



Original research

# Family Experiences in Caring for a Stroke Patient with Decubitus Ulcer at Home

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## Abstract

**Background:** The role of the family in caring for stroke patients with decubitus ulcers involves assisting with daily needs such as nutrition, elimination, personal hygiene, and mobilization. Caring for a stroke patient with decubitus ulcers places significant burdens on the family, impacting their physical, social, psychological, and financial well-being.

**Objective:** To gain a deep understanding of the family's experience in caring for a stroke patient with decubitus ulcers at home.

**Methods:** This research employs a qualitative design with a phenomenological study approach. Participants were selected using a purposive sampling technique. The study included 8 participants who had a family member with a stroke and decubitus ulcers being treated at home. Data were collected through semi-structured interviews, using audio recorders and field notes. The data were analyzed using the Collaizi method.

**Results:** The analysis revealed three themes: a) Physical, psychological, social, and financial barriers experienced by caregivers while caring for stroke patients with decubitus ulcers; b) The role of family caregivers in meeting basic needs: nutrition, personal hygiene, elimination, and mobilization; c) The type of treatment chosen by the caregiver based on the family's financial condition.

**Conclusion:** Family members play a crucial role in helping meet the basic needs of stroke patients with decubitus ulcers. However, they also face significant obstacles, including physical, psychological, and financial challenges. These obstacles influence the type of treatment families choose for the patients.

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## Background

Patients with stroke who experience prolonged bed rest are at higher risk of developing decubitus ulcers caused by prolonged pressure on bony prominences, leading to decreased blood circulation in the compressed area. This condition results in hypoxia, ischemia, and necrosis of the tissues in that area, ultimately causing decubitus ulcers (Elmawati, 2019). If decubitus ulcers are left untreated for too long, they can become deeper and lead to infections (Amirsyah et al., 2020; Faridah et al., 2019).

World Health Organization (WHO) data report a global incidence of 21% or approximately 8.50 million cases of decubitus ulcers. The percentage of decubitus ulcer incidents is 5-11% in acute care settings, 15-25% in long-term care settings, and 7-12% in home health care settings (WHO, 2018).

According to data from the Indonesian Ministry of Health in 2017, the incidence of decubitus ulcers in Indonesia reached 33.3%, which is relatively high compared to the prevalence of decubitus ulcers in Southeast Asia, ranging from 2.1% to 31.3% (Ministry of Health RI, 2018). Based on a preliminary study conducted in the stroke unit in Bengkulu, Indonesia the incidence of stroke in 2019 was 312 patients, in 2020 there were 257 stroke patients, in 2021 there were 265 patients, and in 2022 there were 260 patients.

The condition of stroke patients experiencing disabilities can lead to the occurrence of decubitus ulcers because the patient is confined to bed and unable to perform activities independently, requiring family members to play a role in managing and caring for the patient properly (Choliq et al., 2020; Kavga et al., 2021). The family's role in caring for post-stroke patients with decubitus ulcers at home can be carried out by assisting in fulfilling daily needs such as nutrition (eating, drinking), elimination (urination, defecation), and personal hygiene. Additionally, the family helps with mobilization by positioning the patient semi-upright and turning them to the right and left every 2 hours, maintaining skin cleanliness and moisture, providing care for the decubitus ulcers, caring for bed linens, and providing motivation and encouragement in the treatment process (Rahmadani & Chayati, 2023; Nina Widyasari, 2021).

The family's role can impose a significant burden and impact the physical, social, psychological, and financial conditions of the family (Maulidah, 2017; Sari, 2017). Kadarwati et al.'s study (2019) on the experiences of families caring for stroke patients found difficulties, limited information, and a lack of knowledge regarding how to care for stroke patients at home. These difficulties lead to changes in physical condition, rest and sleep patterns, psychological state, social activities, economic status, and challenges in assisting with the patient's Activities of Daily Living (ADL) (Kadarwati et al., 2019). This aligns with the research by Alifudin & Ediati (2019) on the experience of wives as caregivers in caring for husbands who suffer from a stroke. The study found changes in the roles experienced by participants, requiring time for adjustment and resulting in both positive and negative behaviors (Alifudin & Ediati, 2019).

Positive behaviors include participants being willing to care for the patient, help meet the patient's needs, and seek information related to the treatment of their husband's illness from healthcare professionals. Meanwhile, negative behaviors involve occasional feelings of fatigue and complaints while caring for a post-stroke patient. This is caused by communication constraints, multiple roles such as dividing time between caring for the husband and taking care of children, and a lack of sleep, resulting in decreased physical well-being (Alifudin & Ediati, 2019). It was found that the family's role in caring for stroke patients can lead to problems in psychological, social, economic, and physical conditions. Therefore, the author is interested in conducting this research with the aim of exploring information from families regarding their experiences in caring for stroke patients with decubitus ulcers at home.

## **Method**

### **Study design**

This study employs a qualitative research method with a phenomenological study approach. The research focuses on exploring the experiences of families caring for stroke patients with decubitus ulcers.

### **Setting**

The study was conducted in the working area of 4 Community Health Centers in the city of Bengkulu, Indonesia.

### **Sample/participants**

Participants in this study were primary caregivers (spouse, child, son/daughter-in-law, sibling) using maximum variation sampling who selected using purposive sampling technique with the inclusion criteria: participants aged >18 years, and caring for stroke patients with decubitus ulcers. The total number of participants in this study was 8 individuals, determined based on data saturation, meaning no new themes were found after analysis.

The participant data collection process was initiated by the researcher by obtaining research permission directed to the Bengkulu City Unity and Politics Agency, then the letter was forwarded to the Bengkulu City Health Office, and after receiving recommendation letters from both institutions, the researcher submitted the letter to the designated community health centers based on the highest stroke prevalence in Bengkulu city, namely in four community health center areas in Bengkulu city. Subsequently, the researcher created relevant health medical records to obtain participant addresses and

scheduled meetings with respondents directly to verify whether they met the criteria set by the researcher.

**Data collection**

Data was collected using a semi-structured interview guide, audio recorder, and field notes. Before the interviews, during the first meeting, the researcher obtained consent from the participants to participate in this study. Subsequently, the second meeting involved the actual interviews, which took place at the participants' homes and lasted an average of 30 minutes per session. The interviews were conducted in local dialects (Bengkulu language). To ensure the validity of the research data, the researcher transcribed the interview results and sent them to the participants for verification, confirming whether the transcripts accurately represented their statements. The interview transcripts were translated from the local Bengkulu language into Indonesia language. The subsequent stages involved coding, sub-themes, and themes, which were performed collaboratively by two researchers. The final stage of data analysis included interpreting the research results and compiling the report.

The main questions which were delivered to participants including:

- a. How did you care for your family member who experienced decubitus ulcers?
- b. How did your feeling during taking care of your family member who experienced decubitus ulcers?
- c. What were your burdens or challenges during taking care of your family member who experienced decubitus ulcers?
- d. What changes have you noticed while caring for your family member with decubitus ulcers?

**Data analysis**

Data analysis in this study uses the *Collaizi* method with 7 steps, namely 1) each transcript is read and reread to get a general idea of all its content, 2) significant statements related to the phenomenon under study are extracted from transcripts, 3) formulated meanings from significant statements, 4) the organization of meaning formulated into groups of themes and subthemes, 5) integration of findings into thorough description, 6) description of fundamental structures of phenomena, 7) validation of findings from research participants. The data were analysed using Open Code software during coding process and then continue manually to determine sub theme and theme.

**Trustworthiness**

The researcher conducted member checking to ensure that the interview transcript accurately reflected the participants' statements by returning the interview transcripts to the participants. Subsequently, the researcher performed triangulation to analyze the determinants of coding, sub-themes, and research themes, as well as to interpret the research findings collaboratively with the second researcher.

**Ethical considerations**

Ethics committee approval was obtained from a university which is relevant.

**Results**

**Participant Characteristics**

The characteristics of the participants in this study are adults ranging from middle-aged to elderly, with an age range of 39-70 years old. The highest level of education is mostly elementary school, with a total of 5 participants. There are 6 female participants and 2 male participants. The majority of participants work as housewives, totaling 4 participants. Most participants have a relationship with the patient, with 4 of them being spouses. The history of caring for stroke patients ranges from 1 year to 6 years (Table 1).

**Table 1** Characteristics of Research Participants (n=8)

Participant number	Age (Years)	Gender	Education	Work	Duration of caregiving	Relationship with Patients
01	70	Female	Elementary school	Farmer	1 year	Mother
02	53	Male	Junior high school	Farmer	3 years	Child
03	61	Female	Bachelor	State officials	1,5 years	Spouse
04	68	Male	Elementary school	Entrepreneurship	3 years	Spouse
05	62	Female	Elementary school	Housewives	2 years	Spouse

06	45	Female	Elementary school	Housewives	5 years	Caregiver
07	46	Female	Elementary school	Housewives	4 years	Spouse
08	39	Female	High School	Housewives	6 years	Child

### Patient characteristics

The age of the patients in this study ranges from middle-aged to elderly, with an age range of 33-89 years, and they have a history of stroke for 1-6 years. A total of 8 patients experienced decubitus ulcers while being treated at home, with a duration ranging from 1 to 4 months. The location of decubitus ulcers experienced by the patients includes 3 in the sacral area, 1 in the sacral and heel areas, and 4 in the waist area (Table 2).

Table 2. Characteristics of Patient Participants (n=8)

Patient Initials	Age (years)	Duration of Stroke (years)	Decubitus Wounds Appear	Duration of Decubitus Ulcers	Location of Decubitus Ulcer
Mr. S	33	1	When being treated at home	3 months	Lower back
Mrs. L	85	3	When being treated at home	4 months	In the area of the sacrum
Mr. S	60	1.5	When being treated at home	3 months	In the area of the sacrum
Mrs. W	45	3	When being treated at home	2 months	Lower back
Mr. J	71	2	When being treated at home	2 months	In the area of the sacrum and heel
Mrs. M	80	5	When being treated at home	1 month	Lower back
Mr. S	50	4	When being treated at home	2 months	Lower back
Mrs. R	89	6	When being treated at home	1 month	In the area of the sacrum

### Theme of Research Analysis Results

Based on the research results and analysis conducted to form coding, sub-themes, and themes. The research results revealed three themes. The presentation of the themes arranged by the researcher is as follows:

#### The theme 1: the physical, psychological, social, and financial obstacles experienced by caregivers while caring for stroke patients with decubitus ulcers.

Theme 1, related to the physical, psychological, social, and financial obstacles experienced by caregivers while caring for stroke patients with decubitus ulcers, was derived from 4 sub-themes, namely caregiver fatigue and challenges during patient care, disrupted physical health of caregivers, mental burden and sadness when caring for patients, and difficulties in financing treatment. Based on the findings from these sub-themes, the researcher then formed the overarching theme in this study, illustrated through the following statements from the participants:

*"Sayo jugo lah capek kalau harus bolak balik karena lah tuo jugo kan pak"*

(I'm also tired of going back and forth because I'm already old, right sir) (P4: Male, 43 years old, caregiving for 3 years)

*"Nyelah ini sego tula, nerambatkan bejalan dio ni, nido teinggal dengan aku"*

(Yes, that's how difficult it is. It sometimes hinders going anywhere because can't be left alone and needs to be taken care of) (P1: Female, 70 years old, caregiving for 1 year)

*"Sedih aku tu, nido diam ndak nangis"*

(I feel sad, can't stop crying: expression of sadness with teary eyes) (P1: Female, 70 years old, caregiving for 1 year)

*"Demam demam tula, badan beghat aku tu. Amo sakit palak ndiak"*

(Fever, fever like that, my whole body feels heavy. Also, I have a headache.) (P1: Female, 70 years old, caregiving for 1 year)

*"Ini mas, karena susah kalau mau bawak kerumah sakit, samo biaya juga mas".*

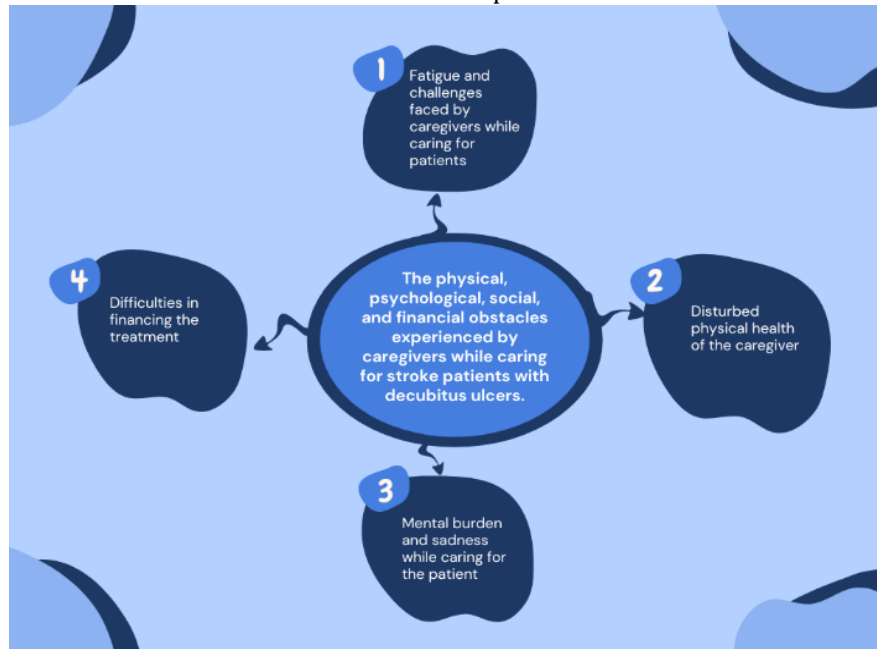
(This, sir, because it's difficult to take to the hospital, and there are also expenses) (P5: Female, 59 years old, caregiving for 2 years)

*"Ini mas, karena susah kalau mau bawak kerumah sakit, samo biaya juga mas"*

(This, sir, because it's difficult to take to the hospital, and there are also expenses.) (P5: Female, 59 years old, caregiving for 2 years)

Based on the results of the study, the formation of themes can be schematically represented in the following Figure 1:

**Figure 1.** Theme of physical, psychological, social, and financial barriers experienced by caregivers during the care of stroke patients



**Theme 2: the role of family caregivers in assisting basic needs: nutrition (eating, drinking), personal hygiene, elimination (urination, defecation), and mobilization**

Theme 2, related to the role of caregivers in assisting basic needs: nutrition, personal hygiene, elimination, and mobilization, is derived from 4 sub-themes, namely assisting in nutrition (eating, drinking), personal hygiene, elimination (urination, defecation), and mobilization, as depicted in the statements of the participants below:

*"Gosok giginyo lah disiapkan, sabun nyo lah di inak i, airnyo tu ndak air panas. Kito air dingin idak ndak dio, tekelenjiagh"*

(For toothbrushing, it's already prepared, soap too, warm water for bathing. If cold water is given, he doesn't want it; it startles him) (P3: Female, 61 years old, caregiving for 1.5 years)

*"Dituntungi dio, ado engkas tetak an botol akua tu. Awu, udim itu minta capakkah dio amo lah udim kemiah, amo aku dang dighumah ni"*

(He rinses it in an empty mineral water bottle; when he's done urinating, he asks for help to dispose of it, what else can be done.) (P1: Female, 70 years old, caregiving for 1 year)

*"Nido, anak dengan sanak ni pasiagh, aku jenguk...Ndo ka tekatang dengan aku. Cucung pasigh pulo"*

"Oh no, luckily one of the grandchildren lives nearby, so they can help with lifting) (Female, 70 years old, has been caregiving for 1 year)

*"Ditulung, digendong anak-anaknyo ni, ngumpul mandikan segalo macam itu awu"*

(Yes, he's helped, carried by her children, like bathing and all that." (P3: Female, 61 years old, caregiving for 1.5 years)

Based on the results of this study, the formation of themes schematically can be illustrated in figure 2 below:

**Figure 2.** Theme The role of family caregivers in helping basic needs: eating and drinking, personal hygiene, elimination, mobilization



**The theme 3: the type of treatment chosen by the caregiver is based on the family's financial condition**

Theme 3 types of treatment chosen by caregivers based on family financial conditions are obtained from 5 sub-themes, namely traditional medicine chosen by caregivers to treat stroke patients, medical treatment chosen by caregivers to treat stroke patients, traditional treatment chosen by caregivers for healing decubitus wounds, medical treatment is chosen by the caregiver for healing decubitus wounds, and the caregiver hopes for healing for the patient. The results of this theme are illustrated from the following participant statements:

*"Kasih ubek idak, idak ado lagi dikasih ubek kelak la lain lagi pulo penyakitnyo. Paling dikasih herbal daun-daun tu duo macam, daun kelor tu"*

(They don't give medicine, they won't give medicine later, when the disease is different. Mostly given herbal leaves, there are two kinds, like moringa leaves.) (P4: Male, 45 years old, caregiving for 3 years)

*"Udim itu balik kerumah diurut. Urut jugo, obat dokter tetap"*

(After that, we go back home, get a massage. We get a massage, still take the doctor's medicine) (P3: Male, 53 years old, caregiving for 3 years)

*"Jadi, amo kato jemo tu diujuk i bedak salisil. Itulah kamiujuk i bedak salisil tu. Ado pulo kato jemo enjuak i itu, tapo namoyo tu lidah buaya katoyo kan. Udim itu kamiujuk i pulo kekadang"*

(So, like they say, use this salicylic powder. That's what we use, salicylic powder. Sometimes they also use aloe vera, but it depends on what they say. Sometimes we use that too, occasionally) (P2: Male, 53 years old, caregiving for 3 years).

*"Sayo kasih kek minyak zaitun pas tiok udah mandi tu pak kan"*

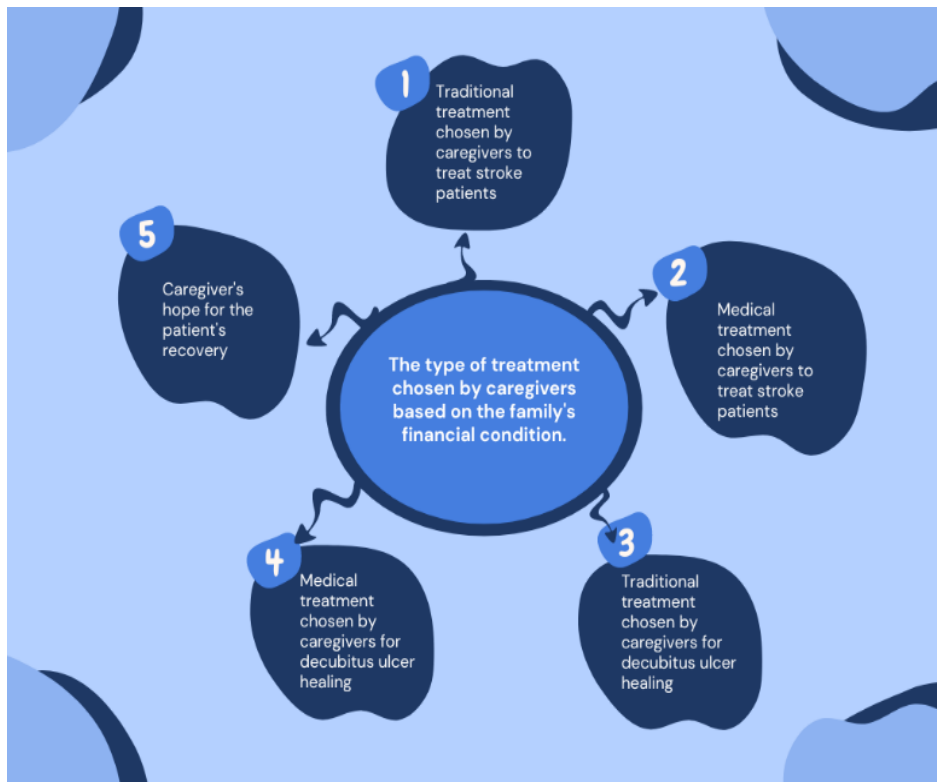
(I also give him olive oil after every bath.) (P4: Male, 43 years old, caregiving for 3 years)

*"Kami bawak i ke klinik karolus. Dienjuk o salap. Amo dio ngulang kelo ngulang batak i lagi kesituujuk obat lagi salap"*

(We took him to Karolus clinic. They applied an ointment. If it runs out, we go there again, and they apply ointment and give medicine again) (P3: Female, 61 years old, caregiving for 1.5 years)

Based on the results of this study, the formation of this theme schematically can be illustrated in figure 3 below:

Figure 3. Theme Type of treatment chosen by caregiver based on the family's financial condition



## Discussion

*Physical, psychological, social, and financial obstacles experienced by caregivers while caring for stroke patients with decubitus ulcers*

These physical barriers occur because families, in their role as caregivers, face physical, financial, and social limitations. Families caring for stroke patients experience physical burdens, including fatigue due to the need to balance caring for the patient with family and work responsibilities. Additionally, the long-term caregiving responsibilities for stroke patients negatively impact the physical health of caregivers, leading to illness, insufficient sleep or rest, and fatigue. Research findings also indicate varied histories of caring for stroke patients, ranging from 1 to 6 years. The longer the duration of caregiving, the different experiences gained. It is also observed that participants who have been caring for stroke patients for an extended period tend to develop a more sincere attitude in caring for the patient, although they still feel sadness and distress seeing their family members bedridden due to illness (Agustiani et al., 2023).

The research results indicate that the participants in this study were middle-aged to elderly, with an age range of 39-70 years. Age is significantly related to the caregiver burden in caring for family members with stroke. The older the caregiver, the higher the perceived burden, as this is due to the physical decline experienced by elderly caregivers, reducing their ability to care for someone. Participants in this study also predominantly had an educational level of elementary school (SD). According to research conducted by Ardiati et al. (2022), which mentions that low educational attainment can influence the caregiver's care abilities to some extent, causing anxiety, depression, and emotional reactions that can be detrimental to the caregiver or family (Ardiati et al., 2022). This is also in line with the concept of caregiver burden, which states that age, gender, employment status, income, marital status, family relationships, and family support are significantly associated with caregiver burden in caring for family members with stroke (Ariska et al., 2020).

The research results indicate that another obstacle perceived by participants is financial. Caregivers, while caring for stroke patients with decubitus ulcers, face difficulties in financing medical treatments and economic challenges. These research findings are consistent with the findings of the study by Archilike et al

(2020), which mention that families of stroke patients experience symptoms of depression and have a heavier caregiver burden (Achilike et al., 2020).

The study also mentions that the majority of participants are women. The majority of women's roles involve household chores, such as cooking, washing, cleaning the house, serving their husbands, and caring for family members. Unlike the responsibilities of men, which are focused on providing for the family, women have a more dominant role in providing care to their sick family members (Firmawati et al., 2020). Four participants mentioned difficulties in financing the medical treatment of stroke patients, having to balance the cost of patient treatment with daily living expenses. The costs of treating stroke patients and rehabilitation are relatively high. The high cost of caring for a family member with a stroke leads to financial disturbances affecting the well-being of the patient and the family's standard of living (Gertrude et al., 2019; Liu et al., 2020; Manan et al., 2022).

*The role of family caregivers in assisting basic needs: nutrition (eating and drinking), personal hygiene, elimination (urination, defecation), and mobilization*

The research results show that 8 participants mentioned that they help meet the dietary needs of patients, such as bringing food and drinks closer, feeding, and assisting in fetching food. Consistent with the study by Agustiani et al. (2023), which states that one of the impacts of stroke for patients is the inability to carry out activities independently, thus requiring family members to play a role in managing and caring for the patient. Meeting nutritional needs, such as eating and drinking, is crucial because it supports the basic needs that sustain life and the healing process for stroke patients (Agustiani et al., 2023). In line with the study by Badaru et al. (2019), 60% of 100 participants played a role in helping to bathe stroke patients.

The caregiver's role is also crucial in meeting the personal hygiene needs of stroke patients. Stroke can cause various physical and cognitive impacts on patients, requiring extra assistance in daily activities, including personal hygiene care. The research results mention that 8 participants help meet the personal hygiene needs of stroke patients, such as bathing, preparing water and soap for bathing, assisting with tooth brushing, and preparing clothes (Gertrude et al., 2019; Nazara, 2020). In line with the study by Badaru et al. (2019), 60% of 100 participants played a role in helping to bathe stroke patients.

Another role of caregivers in meeting the basic needs of stroke patients is assisting in elimination for patients treated at home. This role involves several essential actions to ensure the comfort and cleanliness of patients. The research results mention that four participants assist patients in toileting, such as helping patients to the toilet by lifting and facilitating the toileting area. The elimination needs of stroke patients refer to various aspects related to the disposal of bodily waste, such as urination and defecation (Nazara, 2020). Family support is crucial in helping with the elimination of stroke patients, especially because patients may experience limitations in movement and daily activities, requiring families to play a significant role in helping meet the elimination needs of patients. With effective family support, stroke patients can feel safer, more comfortable, and receive better care for their elimination needs (Maria et al., 2022).

One role of caregivers in meeting the basic needs of patients is fulfilling mobility needs. Physical mobility impairment is a common consequence of stroke. Stroke can affect a person's ability to move, walk, or engage in other physical activities. The research results indicate that 5 participants play a role in assisting patients' mobility needs, such as assisting in transfers by lifting, aiding patients in walking and moving their hands, and helping patients to the toilet. Physical mobility impairments in stroke patients can vary depending on the location and severity of brain damage. The impact on stroke patients is perceived, including difficulties in walking, performing daily activities, and moving hands and feet (Dodik & Bagaswara, 2019). These research findings are consistent with and supported by the study by Jona et al (2022), which mentions that families can help provide physical support to patients when moving or transferring from one place to another. In line with other studies stating that the role of families can be performed by assisting patients in standing, walking, or transferring from a chair to a bed as examples of physical tasks that families can perform (Jona et al., 2022; D. Rahmawati et al., 2023).

*The type of treatment chosen by the caregiver is based on the family's financial condition*

The role of a caregiver is crucial because the success of stroke patient treatment and care is closely tied to the assistance and support provided by family members acting as caregivers. Research indicates various interventions given by caregivers to patients, including both medical and traditional treatments. Medical treatments in this study involve efforts to treat stroke, such as administering pain relievers and routine medications prescribed by doctors. Additionally, traditional treatments, like massaging with oil combined with ginger and providing herbal remedies like moringa leaves, are also given.



Factors influencing the choice of treatment by families include financial constraints, economic considerations, and activity limitations. Some participants mention opting for traditional treatments due to financial difficulties and economic constraints. Moreover, participants express challenges in balancing work to earn money for medical expenses while caring for stroke patients at home (Firmawati et al., 2020; Nurhidayah et al., 2020; Rohmah, 2018).

The research highlights traditional treatments chosen by families for healing pressure ulcers in stroke patients, such as applying olive oil, coconut oil, aloe vera, and using powder on the affected areas. Studies by Wallace (2019) emphasize that virgin coconut oil contains 32.73% lauric acid, acting as an anti-inflammatory, analgesic, and antipyretic agent, reducing transudate formation, granuloma formation, microbial activity, and preventing bacterial and fungal growth. The results of this study are also in line with and supported by other research conducted by Rahmadani & Chayati (2023), which states that the prevention and treatment of decubitus ulcers can be done by applying topical virgin coconut oil (Wallace, 2019; Rahmadani & Chayati, 2023).

Another alternative for pressure ulcer treatment is the use of olive oil or virgin olive oil. Olive oil contains fatty acids and vitamins (A, B, C, D, and E), providing moisture and skin smoothing. Olive oil, along with coconut oil, is easily absorbed by the skin and contains vitamin E, stabilizing cell membranes and protecting against free radical damage and lipid accumulation in organelles (Laily et al., 2019; Negari et al., 2022; Sumah, 2020).

Research by Ria Ranti et al. (2023) suggests aloe vera as an intervention for pressure ulcer healing. Aloe vera contains polysaccharides, essential amino acids, and protein-degrading enzymes, facilitating cell replacement and skin repair. This research is also in line with and supported by other research by Mulianingsih (2021) that aloe vera also contains various substances like vitamins, minerals, enzymes, and amino acids, inhibiting the growth of skin disease-causing organisms (Mulianingsih et al., 2021; Ria Ranti et al., 2023).

Family caregivers also choose the use of powder for pressure ulcer treatment, believing that it accelerates wound drying and, consequently, speeds up the healing process. However, this contrasts with research by Simamora et al. (2023), which suggests that maintaining cleanliness and moisture in the wounded skin area using both medical (specific pressure ulcer ointments) and herbal (such as virgin coconut oil, olive oil, and honey) moisturizers can accelerate the healing and regeneration of damaged cells compared to keeping the wound either too dry or too wet (Simamora et al., 2023; Sulistyoningtyas & Khusnul Dwihestie, 2022).

Family involvement in choosing pressure ulcer treatments is influenced by factors such as knowledge, financial status, economic conditions, and daily activities. The majority of participants in this study, being housewives with husbands experiencing stroke, face challenges in providing treatment and taking patients to healthcare facilities due to insufficient financial resources (Aruan & Sari, 2018; Alifudin & Ediati, 2019). Possible solutions suggested by families in selecting pressure ulcer treatments include opting for alternative treatments such as maintaining cleanliness, providing herbal or traditional medicines (Krisnawati et al., 2022; Prastiwi & Lestari, 2021).

Family roles in selecting and administering treatments for strokes and pressure ulcers give rise to hopes and desires for the patient's recovery and restored health. Family expectations for stroke patients to improve involve a lengthy process requiring time, effort, and patience. The research indicates that participants hope for the patient's speedy recovery and return to good health. These findings align with Rahmawati's (2019) research, which identifies family hopes related to the function, source, and form of support. Caregivers hope for their own health, recovery for the patient, and government assistance regarding the comprehensive care costs for post-stroke patients at home (Alifudin & Ediati, 2019; L. Rahmawati, 2019).

## Conclusion

The family's experience in caring for stroke patients with decubitus ulcers plays a role in helping meet the patients' basic needs. Families also face obstacles, including physical, psychological, and financial challenges. These barriers influence the family's choice of care for the patient. The family's role in caring for stroke patients with decubitus ulcers also brings hope for the patient's recovery and return to health. The research results related to the family's experience in caring for stroke patients with decubitus ulcers are consistent with the concept of caregiver burden theory, and the analysis of various themes in the research findings is interconnected. It can serve as considerations, information, and support for both families and healthcare providers in caring for stroke patients comprehensively while still considering the needs of the family itself.

## Declaration of conflict of interest

The authors stated that there is no conflict of interest.

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## Author contribution

WR as the main investigator responsible for data collection, interview transcription; NC, WR subsequent analysis to determine coding, sub-themes, and research themes; NC, WR preparing the research report, manage and check the manuscript of possibility of publication; NC looking for research funding.

## Author Biography

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## References

- Achilike, S., Beauchamp, J. E. S., Cron, S. G., Okpala, M., Payen, S. S., Baldrige, L., Okpala, N., Montiel, T. C., Varughese, T., Love, M., Fagundes, C., Savitz, S., & Sharrief, A. (2020). Caregiver Burden and Associated Factors among Informal Caregivers of Stroke Survivors. *Journal of Neuroscience Nursing*, 52(6), 277–283. <https://doi.org/10.1097/JNN.0000000000000552>
- Agustiani, S., Deschara, A., & Maryana. (2023). Pengalaman Keluarga Dalam Merawat Pasien Stroke. *Jurnal Penelitian Perawat Profesional*, 5(1), 677–690.
- Alifudin, M. R., & Ediati, A. (2019). Pengalaman Menjadi Caregiver: Studi Fenomenologis Deskriptif Pada Istri Penderita Stroke. *Jurnal EMPATI*, 8(1), 111–116. <https://doi.org/10.14710/empati.2019.23583>
- Amirsyah, M., Amirsyah, M., & Putra, M. I. A. P. (2020). Ulkus Dekubitus pada Penderita Stroke. *Kesehatan Cegahadum*, 2(03), 1–8.
- Ardiati, E. A., Anggraini, M. T., & Fuad, W. (2022). Hubungan Pengetahuan Dan Lama Merawat Dengan Sikap Keluarga Dalam Merawat Penderita Stroke. *Jurnal Kesehatan*, 15(1), 36–44. <https://doi.org/10.23917/jk.v15i1.16378>
- Ariska, Y. N., Handayani, P. A., & Hartati, E. (2020). Faktor yang Berhubungan dengan Beban Caregiver dalam Merawat Keluarga yang Mengalami Stroke. *Holistic Nursing and Health Science*, 3(1), 52–63. <https://doi.org/10.14710/hnhs.3.1.2020.52-63>
- Badaru, U. M., Fatima, B. S., Ahmad, R. Y., Lawal, I. U., Ogwumike, O. O., & Usman, J. S. (2019). Influence of Duration of Caregiving on the Burden and Quality of Life of Informal Caregivers of Stroke Survivors. *Indian Journal of Physiotherapy and Occupational Therapy - An International Journal*, 13(3), 171. <https://doi.org/10.5958/0973-5674.2019.00114.x>
- Choliq, I., Nasrullah, D., & Sukadiono. (2020). Role of Family in Caring Patient with Post Stroke at Home: A Systematic Review. *International Journal of Psychosocial Rehabilitation*, 24(8), 11004–11013.
- Dodik, W. A., & Bagaswara, S. D. (2019). Gambaran Peran Keluarga Tentang Pencegahan Ulkus Dekubitus Pada Pasien Stroke Dengan Gangguan Mobilitas Fisik. *Jurnal ILKES (Jurnal Ilmu Kesehatan)*, 10(1), 1–7.
- Elmawati, C. (2019). Hubungan Peran Keluarga Dengan Pencegahan Decubitus Pada Pasien Stroke Di Ruang Rawat Inap RSUD Muntilan Kabupaten Magelang. *Jurnal Universitas Aisyiyah Yogyakarta*, 53(4), 130.
- Faridah, U., Sukarmin, & Murtini, S. (2019). Pengaruh Posisi Miring Terhadap Dekubitus Pada Pasien. *Jurnal Ilmu Keperawatan Dan Kebidanan*, 10(1), 155–162.
- Firmawati, E., Fitria Permata, & Rochmawati, E. (2020). Beban Keluarga dalam Perawatan Pasien dengan Stroke Di Rumah Sakit PKU Muhammadiyah Gamping. *Repository.Umy*.
- Gertrude, N., Kawuma, R., Nalukenge, W., Kamacooko, O., Yperzeele, L., Cras, P., Ddumba, E., Newton, R., & Seeley, J. (2019). Caring for a stroke patient: The burden and experiences of primary caregivers in Uganda – A qualitative study. *Nursing Open*, 6(4), 1551–1558. <https://doi.org/10.1002/nop2.356>
- Jona, R. N., Juwariyah, S., & Maharani, N. W. D. (2022). Hubungan Tingkat Pengetahuan Keluarga Terhadap Kejadian Resiko Dekubitus Pada Pasien Stroke. *Jurnal Rumpun Ilmu Kesehatan*, 2(3), 131–142. <https://doi.org/10.55606/jrik.v2i3.699>
- Kadarwati, Ulfa, R., & Oktarina, E. (2019). Studi Fenomenologi: Pengalaman Keluarga Merawat Penderita Pasca Stroke di Kota Jambi Tahun 2019. *Jurnal Ilmiah Universitas Batanghari Jambi*, 19(3), 476. <https://doi.org/10.33087/jiubj.v19i3.706>

- Karunia, E. (2016). Hubungan antara dukungan keluarga dengan kemandirian Activity of Daily Living Pascastroke. *Jurnal Berkala Epidemiologi*, Vol. 4(July), 213–224. <https://doi.org/10.20473/jbe.v4i2.2016.213>
- Kavga, A., Kalemikerakis, I., Faros, A., Milaka, M., Tsekoura, D., Skoulatou, M., Tsatsou, I., & Govina, O. (2021). The effects of patients' and caregivers' characteristics on the burden of families caring for stroke survivors. *International Journal of Environmental Research and Public Health*, 18(14). <https://doi.org/10.3390/ijerph18147298>
- Kemkes RI. (2018). Profil Kesehatan Indonesia. In *Health Statistics*. <https://www.kemkes.go.id/downloads/resources/download/pusdatin/profil-kesehatan-indonesia/profil-kesehatan-indonesia-2018.pdf>
- Krisnawati, D., Faidah, N., & Purwandari, N. P. (2022). Pengaruh perubahan posisi terhadap kejadian decubitus pada pasien tirah baring lama di ruang Irin Rumah Sakit Mardi Rahayu Kudus. *The Shine Cahaya Dunia D-III Keperawatan*, 7(1), 15–26. <https://ejournal.annurpurwodadi.ac.id/index.php/TSCD3Kep/article/view/332>
- Laily, E. I., Saragih, N. P., & Sirait, L. L. (2019). Pengaruh Penggunaan Extra Virgin Olive Oil Pencegahan Luka Tekan pada Pasien Berisiko dengan Skala Braden. *Coping: Community of Publishing in Nursing*, 7(3), 153–158. <https://ojs.unud.ac.id/index.php/coping/article/view/55798>
- Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, 7(4), 438–445. <https://doi.org/10.1016/j.ijnss.2020.07.012>
- Lutfi, B., & Mintarsih, A. M. (2020). Perawatan Pasien Sequelae Stroke Dengan Peningkatan Kapasitas Fungsional Tubuh ( Rom ) Di Klinik Syaraf Rsud Dr . Soekardjo. *Jurnal Keperawatan & Kebidanan*, 5, 63–69.
- Manan, A., Septianingrum, Y., Wijayanti, L., & Setiyowati, E. (2022). Beban Keluarga Pasien Stroke Ditinjau Dari Ekonomi: a Systematic Review. *Jurnal Keperawatan*, 14 S4(Desembar), 1019–1028.
- Maria, K., Widuri, & Islamarida, R. (2022). Peran Keluarga Sebagai Caregiver Pada Pasien Stroke: Studi Literatur. *Jurnal Keperawatan*, 14(1), 1–23.
- Maulidah Nur Atiqoh. (2017). *Gambaran Pengetahuan Dan Persepsi Family Caregiver Tentang Pencegahan Dekubitus Pada Anggota Keluarga Yang Berisiko Dekubitus di Wilayah Kerja Puskesmas Pisangan dan Ciputat*. 1–14.
- Mulianingsih, A. M., Studi, P., Tiga, D., Rias, T., Teknik, F., & Jakarta, U. N. (2021). Pemanfaatan Lidah Buaya ( Aloe Vera ) Sebagai Bahan Baku. *Tata Rias*, 11 No 1(Vol 11 No 1 (2021): Jurnal Tata Rias).
- Nazara, F. S. (2020). Gambaran Pengetahuan Keluarga Tentang Self-Care Pada Anggota Keluarga Yang Menderita Stroke Tahun 2020. *Repository.Stikeselisabethmedan.Ac ....* <https://repository.stikeselisabethmedan.ac.id/wp-content/uploads/2021/04/Fiber-s.-Nazara.pdf>
- Negari, P. M., Rakhmawati, N., & Agustin, W. R. (2022). *The Effect Of Massage Effleurage With Olive Oil (Olive Oil) On Decubitus Prevention In Bedrest Patients In Hcu, Hcu Anggrek Room RSUD dr Moewardi*. 23.
- Nina Widyasari. (2021). Faktor yang Berpengaruh Terhadap Kejadian Hipertensi pada Remaja di Indonesia. *Medicinus*, 34(2), 65–74. <https://doi.org/10.56951/medicinus.v34i2.75>
- Nurhidayah, I., Nismah, Tombong, A. B., Yullizar, & Kasih, L. C. (2020). Pengalaman Keluarga Dalam Merawat Anggota Keluarga Stroke Dengan Hemiparese di RSUD H.A. SULTHAN Daeng Radja Bulukumba. *Jurnal Perawat Indonesia*, 4(2), 29–43.
- Prastiwi, F., & Lestari, S. P. (2021). Tinjauan Literatur : Efektifitas Minyak Zaitun Dalam Pencegahan Ulkus Dekubitus. *Majalah Kesehatan*, 8(4), 233–241.
- Rahmadani, W., & Chayati, N. (2023). Massage in prevention of decubitus ulcers in bedrest patients: A literature review. *Jurnal Aisyah : Jurnal Ilmu Kesehatan*, 8(2), 649–656. <https://doi.org/10.30604/jika.v8i2.1989>
- Rahmawati, D., Umaedi, M., Lusiani, M., & Silfiah. (2023). Studi Fenomenologi : Pengalaman Keluarga Sebagai Care Giver Dalam Melakukan Perawatan Pasien Pasca Stroke Di Rumah. *Edu Masda*, 07(02), 89–99.
- Rahmawati, L. (2019). Pengalaman Keluarga dalam Merawat Lansia Pasca Stroke di Indramayu Family Experience in Treating The Elderly Post Stroke in Indramayu. *Jurnal Kesehatan Masyarakat*, 7(2), 299–307.
- Ria Ranti, S., Sari Lubis, M., Munandar Nasution, H., & Yuniarti, R. (2023). Antibacterial Activity Of Leaf Bark, Exudate, And Leaf Fleshaloe Vera (Aloe vera (L.) Burm.f.) AGAINST BACTERIA Staphylococcus epidermidis. *Agustus*, 3(1), 22–28.
- Rohmah, E. F. (2018). *Pengalaman Keluarga Merawat Lansia Pasca Stroke Dalam Pemenuhan Kebutuhan Hidup Sehari-hari di Wilayah Puskesmas Dukun Kabupaten Gresik*. Perpustakaan Universitas Airlangga.
- Sari, R. (2017). Pengalaman Keluarga Dalam Merawat Dekubitus Family's Experience in Taking Care Decubitus Ulcer. *Wacana Kesehatan*, 1(1).
- Simamora, T. Y., Kristanti, F., & Wibawa, S. R. (2023). Manajemen Luka Tekan pada Pasien Tirah Baring: *Jurnal Keperawatan Klinis Dan Komunitas*, 7(November), 155–164. <https://doi.org/10.22146/jkkk.80144>
- Sulistyoningtyas, S., & Khusnul Dwihestie, L. (2022). Pengaruh Massage Effleurage Dengan Virgin Coconut Oil (Vco) Terhadap Pencegahan Risiko Dekubitus Pada Pasien Stroke Non Hemoragik. *Jurnal Ilmiah Permas: Jurnal Ilmiah STIKES Kendal*, 13(April), 665–672.
- Sumah, D. F. (2020). Keberhasilan Penggunaan Virgin Coconut Oil secara Topikal untuk Pencegahan Luka Tekan (Dekubitus) Pasien Stroke di Rumah Sakit Sumber Hidup Ambon. *Jurnal Kedokteran Dan Kesehatan*, 16(2), 93–102.
- World Health Organization. (2015). The Global Prevalence of Pressure Ulcers in 2018.

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