

Caregiving for Patients with Chronic Diseases: The Process of Caregiver Empowerment

Shahzad Pashaeypoor^{1,2}, Ameneh Yaghoobzadeh^{3,4}, Fon Sim Ong⁵, MohammadAli Cheraghi⁶, Sahar Khoshkesht⁷, Leila Mardanian Dehkordi⁸

¹Department of Community Health and Geriatric Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

²Community Based Participatory Research Center, Tehran University of Medical Sciences, Tehran, Iran

³Nursing Care Research Center, Semnan University of Medical Sciences, Semnan, Iran

⁴School of Nursing and Midwifery, Semnan University of Medical Sciences, Semnan, Iran

⁵Malaysian Research Institute on Ageing, Malaysia and Emeritus Professor, University of Nottingham Malaysia, Selangor, Malaysia

⁶Department of Nursing Management, School of Nursing & Midwifery, Tehran University of Medical Sciences, Tehran, Iran

⁷Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

⁸Nursing and Midwifery Care Research Center, Isfahan University of Medical Sciences, Isfahan, Iran

*Corresponding Author: Leila Mardanian Dehkordi, Email: mardanian@nm.mui.ac.ir

Abstract

Background: Family caregivers often provide non-professional care to family members with chronic diseases, requiring assistance with daily living activities. Caregivers typically experience significant stress, including physical, psychological, and emotional burdens, as well as social isolation associated with long-term care provision. As caregivers often do not have a role in care-related decisions, their stress levels can increase substantially. Empowerment of caregivers is essential to enable informed decision-making in care-related issues, thereby enhancing patient care outcomes and ameliorating caregiver stress. Accordingly, this study aimed to define and describe the features of the empowerment process for family caregivers providing care to patients with chronic diseases.

Methods: This study was conducted using Walker and Avant's concept analysis method. A total of 33 articles published from 2008 to 2024 focusing on family caregiver empowerment in chronic disease contexts were selected from CINAHL, PubMed, Scopus, and Google Scholar databases.

Results: Key attributes identified in the family caregiver empowerment process included support for care recipients, constructive relationships with others, knowledge, skills, and an improved sense of positive feelings. Understanding caregiver needs is crucial for public policymakers, healthcare providers, and families in improving care quality and promoting the health of the family, self-reliance, adherence, and patient care outcomes.

Conclusion: Clarifying the components of this concept will assist healthcare service providers to design and implement appropriate intervention programs, including support systems that enhance family caregivers' empowerment in their caregiving roles.

Keywords: Family caregivers, Empowerment, Caregiving, Concept analysis

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Introduction

The number of individuals living with chronic diseases continues to increase worldwide (1, 2) due to advancements in medical knowledge and treatment practices (3). Patients with chronic diseases often experience varying degrees of disability, which affect their cognitive, functional, and daily activities (4). In such cases, caregiving responsibilities usually fall on family members who become the main caregivers to meet the daily needs of the patients with chronic diseases (5).

Family caregivers are defined as individuals who accept

the caregiving role (6) and provide unpaid long-term care to a family member with a chronic illness or disability (7). They engage in various tasks, including managing care needs and assisting with functional limitations (8). In addition, family caregivers provide clinical assistance, complete formal care services, offer emotional support to patients, and play a role in clinical decision-making (9). However, caregiving is usually a complicated task, and many caregivers undertake it with little or no formal training or preparation (10). This can lead to a demanding caregiving experience associated with financial burdens,



psychological stress, and physical exhaustion (11) which may negatively impact the clinical outcomes (12). At the individual level, the financial burden on families coping with chronic diseases can significantly hinder access to treatment (9). Moreover, as literature indicates, non-professional caregivers engaged in physical and emotional care, often experience different levels of stress (9-11). Therefore, it is essential to provide caregivers with the confidence and strength necessary to deliver appropriate care. One effective approach to achieve this is through empowerment (13,14).

Empowerment of family caregivers can foster trust and facilitate collaborative decision-making with health professionals (15), ultimately enhancing the health and well-being of the entire family (16). Empowerment helps caregivers strike a balance between coping mechanisms, self-care for patients and caregivers, and the effective use of resources in clinical settings and at home (15). Family caregiver empowerment represents an intervention that healthcare providers can employ to help families achieve better care outcomes for both patients and caregivers (17).

Previous research has largely overlooked the empowerment of caregivers, particularly the processes involved in family caregivers' empowerment. Empirical studies that explore effective support mechanisms for family caregivers are still in the early stages, despite a recognized need for such support from healthcare and social care professionals. In many instances, this support is suboptimal (18). Previous studies, whether qualitative or quantitative, have discussed family caregivers' support needs without addressing the timing of these needs or identifying optimal interventions for caregiver support (19-21).

The World Health Organization (WHO, 1998) defined empowerment within the healthcare context as a process through which individuals gain greater control over decisions and actions that affect their health, encompassing both individual and community dimensions of the process (22). Research indicates that the empowerment of family caregivers is effective in alleviating their physical and mental burdens, increasing self-efficacy, obtaining ongoing social support, fostering mutual trust between care recipients and caregivers, and promoting personal growth through experiential learning. Enhancing empowerment among family caregivers who experience physical and social burdens is vital for restoring their agency and maintaining or improving their quality of life (23). It is of paramount importance to understand the empowerment processes, the challenges caregivers face, and the support they require. Thus, this study focuses on family caregiving and analyzes the empowerment processes to enable healthcare providers to support informal caregivers and promote their health and well-being. By clarifying the dimensions and components of the concept of the empowerment process for family

caregivers, this study aims to identify the timing and types of support required by family caregivers.

This study aims to conduct a concept analysis of family caregiver empowerment in the context of chronic diseases and identify its attributes, antecedents, and consequences. The research questions guiding this study are as follows:

1. What is the concept of the process of family caregiver empowerment in caregiving for patients with chronic diseases?
2. What are the components/features of family caregiver empowerment in caregiving for patients with chronic diseases?
3. What are the manifestations of family caregiver empowerment?

Methods

This study was conducted using the concept analysis method proposed by Walker and Avant to analyze the process of family caregiver empowerment (Box 1). This method was chosen for its logical framework, clarity, and the possibility to facilitate a clear understanding of how a definition evolves through application in clinical environments. The key procedures in concept analysis include selecting a concept, determining the purpose of the analysis, identifying the possible uses of the concept, discerning the defining attributes, determining a model case, identifying borderline, related, contrary, invented, and illegitimate cases, and determining antecedents, consequences, and the empirical referents of the concept (24).

Multiple searches were conducted using the Ovid, PubMed, and Google Scholar databases. Dissertation abstracts and conference proceedings were excluded. Publications from 2008 to 2024, covering a decade, were included in this study. The initial search was carried out using the following keywords: "caregiving" OR "caregiver" OR "giving care" AND "empowerment" OR "empowering" OR "empower" AND "chronic illness" OR "chronic disease" OR "chronic condition". The search was limited to literature on human subjects, specifically adults, published in English, and available in full text for free. Following these searches (N=2577), a focused analysis of relevant references and major and minor subject headings was used to refine the search criteria and identify pertinent sources. All relevant abstracts and titles were reviewed and those specifically addressing the concept of the process of family caregiver empowerment

Box 1. Walker and Avant's concept analysis stages

Stage Action

1. Select a concept
2. Determine the aims of the analysis
3. Determine the definition attitudes of concept
4. Identify all uses of concept that can discover
5. Identify a model case
6. Identify borderline cases, related cases, contrary cases, ...
7. Identify antecedents, consequences
8. Define empirical referents

were included. In concept analysis, the quality of studies is not usually evaluated using conventional tools. However, an attempt was made in this study to select the resources closely aligned with the concept and those published in reputable journals that adopt blind peer review.

Finally, a total of 33 articles were selected from the initial studies (Figure 1). The selected articles met the requirements or addressed components of the empowerment process, as outlined by Walker and Avant. Thus, they help to define the attributes of empowerment, identify examples and related cases, develop a base model, and determine empirical referents (24).

Results

Selecting the concept

It is widely known that family caregivers experience stress, anxiety, and burden in the caregiving process (25-28). Powerlessness, which is the opposite of empowerment and serves as a starting point for it, encompasses feelings of stress, frustration, and hopelessness. Empowerment can be considered both as a process, incorporating actions, activities, or structures, and as an outcome, suggestive of an achieved level of empowerment (29). Consequently, empowerment serves as a critical concept in the caregiving process as it enhances people's ability to identify their requirements and utilize their resources

effectively for problem-solving (13)

Uses of the concept

In this study, caregiving refers to the act of providing unpaid care and support to family members or acquaintances who have physical, psychological, or developmental needs. Caregiving is often a multifaceted endeavor that entails both instrumental and emotional support (30). Depending on the type and severity of the disability, the frequency and intensity of caregiving may vary. Some of the most common care tasks include transportation, activities both inside and outside of the patient's home, care management, personal care, and medical care tasks. This caregiving can be a long-term process, especially when providing care to close family members (10), and it requires specific skills and knowledge (31). Caregivers need strong support and empowerment to ensure positive outcomes for both families and patients (10). When caregivers are empowered, they can deliver care that enhances their own psychological well-being (32) as well as the quality of life of patients, caregiver, and their families (33).

Caregiver empowerment is defined as an increase in one's ability to appraise, influence, and manage a situation using contextual and personal resources to achieve desired outcomes (34). The WHO in 1998 defined empowerment

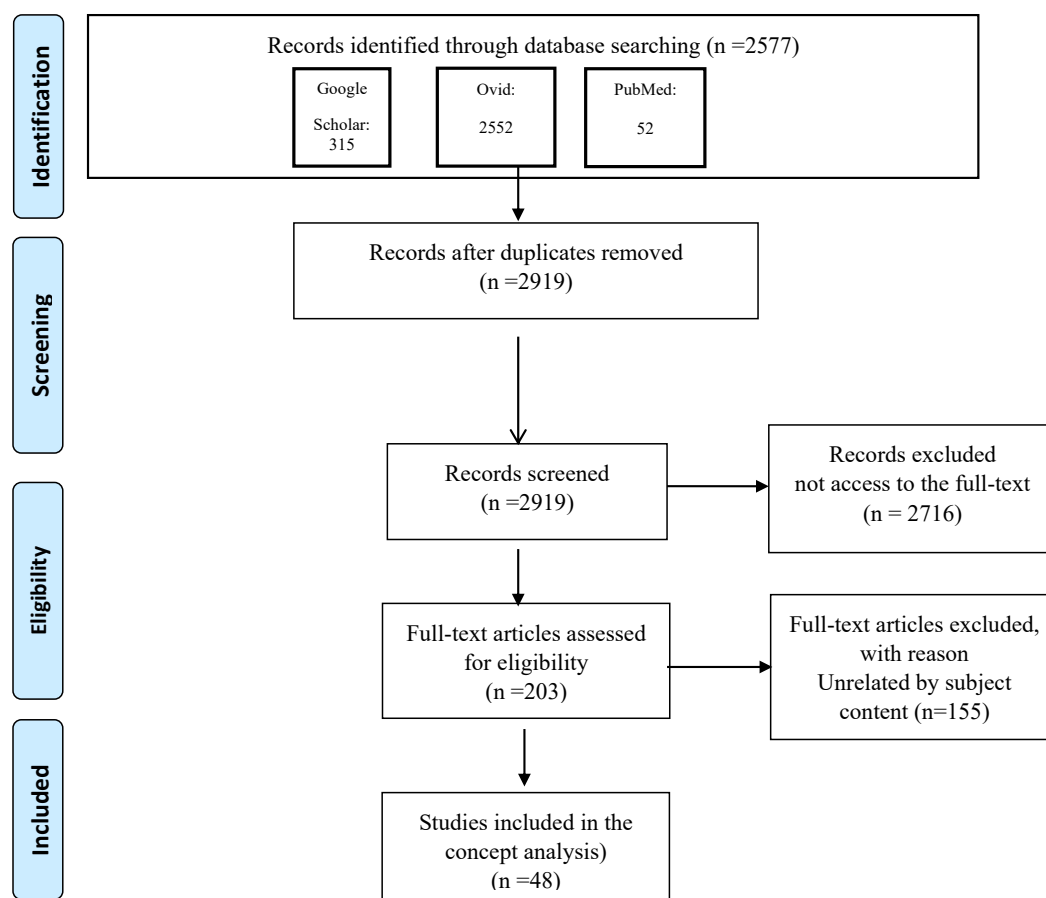


Figure 1. PRISMA flowchart of literature search strategy

in the healthcare context as a process through which individuals attain greater control over the decisions and activities that affect their health in both individual and community dimensions (35).

Although empowerment has its roots in the black power movement of the 1960s and the gay and women's rights movements of the 1970s and 1980s (36), since the early 1990s, increased attention has been given to the concept of empowerment in various disciplines such as management, psychology, social anthropology, sociology, political science, and nursing (35-41). In the nursing field, empowerment is defined as an active, internal process of growth shaped by culture and personal beliefs, which aims to realize an individual's full potential within a nurturing nurse-client relationship (42).

The theory of empowerment can be viewed as both a process and a consequence. The process focuses on activities that empower a person or community, while the consequence reflects the level of empowerment achieved (43). Empowerment involves purposefully taking part in the process of changing self and environment, identifying patterns, and leveraging inner resources to enhance well-being (44).

Defining attributes

According to Walker and Avant, defining attributes or characteristics of a concept is central to concept analysis, which includes determining descriptive attributes that are used frequently while discussing the concept and play a major role in differentiating between concepts (24). The purpose is to show the cluster of characteristics that provide the best insight into the concept. Empowered family caregivers engage in support programs and guidelines designed by healthcare providers based on caregiver needs (45). They can exert constructive control,

foster positive attitudes, proactively try to understand their role as caregivers to improve caregiving abilities, promote the independence of care recipients, and build constructive relationships with others (46). Empowered caregivers positively impact disease management (47) and possess the knowledge and practical skills necessary to perform caregiving (48). Besides, they derive satisfaction or enjoyment from witnessing their care recipient's comfort, joy, and progress in overcoming difficulties in their life (49) (Figure 2).

Model case

A model case is a specific example illustrating the intended concept that should encompass all features of that concept (24). The following model case was constructed based on the procedures suggested by Walker and Avant:

A 57-year-old woman was discharged from the hospital after treatment for a hip fracture. However, she could not do her activities of daily living (ADLs) and needed assistance. Before discharge from the hospital, the nurse asked her family to talk about their concerns, specifically their worries about providing adequate care. The nurse listened to them and acknowledged their anxiety. She answered their questions and explained the procedures that needed to be carried out at home by caregivers. Furthermore, she provided information on care support centers for chronic illnesses. Her actions alleviated their concerns. Follow-up support was provided post-discharge, continuing to assist both the family and the patient. The family caregivers felt that with increased empowerment, their ability to care for their family member improved (50). With informational support from healthcare professionals, social media, related books and magazines, and peers, they acquired essential caregiving knowledge, and with social and instrumental support

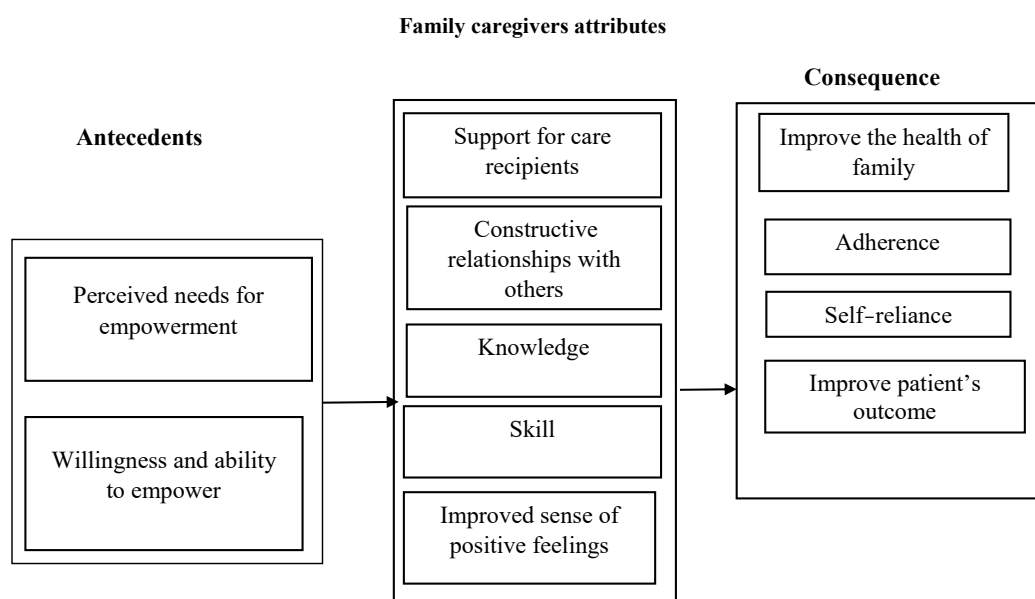


Figure 2. Conceptual model of the process of caregiver empowerment

they could manage their stress and sense of burden, hence enhancing their overall well-being.

Borderline case

Borderline cases include some attributes that overlap with the concept but are often mistakenly used instead of the concept (24):

Resilience is one of the borderline cases of empowerment. Resilience and empowerment are two independent but interrelated concepts that sometimes lead to confusion for readers. Both resilience and empowerment are fueled by unsatisfying states but are differentiated by, among other things, internally (resilience) versus externally (empowerment) focused change goals (51).

A 57-year-old man had a car accident, and the physician informed his family of the poor prognosis. Initially, the family fell into despair, but they soon decided to seek information to manage the situation (showing their ability to control stress). The wife thought she needed to be a “strong wife”. She quit her job to care for her husband and viewed the accident as a divine test, believing that her family’s utmost efforts would lead to her husband’s recovery (demonstrating a sense of control and a positive outlook). After the diagnosis, she relied increasingly on her religion (faith, transcendence, and spirituality). She tolerated difficulties to overcome adversity while taking pride in her ability to cope with this difficult situation. In addition to caring for her husband, she enjoyed helping other caregivers and sharing her experiences (self-esteem) with them.

In this case, the caregiver showed flexibility in seeking appropriate support while simultaneously trying to normalize the situation.

Contrary case

A contrary case is a clear example that does not fit the concept (24). Analyzing contrary cases provides insight into the defining attributes of the concept by excluding those from the contrary case. The following is an example of a contrary case of family caregiver empowerment as it does not depict the concept of empowerment.

A 57-year-old woman with a diabetic foot ulcer was referred to the hospital. After foot amputation, she was discharged, and the nurse asked her partner to continue to care for her. However, the partner lacked the requisite knowledge and skills to care for her partner, and the medical staff did not train him. He felt unprepared, hopeless, and unable to provide the needed care.

In this case, the family caregiver did not acquire essential knowledge and skills and experienced a sense of powerlessness.

Antecedents

According to Walker and Avant, antecedents are components, events, or phenomena that precede the

occurrence of a phenomenon, and the main concept emerges due to the presence of these antecedents. Identifying antecedents helps refine the concept (24). Antecedents identified for the process of family caregiver empowerment included situations that prepare families to accept the caregiving role (10). Two factors precede the occurrence of family caregiver empowerment including perceived needs for empowerment and the willingness and ability to empower (9,10). Self-awareness of the need for empowerment is one of the underlying principles of empowerment. Family caregivers who experience strain, anxiety, stress, and the burden associated with caregiving are aware of their perceived need for empowerment (9,10,52). In addition, the willingness and ability to pursue empowerment are essential factors that affect the process of empowerment. Family caregivers should have the motivation and ability to achieve empowerment. Empowered family caregivers need healthy physical and psychological conditions (53-55) (Figure 2).

Consequences

Consequences follow from the occurrence of a phenomenon. Empowerment improves the health of the family, and empowered family caregivers experience reduced stress levels and lessened burden (56,57). Family caregiver empowerment is associated with improved treatment adherence (58), self-reliance, and the ability to care for patients (59). This improvement results from the enhanced knowledge, attitudes, and self-efficacy of caregivers in the empowerment process (60). The process of family caregiver empowerment also positively influences patient outcomes (61) (Figure 2).

Empirical referents

Empirical referents are recognizable attributes of a concept that signify its existence. These referents are particularly important when dealing with abstract concepts that are difficult to measure. Empirical referents aim to identify the concept and facilitate its measurement (24). In this study, various tools were identified for assessing family caregiver empowerment. Degeneffe et al. developed the Caregiver Empowerment Scale, which serves as a resource for working with family caregivers of patients with traumatic brain injuries (53). Moreover, Kageyama et al. developed the Japanese version of the Family Empowerment Scale for family caregivers of adults with mental health issues (62). It is noteworthy that this is a widely-used scale applicable to different conditions (62,63).

Discussion

This study explored the concept of family caregiver empowerment. The literature review, which focused on family caregivers of patients with chronic diseases, revealed structured aspects of empowerment among family caregivers.

Empowering family caregivers of patients with chronic diseases was found to be a complicated concept. Five attributes were identified in this study including support for care recipients, constructive relationships with others, knowledge, skills, and an improved sense of positive feelings, which are all discernible in other relevant studies.

Empowered family caregivers effectively support patients with chronic diseases. Their role may include physical and psychological symptom management, financial and social support, and participation in planning advance care (9,10,52). Communication with others is a key component of empowering family caregivers, as it allows them to learn from their connections and provide support while caring for their patients (23). To achieve this, caregivers need to acquire information about health conditions and learn how to perform healthcare tasks safely, skillfully, and confidently (64,65). Thus, knowledge and skills are important elements of empowerment.

Empowered family caregivers can manage their negative emotions and adjust to their caregiving role (66). Without using a range of coping strategies, family caregivers might not be able to deliver positive care as they face different challenges in long-term care for patients with chronic diseases and experience physical, psychological, social, and financial (9,10). Accordingly, it can be inferred that positive feelings are essential elements that influence empowerment.

The findings from this study can be beneficial not only for patients but also for their caregivers, who are involved in patient care. Besides, nurses are an important workforce to implement nursing interventions that empower family caregivers (67). The empowerment process should begin when family caregivers perceive their need for empowerment and are willing and able to pursue empowerment. Similar studies have also indicated nurses can help family caregivers when they perceive their need for empowerment and support (68).

The family caregiver empowerment process is associated with improving the health of family caregivers, patient outcomes, adherence, and self-reliance. Similarly, other studies have shown family caregiver empowerment reduces the caregiving burden related to role changes, improves the caregiver's quality of life, and has benefits for both caregivers and patients (67,68).

According to the identified integral components of empowerment, this study revealed empowerment is a complicated concept encompassing support for care recipients, constructive relationships with others, knowledge, skills, and an improved sense of positive feelings. Therefore, effective interventions to empower family caregivers may result in improving their adjustment, skills, and knowledge.

Conclusion

This study identified various empowerment resources

such as skills, spirituality, instrumental support, emotional support, and knowledge that could be beneficial for family caregivers. Therefore, the findings of this study are useful for health professionals in planning empowerment interventions and can aid in training nursing students, healthcare providers, and patients' family members.

All features of family caregiver empowerment are interrelated and affect one another. To achieve empowerment and its positive outcomes, it is necessary to take into account all aspects of empowerment including skills, spirituality, instrumental support, emotional support, and knowledge. Family caregiver empowerment is a critical concept as it ultimately affects care outcomes. This concept holds significant implications for healthcare providers who prepare family caregivers for home care responsibilities. Family caregivers should be encouraged and given opportunities to attend training that prepares them in terms of skills, mental readiness, and other areas when they first learn about their caregiving responsibilities.

Authors' Contribution

Conceptualization: Leila Mardanian Dehkordi.

Data curation: Leila Mardanian Dehkordi, Ameneh Yaghoobzadeh, Sahar Khoshkesht.

Formal analysis: Leila Mardanian Dehkordi.

Funding acquisition: Leila Mardanian Dehkordi.

Investigation: Leila Mardanian Dehkordi, Ameneh Yaghoobzadeh.

Methodology: Leila Mardanian Dehkordi, Mohammad Ali Cheraghi, Shahzad Pashaeypoor, Sahar Khoshkesht.

Project administration: Leila Mardanian Dehkordi.

Resources: Leila Mardanian Dehkordi, Ameneh Yaghoobzadeh.

Supervision: Shahzad Pashaeypoor, Fon Sim Ong, Mohammad Ali Cheraghi.

Validation: Leila Mardanian Dehkordi, Shahzad Pashaeypoor, Fon Sim Ong.

Visualization: Leila Mardanian Dehkordi, Ameneh Yaghoobzadeh, Fon Sim Ong.

Writing—original draft: Leila Mardanian Dehkordi.

Competing Interests

The authors declared no conflict of interest.

Ethical Approval

Ethical approval was obtained from the ethics committee of Isfahan University of Medical Sciences, Isfahan, Iran (IR.MUI.REC.1402.043).

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