psychological symptom of fear and hopelessness, which was reported by most participants, is consistent with the literature (29-31). Hopelessness may undermine the sense of control which is the key to improving the health-related quality of life of COPD patients. This is harmonious with the findings of other researchers who have also found that depression and helplessness are barriers of empowerment in the elders with COPD (32-34). Therefore, this should be an integral part of disease management for those clinicians who want to support the elders with COPD to manage their conditions better and to lessen their associated emotional burden.

All participants mentioned the poor formal support system. They reported that the elderly with COPD and their families did not receive appropriate and sufficient social support for their personal needs and managing their costs. The stated reasons included deteriorated health care system, little attention to client-centered care by health care providers and insufficient social support systems. Studies among patients with COPD revealed a positive relationship between social support and health-care outcomes (22). Then, it is of prime importance to provide social support in insurance, economic support and develop special associations for the patients with COPD (similar to those developed for other chronic diseases; for example, diabetes mellitus).

Social support includes many resources such as social support organizations like health care agencies and social welfare or-
ganizations. This result is equal to that of studies reported by other researchers who have also found that insufficient social support was a barrier for the empowerment of old people (34,35).

Shearer found that elderly patients with chronic diseases require social support (36) and supporting systems are very important to old people (37). In the study reported by McCathie, high levels of positive social support predicted lower levels of depression and anxiety, while higher levels of negative social support predicted higher levels of depression and anxiety in COPD patients (38).

The present study showed that health care providers are unable to facilitate capabilities of elderly patients with COPD. They focus more on providing clinical care, and education of self-management programs is less likely to be implemented. Lack of time and manpower shortage is the problem that was mentioned by participants. With respect to the support of health care providers, old people with COPD and their families demanded to know what health care providers were doing and what they could do to help and whether they had a genuine interest in them as individuals. However, health care providers did a poor job to manage the disease by communicating poorly or being disrespectful to the patients. This finding is not harmonious with the results of Nasiri-pour's study, in which nurses used six strategies to empower Iranian patients; one of these strategies was good communication (39). Therefore, good communication between nurses and their elderly patients can promote patients’ good decision-making about the treatments. Health professionals have also a responsibility to help the elders with COPD to learn how to effectively control their disease as opposed to letting it control them (22).

The results of this study also revealed that one of the major obstacles to empower the elders was poor economic status. In the studies conducted by other researchers, poor economic status was considered a barrier in patients’ self-management (28, 35, 40). In a study conducted by Ferreira et al. (2002), the low-income patients who used the long term oxygen therapy were significantly less independent in their ADL than the control group (27).

Common barriers to self-empowerment were similar to those of other chronic diseases: ineffective healthcare systems, poverty and illiteracy. In this process, the educable status of the elderly had a prominent role in their empowerment. Old people with COPD are empowered when they have the necessary knowledge, skills and self-awareness to influence their behavior and that of others in order to improve their quality of life. The enabling act of empowerment, therefore, begins with information and education. In a study conducted by Fotoukian et al. (2014), it was concluded that awareness promotion in problem solving is an attribute of empowerment in the elderly with COPD (41). However, the results found by Robinson (2010) showed that 30% of the elderly patients with COPD were not aware of management practices and did not have enough knowledge about their condition (11). Overall the results of this study revealed that many older people knew little about their condition and were unaware of strategies to manage it. This finding is supported by Boot who found that 30% of the patients did not know they had this condition (42). Also, Hyland found that patients with COPD did not always know their respiratory medication (43).

In the current study, the elderly patients with more experience seemed to manage their disease better than others with less experience. An awareness of these strategies may be useful in understanding how people with COPD manage their disease and make decisions to seek care from a health care professional.

Trust in the healthcare staff was found to be of importance for the elders’ experiences of empowerment. Research on intensive care has shown that a caring atmosphere where the elders receive continuous and honest information increases their empow-
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