

Original Article

An Exploration Into the Challenges of Self-care Practice Among Diabetic Amputation Patients: A Phenomenological Study

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Article history:

Received: March 9, 2025

Revised: April 8, 2025

Accepted: April 15, 2025

ePublished: April 29, 2025

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Abstract

Background: Diabetic amputee patients require lifelong care and maintenance services, making self-care a particularly important aspect for these patients. Unfortunately, the realization of this concept faces challenges that require more attention. This study explored the challenges of self-care practice among diabetic amputation patients.

Methods: This qualitative study was conducted with a Husserl's descriptive phenomenological approach. The required data were collected at the Besat hospital in Hamadan, Iran, from August to October 2022. Semi-structured interviews were purposively conducted with 10 female and 7 male participants between the ages of 41–73. Eventually, the data were analyzed by Colaizzi's method.

Results: Four themes and fifteen sub-themes were extracted from the obtained data. The themes included the limiting nature of the disease, biological dependency, lack of a dedicated self-care model, and inhibiting psychological stresses. The sub-themes of the first theme were inhibiting movement limitations, need for vital care, phantom pain, risk of dangerous complications, and exhausting dietary restrictions. Those of biological dependency included the need for direct care, inability to assess one's own needs, and importance of diet and medication. In addition, sub-themes related to the lack of a dedicated self-care model were lack of awareness, lack of self-care knowledge, and not being taught self-care methods in specific situations. The sub-themes of the fourth theme encompassed depression, despair, loss of motivation, and negative self-perception.

Conclusion: By elucidating the various aspects of self-care challenges in diabetic amputee patients, it is possible to suggest necessary planning and successful self-care education to reduce the complications faced by patients, their families, and society.

Keywords: Self-care, Amputation, Diabetes, Qualitative research



Please cite this article as follows: Zare F, Imani B, Mostafayi M, Zandi S. An exploration into the challenges of self-care practice among diabetic amputation patients: a phenomenological study. *Avicenna J Care Health Oper Room*. 2025;3(1):27-34. doi:10.34172/ajchor.85

Introduction

Diabetes is characterized by chronic hyperglycemia resulting from disturbances in carbohydrate, protein, and fat metabolism. More than 422 million people worldwide have diabetes, and one in eleven suffers from this disease (1,2). The results of a national survey in Iran indicate that approximately 11% (4.5 million people) of the Iranian adult population have diabetes, and it is estimated that about 2.9 million Iranians will develop diabetes by 2030 (3). Individuals with diabetes often lose their lives due to complications of the disease, including cardiovascular diseases, neuropathy, and high blood pressure. About one-fourth of diabetes-related deaths are due to these

complications, and diabetes contributes to 91% of lower limb amputations (4,5). In diabetic patients, the effective performance of self-care behaviors is crucial for disease control, prevention of long-term complications, and improvement of patients' quality of life (6,7). Self-care is a key concept in promoting health, referring to a set of decisions and activities that an individual would employ to cope with health-related challenges or improve their health (8). Self-care in diabetes includes proper and timely insulin injection, adherence to diet, regular physical activity, recognition of symptoms of high or low blood sugar, regular medication use, foot care, and overall well-being improvement (9). However, the results



of some studies demonstrate that self-care in diabetic patients is not satisfactory, and patients have limited self-care abilities (10,11).

Any shortcomings in self-care behaviors lead to increased complications in individuals with diabetes, and providing optimal self-care behaviors reduces the risk of cardiovascular complications, which are responsible for 70%–80% of deaths in these patients. Furthermore, the lack of self-care behaviors is a significant factor in mortality in diabetic patients (11,12).

Chronic diseases, such as diabetes, affect all aspects of the economic, financial, social, and emotional aspects of individuals, families, and society (13). Therefore, the recognition of problems, anxiety, and self-care challenges in this group of patients can be a priority in the present era. Although a variety of research has been conducted in our country, there is no qualitative research method for self-care in this group of patients. According to mentioned cases, it is necessary to study self-care challenges in diabetic patients by performing a qualitative study. More understanding of self-care behaviors in this group of patients can be an important and effective step toward improving health, symptoms, and disease symptoms and enhancing their quality of life.

This study aims to clarify the relevant concepts by examining patients' experiences, which is undoubtedly essential for various health professionals to understand these experiences to investigate moments when a patient experiences a lapse in self-care. Accordingly, the present study seeks to elucidate the challenges of self-care practice among diabetic amputation patients.

Materials and Methods

Design

The present study was conducted using Husserl's descriptive phenomenology approach to explore the experiences related to challenges of self-care practice among diabetic amputation patients in the Besat hospital in Hamadan, from August to October 2022. This method aims to awaken us to the fact that phenomena do not have an independent existence outside of humans. In such a system, specific phenomena are described and explained based on the experiences of the subjects under consideration, and in the process, the focus is on describing what people express to discover new phenomena (14). Husserl's phenomenological system seeks to make us aware of the "essence" of phenomena (15). This method was chosen in this research to reveal the experiences of self-care challenges among patients with diabetic amputation in Iran.

Participants

The participants of the present study were patients with diabetic amputation in Besat hospital (Hamadan) who were purposefully selected by the researcher through a face-to-face meeting.

The inclusion criteria were showing interest in

participating in the research and expressing their experiences, being >18 years old, suffering from no confirmed psychiatric illness, having the ability to speak, and having diabetes with a history of at least two months of amputation. Furthermore, individuals were excluded from the study based on some conditions, including the inability to effectively convey their experiences, refusal to answer the interviewer's questions, and unwillingness to continue participation.

The sampling process and determination of the number of samples continued until theoretical saturation was achieved, implying that no new information about the patients' lived experiences was obtained. In the present study, interviews were conducted with 14 male and female patients suffering from diabetic amputation, and provided responses did not add any new information to the data. Thus, to ensure the data saturation process, interviews were conducted with three more individuals, and data analysis was performed on 17 participants (Table 1).

Data Collection

Every interview was conducted in accordance with the explanation of the study's purpose, which was to characterize the phenomena of self-care difficulties experienced by patients with diabetes amputation. The one-on-one in-depth interview was performed with consent, and the data were published without any personally identifiable information. The interview consisted of closed-ended demographic questions in the first part and open-ended questions on the research goal in the second, with additional questions arising from the interviewer-patient exchange. Experiences and difficulties with self-care among individuals with diabetes amputation were among the issues covered in the questions.

Table 1. Demographic Characteristics

Participant	Gender	Age	Education Level	History of Diabetes (y)	Duration Amputation
P1	Female	71	Illiterate	13	7 Months
P2	Female	73	Illiterate	16	2 Years
P3	Female	62	Elementary	5	2 Months
P4	Female	65	Illiterate	10	9 Months
P5	Female	56	Elementary	25	3 Years
P6	Male	50	Middle School	6	1 Year
P7	Male	57	Elementary	11	1.5 Years
P8	Female	68	Illiterate	20	7 Months
P9	Female	50	Elementary	20	2 Months
P10	Male	53	Diploma	12	3 Years
P11	Male	67	Illiterate	10	1 Year
P12	Male	59	Elementary	7	1 Year
P13	Female	70	Illiterate	26	3 Months
P14	Male	57	Middle School	12	1 Year
P15	Male	64	Illiterate	10	7 Months
P16	Female	41	Diploma	8	2 Years
P17	Female	55	Middle School	15	2 Months

The interviews began with an unstructured question (*How do you define self-care?*) and progressed with semi-structured questions. An interview guide was constructed before the interview to guarantee the collection of relevant information (Table 2). The duration of each interview varied depending on the interviewee's condition and the patient's need for caregivers. The minimum and maximum times of the interview were 35 minutes and 55 minutes, respectively. Three interviews were repeated due to the need to clarify the obtained information. The first author, who had prior experience in qualitative research and interviews, conducted all interviews. Thirteen interviews were recorded with the participants' consent using a tape recorder. However, four interviews were written down due to participants' preferences. The interviews continued until the theoretical saturation of the data.

Data Analysis

Colaizzi's data analysis method was applied to comprehend self-care difficulties among amputation patients. Colaizzi maintained that to extract phenomenological knowledge, researchers should convey data by Husserl's philosophy (16). The first author completed all the interviews and transcribed them verbatim 48 hours after finishing them. The writers preserved field notes for future contemplation. The three authors (F.Z., S.H.Z., and B.I.) regularly and carefully read the transcripts to get a sense of the entire content and extracted significant statements. In addition, they formulated meaningful sentences and meanings. Then, the researchers analyzed and synthesized common characteristics to form categories and clusters of themes and organize similar conceptual themes to establish themes. Furthermore, they integrated the findings into an exhaustive description of the phenomenon being researched and established the fundamental structure of the phenomenon. Finally, they presented the findings to the participants for confirmation. To understand the core of the patients' reported self-care experiences with diabetes amputation, the researchers read the interview transcripts several times to investigate any hidden implications

Rigor/Trustworthiness

For the study's rigor, the Guba and Lincoln criteria were used for credibility, confirmability, dependability, and transferability (14,17). By consistently interacting with

the data, bracketing opinions on the subject, and having the participants, research team and two faculty members outside the research team verified the data, attaining credibility and confirmability. There was extensive agreement in the judgments of the two study team members who coded the interviews to establish dependability. Additionally, great attention was paid to gathering, implementing, and documenting data, as well as setting out enough time for data collection. The information was examined and validated for transferability by two faculty members who were not part of the research team and by specialists in qualitative research.

Results

Interviews with patients suffering from diabetic foot amputations were conducted at the Besat hospital from August to October 2022. Overall, 17 participants were interviewed, including 10 women and 7 men (Table 1). As a result of the analysis, 305 primary codes were obtained, which were divided into 4 main categories. They included the limiting nature of the disease, biological dependency, lack of a personalized self-care pattern, and unrecognized psychological stressors, along with 15 subcategories (Table 3).

Limiting Nature of the Disease

Data analysis revealed that patients with diabetic amputation have experienced the limiting nature of the disease, confirming that the disease has caused limitations in their nutrition, activities, and normal life patterns. The patients described being affected by the complications of the disease and feeling as if they were awaiting death. Within the main category of the limiting nature of the disease, there were five subcategories, including inhibiting mobility constraints, the need to receive vital care, phantom pains, the likelihood of dangerous accompanying complications, and exhausting dietary restrictions.

Table 3. Themes and Sub-Themes

Theme	Sub-Theme
The limiting nature of the disease	Restrictive mobility limitations
	Need for intensive care
	Phantom pain
	Risky accompanying complications
	Exhausting dietary restrictions
Biological dependency	The need for direct care
	Inability to assess personal needs
	Importance of diet and medication
Lack of a personalized self-care pattern	Lack of awareness
	Lack of self-care knowledge
	Lack of teaching self-care methods in specific situations
Unrecognized psychological stressors	Depression
	Despair
	Loss of motivation
	Negative self-perception

Table 2. Interview Questions

1	How do you define self-care?
2	What is your experience of your problems and challenges when taking care of yourself due to diabetic foot amputation? Explain.
3	Has leg amputation made any changes in your life? If so, how have you dealt with it?
4	To what extent do you think self-care helped you cope with your disability?
5	Do you share the feelings you experienced as a diabetic patient?

Restrictive Mobility Limitations

The participants' experiences indicated the presence of this concern in patients, making their lives difficult and causing serious complications in these patients. One 56-year-old participant states:

"... It's been almost two years since they amputated my foot. During this time, I've spent many hours lying in bed and I can't sit up, let alone sit on a wheelchair, or walk with a cane, and I even developed bedsores due to excessive immobility..." (P5).

Need for Intensive Care

Patients expressed their concerns about receiving intensive care to prevent disease progression. Patients described limitations in eating, drinking, and using the restroom. One patient mentioned that:

"...I must take care of myself in every aspect, including taking my medications on time, and sweets are forbidden. I also have to change my wound dressing three or four times a day. Following all these rules is challenging and exhausting for me..." (P4).

Phantom Pain

Content analysis of the data showed that patients endure phantom pain during their illness. One of the patients stated:

"...After a while since my leg was amputated, I felt pain in the tip of my toe, even though it was amputated above the knee. I also have a tingling sensation in this area..." (P3).

Risky Accompanying Complications

Based on the experiences of participants, this disease leads to dangerous complications. They reported that they become fatigued and sweat heavily due to an imbalance in blood sugar levels. One patient described it as follows:

"...When my blood sugar goes up, I get cold sweats, and my whole body sweats, causing my entire bed to become soaked in water. When my blood sugar drops, I experience extreme fatigue and weakness. I used to be very overweight, but insulin caused me to lose too much weight, and I lost a lot of weight..." (P1).

Exhausting Dietary Restrictions

One of the care points that are important for self-care in these patients is the need to observe exhausting dietary restrictions to control blood sugar levels:

"...One of the things that was difficult for me to observe was to refrain from drinking cold water, but not observing this issue caused my foot infection to worsen, and my illness became more severe..." (P9).

Biological Dependency

Patients with diabetic amputation have developed a biological dependency due to their specific conditions and unstable clinical status. In this main category, there were three subcategories, including the need for direct care, the inability to meet their own needs, and the importance of diet and medication.

The Need for Direct Care

Patients with special conditions require focused attention to help them cope with their limitations through social support. The family members, as the closest individuals to the patient, play a crucial role in caring for these patients and improving their well-being:

"...I need the help of my family for the smallest personal tasks. There always has to be someone looking after me; for example, when I get cold sweats, they change my clothes and check my blood sugar twice a day..." (P10).

Inability to Assess Personal Needs

Patients with diabetic amputation lack the ability to meet their own needs and express concern about the pain and difficulties faced due to the severe consequences of the disease:

"...Before my foot was amputated, I used to slowly get up and walk with a cane. I would cook, do the dishes, but now I can't do anything, not even drink a glass of water, and I don't have the ability to go to the bathroom..." (P4).

Importance of Diet and Medication

Due to insulin injections and the use of specific medications, and the wide range of interactions between these medications and their diet, the patients must adhere to the prescribed dietary regimen to take care of themselves and prevent undesirable incidents:

"...I tried to follow my diet. I didn't eat fried foods, sweets, or pasta. I always took my insulin regularly and on time. All fruits have sugar, but I ate them in small amounts. I couldn't stand hunger, so I ate food, but in small quantities. I consumed a lot of vegetables..." (P4).

Lack of a Personalized Self-care Pattern

The occurrence of self-care in patients requires education and familiarity with self-care methods. Accordingly, patients should possess the ability to learn to grasp self-care tips. This main category included the subcategories of lack of awareness, lack of self-care knowledge, and lack of teaching self-care methods for specific circumstances.

Lack of Awareness

Patients who undergo diabetic foot amputation naturally face a series of limitations and difficulties. Therefore, it is necessary for the patient to become aware of these events at the beginning of the surgery so that they can prepare themselves to confront these occurrences:

"...When my foot was injured, I hid it from my family, wore socks, and lied to them that I had been hit. At first, my wound was minor, but due to the lack of taking care of it and lacking the necessary awareness, I ended up in the hospital and was hospitalized..." (P16).

Lack of Self-care Knowledge

Based on the interviews conducted with the patients, it can be understood that a lack of self-care knowledge can have severe physical and psychological consequences for

the patient. One of the patients expressed:

"...When I developed a diabetic foot ulcer, I continued to walk on it, and after some time, I realized that the wound had expanded, and the doctor said that I needed surgery as soon as possible, otherwise, the infection would worsen, and more parts of my foot would be removed..." (P17).

Lack of Teaching Self-care Methods in Specific Situations

The interviewees stated that healthcare staff lacked the ability to make logical decisions regarding patient care and were not provided with the necessary education on clinical conditions and self-care for these individuals.

"...On April 6th, they removed my ankle, and on April 7th, they discharged me. My daughter told the staff, 'My mother has just had a surgery, where should we take her?' I did not sleep all night because of pain and was constantly crying. They said, 'she takes antibiotics and analgesics here, and she will receive the same medications for home care'. However, when they took me home, they only gave me painkillers and anticoagulants rather than antibiotics. They told me to come back after two weeks to remove the stitches. They provided no instructions on how to care for my wound. During these two weeks, I referred to the emergency room four or five times because blood and pus were coming out of my wound..." (P4).

Unrecognized Psychological Stressors

The mental health of these patients can be severely affected by this disease. This main category includes subcategories of depression, despair, loss of motivation, and negative self-perception.

Depression

Inability to cope and manage the current situation can create a condition for depression in the patient, which stems from fatigue and increased psychological pressure. Therefore, proper recognition of depression symptoms and timely treatment can improve the quality of life of these patients.

"... Since my amputation, I've become severely depressed. I quickly become angry, cry over the smallest issues, and have become impatient and sensitive about everything. Sometimes, I don't even talk to anyone and sleep for long hours just to pass the time..." (P6).

Despair

The experiences of these patients show that diabetic foot amputations are followed by a detrimental sense of despair, causing them to become disheartened with their lives and think that their goals and aspirations have faded away. They feel as if they have reached the end of the line and everything is over for them.

"... During this time, I experienced too much psychological pressure. I kept thinking that I wouldn't survive if I underwent a surgery. I'm tired of the hospital environment; the air here suffocates me. I know I won't

get better; they just want to cut me to pieces..." (P4).

Loss of Motivation

There are many reasons for losing motivation. One reason for these patients' loss of motivation may be despair from the recovery process and social rejection.

"Your blood sugar keeps fluctuating, and it gets on your nerves. You keep saying, I've been following all the rules as much as I could, so why does it have to be high?" (P2).

Negative Self-Perception

Negative self-perception is an unpleasant experience that diabetic patients encounter after diabetic foot amputation. It can lead to depression and a lack of motivation to continue living among these patients.

"... During the past two weeks, I referred to the emergency room four or five times due to a foul smell and blood coming from my wound. I was so disgusted with myself; it felt like I was just a piece of meat falling in the hospital..." (P4).

Discussion

This study investigated the challenges of self-care practice among diabetic amputation patients. Based on the results, numerous factors were identified, each of which has posed a challenge and obstacle to the self-care of this disease. Following the analyses, the patients' self-care challenges were grouped into four main themes; including disease-limiting nature, biological dependence, lack of a specific self-care model, and inhibiting psychological stressors, each composed of multiple sub-themes.

The disease-limiting nature was identified as the first main category of self-care challenges faced by patients with diabetic amputations. Mobility restriction is one of the most important sub-themes of this phenomenon. In this regard, de Oliveira et al pointed out that the physical activity of patients is affected after lower-extremity amputations, resulting in disability (18). According to the results of this study, one of the limiting issues of the disease was the need for vital care. Isaacs-Itua and Sedki reported that patients with amputations require vital care, such as regular physiotherapy sessions, appropriate rehabilitation, and the use of compression stockings, to reduce swelling of the amputated limb and prepare it for prosthesis use (19). Another issue related to the disease-limiting nature was the phantom pain endured by these patients. Culp and Abdi concluded that phantom pain is one of the barriers to physical activity in diabetic patients (20). The findings of this study also revealed that another self-care challenge for patients with diabetic amputations was the occurrence of dangerous complications, which conforms to the findings of Sun et al, demonstrating that patients suffer from complications related to diabetic foot, such as neuropathy, burning sensation, numbness, nocturnal foot pain, and changes in the appearance of the diabetic foot (21). Adherence to a strenuous diet was another sub-theme of the disease-limiting nature.

Wang et al found that dietary intervention is a strategy for managing diabetes, which can improve blood sugar levels, lipid profiles, and cognitive status in patients. In China, a low-fat diet is mainly recommended to help improve blood sugar levels in diabetic patients, indicating the adherence to a difficult and strenuous diet in these patients (22).

Some studies have proven that excessive consumption of fatty acids, saturated fats, carbohydrates, excessive sugar and sweets, carbonated beverages, weight gain and obesity, reduced intake of fruits and vegetables, and micronutrient deficiencies have a negative impact on diabetes control and decrease the quality of blood sugar control (22,23). Another main theme identified in this study was biological dependence. This phenomenon manifests itself in these patients as the need for direct care, inability to meet their own needs, and the importance of dietary and medicinal regimens. Molla et al showed that amputation was associated with increased dependence, and patients were concerned about being a burden on their relatives (24). Similarly, Meiliana et al reported that diabetic patients have concerns such as becoming dependent on others, inability to walk, the unsightly appearance of diabetic wounds, and increased treatment costs (25). In this regard, some studies have expressed concerns about increased dependence after amputation (26,27). The importance of diet was another self-care challenge mentioned by patients. Nutrition is one of the critical factors in diabetes control. Diet can significantly impact blood sugar, body sensitivity to insulin, and glucose consumption (28). In fact, healthy nutrition is the most important and perhaps the most fundamental way to achieve a healthy body, and the role that self-care plays in maintaining patients' health makes them consider self-care highly important (29).

Another self-care challenge for these patients was the lack of a specific self-care model, which they experienced due to a lack of awareness, self-care knowledge, and lack of instructions on how to care for themselves in specific situations. Generally, according to the participants, self-care practices are ineffective because the lack of a proper self-care plan leads to the strong association of these patients with other family members, so they attempt to improve their personal life quality because their attempts to improve self-care will have desirable results. Therefore, it is necessary to inform the patient and provide nurses and family members with appropriate training regarding planning for self-care and improving their conditions.

Awareness is one of the essential dimensions of health. Good awareness allows patients and those at risk to perform early interventions and prevent many disease complications by making simple lifestyle changes, including increasing physical activity, controlling diet, and practicing proper self-care methods (30). Bonner et al found that diabetic foot ulcers were associated with poor foot-care knowledge (10). A review of studies indicates that educating people with diabetes about foot care leads

to improved self-care knowledge (11).

Based on the lived experiences of these patients, psychological stressors act as inhibitors and constitute another phenomenon in this study. This phenomenon manifests in patients as depression, hopelessness, loss of motivation, and negative self-perception. The results of the study performed by Sopjani et al revealed that the prevalence of depression in diabetic patients in Kosovo was 66.5% (31). According to the lived experiences of patients, depression decreases treatment adherence. In this regard, the findings of Al-Ozair et al demonstrated that depression could decrease self-care behaviors and consequently the occurrence of diabetic complications (32). Diabetic amputee patients also reported that adapting to their new lifestyle has disheartened them, and they no longer have hope or motivation to continue living, a phenomenon referred to in the study by Tachkov et al (33). Negative self-perception was another self-care challenge experienced by these patients. A Danish national clinical guideline on limb amputation recommends peer support, as it may have a beneficial impact on patients' psychological adaptation following amputation (34).

In this study, through interviews with the researchers, patients shared their experiences and challenges of self-care practice after amputation, acknowledging improvements of their self-care levels.

The limitations of this study included the patients' poor psychological and emotional conditions and their reluctance to speak due to the specific nature of their illness. However, the researchers attempted to establish effective communication and gain the patients' trust to encourage their collaboration. The employment of just one research method—interviews—was another drawback of this study. Therefore, future research should focus on a number of instruments, such as surveys, which might be helpful for gaining broader insights.

Conclusion

The results of the research in response to the research question "*What are the perceptions of diabetic amputation patients about the challenges of self-care?*" revealed that self-care in diabetic amputation patients is dependent on their background and level of knowledge and can be different based on the stages and severity of the disease. The complications of the disease and the lack of a tangible educational program for self-care were identified as the most important concerns of this group of patients. Therefore, it is recommended that the families of these patients and the treatment staff provide comprehensive and complete training (e.g., pamphlet and use of social media) regarding the self-care of these people so that the patients' self-care problems can be reduced as much as possible through an efficient management approach. It is also necessary to encourage patients to exercise by using assistive devices, such as wheelchairs and artificial prostheses, to maintain balance and prevent complications caused by fluctuations in blood sugar levels. The results of

this study can provide the basis for further research on the self-care challenges of diabetic amputation patients in order to provide effective solutions to improve their quality of life.

Acknowledgments

The authors would like to express their gratitude to everyone who took part in this study and offered their insightful perspectives.

Authors' Contribution

Conceptualization: Shirdel Zandi, Fatemeh Zare, Behzad Imani, Mehrnush Mostafayi.

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Competing Interests

There is no potential conflict of interests related to the research, authorship, or publishing of this paper, as stated by the authors.

Ethical Approval

The current study was authorized by Hamadan University of Medical Sciences in 2022 (under ethical No. IR.UMSHA.REC.1401.273). The researcher provided the patients with a brief introduction and informed them of their background, current role, and areas of interest before starting the interview. Moreover, they were assured of data confidentiality. All participants gave their consent after being informed of the study's goal.

Funding

The study was funded by the Vice-Chancellor for Research and Technology, Hamadan University of Medical Sciences (No. 140105043185; <https://research.umsa.ac.ir>).

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