Original Article

# Family Caregiver Experiences in Caring for Diabetic Ulcer Patients: A Phenomenological Qualitative Study

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**Abstract**

**Background:** Diabetic ulcers are a complication of diabetes that can affect patients' self-esteem, role, physical mobility, psychology, social, economic status, and life quality. Generally, patients will also experience interference in their daily activities, which requires the help of family caregivers to improve their health status. This study explores family caregivers' experience caring for diabetic ulcer patients at home.

**Methods:** The research method used was qualitative with a descriptive phenomenological design. A total of 9 participants were recruited as research samples using a purposive sampling technique. Data were collected through in-depth interview techniques and analyzed manually using the Colaizzi Method.

**Results:** The results of data analysis showed a number of main themes related to patient care by family caregivers, namely to meet basic needs, get care support from the family, benefit the sick family, benefit the family caregiver, lack of wound care support, and no division of roles in caring for patients.

**Conclusion:** It is recommended to provide educational programs to family caregivers to improve their ability to care for diabetic ulcer patients at home.

**Keywords:** Diabetic Ulcer, Family Caregiver, Self-Care Deficit

## Introduction

Diabetic ulcers are the most common complication of diabetes mellitus (DM), with a risk of amputation and sensory nerve disorders in the extremities, which requires much money for the healing process.[1] The World Health Organization (WHO) estimates an annual increase in the number of people with DM, about 4-10% of them will suffer from diabetic ulcers[2]. Every 21 seconds, one person is diagnosed with DM, which is almost half of the adult population in America[3]. Approximately one million individuals are estimated to undergo amputationevery year, and every 30 seconds, a person with diabetes undergoes amputation due to a diabetic foot ulcer[4].

DM is the 6th leading cause of death in Indonesia[5]. The prevalence of diabetic ulcers in Indonesia is 15%, with a 30% amputation rate and a 14.8% post-amputation mortality rate[6]. Data from the Ministry of Health's Basic Health Research of the Republic of Indonesia in 2019 ranked the Aceh Province as the

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seventh-highest in the prevalence of DM nationally, after East Java. Diabetic patients with diabetic ulcers will generally experience impairment in their daily activities, interpersonal relationships, and social roles.[1]

Family caregivers play an important role in diabetic foot ulcer care to improve the health status of patients[7]. Family caregivers are directly involved in patient care at home to accelerate the healing process of wounds and infections and meet the various needs of patients with diabetic ulcers.[8] It is crucial to provide diabetic ulcer patient care according to the level of patient needs, be it total care, partial care, or only educational support[9].

Previous studies reported that the experience of family caregivers while providing care for patients with diabetic foot ulcers shows that the family's daily routine is disrupted due to care, feelings of guilt because the wound is getting worse, lack of information related to health care, anxiety related to the disease, an increase in the burden of caregiving, and lack of social support and care assistance[8] Although research related to family experiences as caregivers in caring for patients with diabetic ulcers already exists, the literature study results show that the application of good and correct care in the family that suits the care needs of patients has not been done much and still needs to be explored. This study aims to understand the experiences of family caregivers in caring for their family members with diabetic ulcers.

## Materials and Methods

This qualitative study used a phenomenological approach. The participants consisted of nine individuals selected through purposive sampling technique in one of the working areas of a community health center in one sub-district in the western part of Indonesia. The sample inclusion criteria: (1) being able to describe the experience of caring for a family member with a diabetic ulcer; (2) living in the same household with diabetic ulcer patient; and (3) having provided care for a diabetic ulcer patient for at least three months.

Data collection was carried out using in-depth interviews. The interview guide was made based on the results of a literature study focusing on the experience of family caregivers in meeting the self-care needs of patients with diabetic ulcers associated with Orem's Self-care theory. The interview guide was not structured and was open-ended. Each interview lasted 30-60 minutes. Field note documents were also used. Data was collected from the end of July to the beginning of August 2022, in the home of a diabetic ulcer sufferer, recorded with a voice recorder.

The interview data were transcribed verbatim to facilitate analysis. Data analysis used the descriptive phenomenological analysis method with Colaizzi's approach. The researchers coded the data and then created sub-themes to derive a theme. The researcher asked an external reviewer to see the theme's suitability with the data obtained.

## Results

### Characteristics of participants

All participants were female, 60% aged between 26 to 45 years, holding a bachelor's degree, and employed as civil servants. The study identified five main themes regarding the participants' experiences caring for family members with diabetic ulcers: meeting basic personal hygiene, nutrition, daily activities, social needs, and infection prevention needs.

### Meeting basic personal hygiene needs

Participants stated that fulfilling the personal hygiene needs of their sick family members was the main care need. Quotes from participants included: "*Yes, whatever it is, if she can't do it, we will still help her. Changing her diapers, for example, changing her clothes, and wiping her body*" (Participant No. 2, age 27, female). "*Maintaining her cleanliness*" (Participant No. 9, age 38, female).

### Meeting nutritional needs

Informants stated that meeting the nutritional needs of patients with diabetic ulcers was another important aspect of caring for them. Participants explained that their families fulfilled the nutritional needs of diabetic ulcer patients by providing a balanced food menu that minimized sugar and fat levels based on their experiences while caring for ulcer patients at home. Some participants stated: "*The need for food. Her drink should not contain much sugar*"

(Participant No. 2, age 50, female). "*Yes, his food is always taken care of because of diabetes. We watch the sugar and calories*" (Participant No. 7, age 26, female).

**Meeting daily activity needs**

This subtheme describes how the family meets the patient's daily activity needs by providing the necessary assistance, whether full or partial. Quotes from participants: "*Her activities have decreased. She can no longer communicate with neighbors and she spends most of their time at home in bed. People sometimes come to visit, and when asked, she will respond. At the very least, she will ask for her hair to be combed... If she can't do something, we will help her…* (Participant No. 9, age 38, female). "*We help each other out, sweeping and cleaning her house inside and out*" (Participant No. 6, age 25, female).

**Meeting social needs**

The informants stated that the family fulfills the social needs of patients with diabetic ulcers by facilitating their interaction processes. The following are the participants' statements: "*Sometimes friends are visiting. He could no longer walk far. He can only interact at close range*" (Participant No. 3, age 38, female). *She still interacts with neighbors or the environment. It's just that if she wants to go around, she has to be helped, cared for, escorted*" (Participant number 7, Age 26, female).

**Meeting infection prevention needs**

Some informants prevent infection in the patient's wounds by performing wound care. The participants' statements as follow: "*I clean the wound twice a day and make sure it doesn't get dirty... For treatment, the wound is routinely cleaned every two days. After cleaning, the wound is bandaged every two days*" (Participant No. 1, age 32, female). "*Usually, when treating mother, we change the bandages and clean the wound*" (Participant No. 3, age 38, female). "*We clean the wound twice a day to prevent it from getting dirty and infected*" (Participant No. 6, age 25, female).

## Discussion

This study aims to explore the experiences of family caregivers in providing care for patients with diabetic ulcers receiving treatment at home. It has been reported that family caregivers should ensure proper nutrition, check regular blood glucose level, facilitate patient interaction with environment, prevent wound infections, and monitor patient activities [10]. Personal hygiene is crucial for diabetic ulcer patients to maintain their quality of life despite living with the condition[1].

The finding of this study suggests that a combination of full and partial assistanceis needed for patients with diabetic ulcers. When meeting the patients' personal hygiene needs, total assistance is provided for those completely bedridden due to physical weakness. In such cases, family members directly assist patients with bathing in bed, changing diapers, changing clothes, and combing the patient's hair. Other participants provide partial assistance, allowing ulcer patients to maintain some degree of independence in their personal hygiene routines and offering help only when needed. The self-care of diabetic ulcer patients is tailored to their specific needs to improve their overall health and well-being[11].

Meeting the patients' nutritional needs is also one of the family experiences when caring for diabetic ulcer patients. Families provided the nutritional needs of diabetic ulcer patients by providing low sugar and low fat foods. Food composition for diabetes mellitus patients should include 50-55% carbohydrates, 25-30% fat, and 20% protein[12]. Family support is needed to keep motivating patients always to maintain the nutrients consumed[7].

The cause of foot ulcers in patients with non-healing diabetic ulcers can be poor food management and hyperglycemia conditions (high blood glucose levels), which result in nerve damage leading to loss of pain sensation, dry skin, muscle weakness, and even tissue death[13]. A good weekly dietary regimen can improve the body's metabolic control, which in turn influences the progression of wound healing[12].

Additionally, research participants revealed that activity needs are among the things that need to be met in patients with diabetic ulcers. Families assist patients according to the level of assistance needed, whether total, partial, or just assistance[9]. When it comes to meeting the needs of daily activities, families try to help with necessary tasks such as combing hair, changing diapers, changing clothes, bathing, and helping with all other daily activities of patients with ulcers.

Diabetes management includes managing diet, physical activity, and controlling blood glucose levels.[14] Diabetic patients sometimes rarely self-monitor their blood glucose levels and have low physical activity; patients often have a strict diet that is not regular, which has an impact on complications due to diabetes[14]. Family support plays an important role in reducing various obstacles to physical activity, family support can generate and trigger positive energy in doing daily physical activity well [15]. With the support provided and routine health care, the quality of the patient's health is increasing[7].

The results of this study also reveal the importance of the need for social interaction of patients with diabetic ulcers with their environment. For patients with total care needs, their need for interaction decreases slightly due to their weak and bedridden condition. Families need to facilitate and help patients so they can still interact with their environment. For example, when family or guests visit, they can talk or invite patients to remain enthusiastic about facing their illness and emphasize that the family will always be there when the patient needs it. Social interaction and support from family, friends, and partners are important components of diabetic ulcer management. Patients feel there is still a place to share their worries and get motivation from the interaction process[16]. Social interaction is crucial in reducing loneliness and can improve the quality of life of the elderly with chronic diseases[1].

Meeting the infection prevention needs is also a concern for family caregivers in this study. Families prevent infections by cleaning wounds and changing bandages at healthcare centers and home care. Patients with diabetic ulcers treated by healthcare teams have a much higher healing rate and avoid amputation than those not treated by healthcare teams[17]. The significant reduction in amputation rates makes treatment with a healthcare team more recommended to improve patients' quality of life with diabetic ulcers[18]. Families stated that their experience in preventing wound infection is by cleaning the wound independently and changing the bandage every two days at home as taught by the nurse. Self-wound care can be done independently by the family, positively affecting care and motivation in healing the disease[19]. However, improper self-care by the family will result in an increased risk of infection, decreased ability to do activities, a longer healing process, and even amputation [19]. Family caregivers need to understand how to properly care for diabetic ulcer patients to support the healing process, prevent and inhibit the growth of germs/ bacteria in the wound. Maximizing wound care can improve patients' activities and social interactions during their illness.

**Research Limitations**

The results of this qualitative study cannot be generalized as a general condition that occurs in the province of Aceh related to the experience of family caregivers' experience caring for diabetic ulcer patients at home, so further research is needed regarding this research.

**Conclusionand Recomendation**

The experience of family caregivers in caring for patients with diabetic ulcers includes meeting patients' basic needs, namely personal hygiene needs, nutritional needs, daily activity needs, social interaction needs, and wound infection prevention needs while at home.Especially community nurses, can further increase their attention to family caregivers' experience caring for diabetic ulcer patients at home.

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**Ethical Considerations**

Ethical recommendation for the study was obtained from the Research Ethics Commission of the Faculty of Nursing, Universitas Syiah Kuala, with license number 1120172805522. All participants provided their written consents for participation in the study.

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**Conflict of Interest:** None

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