

The Burden Experience of Family Caregiver of Older Adults with Chronic Illness

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Purpose: This study aims to find out further about the burden on families in undertaking caregiving for the elderly with chronic illnesses.

Methods: A qualitative study was developed using in-depth interviews with 12 family caregivers selected by purposive sampling in July 2022. The thematic analysis was then carried out using the Colaizzi method, and N-Vivo 12 Qualitative Data Analysis Software was used to assist with the content analysis.

Results: The result from the experience interview analysis of caregivers participating in this study were 54 codes which were categorized into thirteen categories. Then, they were derived into four themes, as follows: 1) Physical burden of the caregivers for the elderly with chronic illness, 2) Psychological burden of the caregivers for the elderly with chronic illness, 3) Obstacle of caregivers for the elderly with chronic illness, 4) The state of caregivers who perform caregiving for the elderly with chronic illness.

Conclusion: The experience of caregivers in undertaking caregiving for the elderly with chronic disease has many obstacles, such as physical, psychological, and economic burdens. Caregivers often find positive aspects of their experiences while caregiving for the elderly, although their burden also constantly increases. Health facilities should pay serious attention to family caregivers and facilitate programs that can help reduce the burden on family caregivers.

Keywords: Family; Caregiver Burden; Older Adults; Chronic Disease

Introduction

Non-communicable diseases (NCDs) were chronic diseases that were not passed from person to person, had a lengthy duration, and grew slowly [1]. At the time, NCDs were the top cause of death worldwide. According to WHO - NCD Country Profile data from 2018, the proportional mortality in Indonesia from NCDs were cardiovascular diseases (35%), cancers (12%), chronic respiratory diseases (6%), diabetes mellitus (6%), injuries (6%), other NCDs (15%) [2]. Furthermore, according to the Indonesia Basic Health Research 2018, the majority of NCDs

such as cancer, stroke, renal disease, diabetes, cardiovascular disease, and obesity exhibited a growing tendency when compared to the previous study in 2013 [3].

Various diseases that often suffer (multi-pathological) and the increase of physical, intellectual, mental, and sensory limitations level in the elderly are indications of the need for long-term care (LTC) [4]. Long-term care for the elderly aims to maintain a level of independence of the elderly, reduce dependence, prevent complications of the disease, and maintain self-esteem, quality of life, and nutritional intake for the elderly [5]. This series of tasks and roles causes high pressure on the family, which can further

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cause families burden [6].

In Indonesia there is a culture called "Ngabdi Wong Tuwo" which is described as self-dedication to parents, this culture causes family caregivers to prefer caring patients by themselves at home rather than at the hospital [7,8]. Moreover, the family is expected to provide instrumental and emotional support to elderly individuals with chronic diseases, which can help them find meaning in life and support the fulfillment of their psychological and spiritual needs [9]. Increasing respite time, self-coping strategies, and the availability of support facilities are important strategies for enabling family caregivers to avoid providing excessive hours of care and to maintain quality of life [10]. However, preparation for becoming a family caregiver for NCDs patients in Indonesia is at a moderate level, causing an increased risk of burden on family caregivers [11].

The burdens of caregivers while undertaking caregiving for sick families over a long period are changes in emotional and physical health and stress [12]. The previous study exploring the stress of female family caregivers who care for elderly with chronic illnesses in a hospital in Sumatra, Indonesia found that four main factors such as financing, caregiver fatigue, culture and negative relationships with families cause stress on female family caregivers which can reduce the quality of life [13]. However, the current study explores how family caregivers' experience caring for elderly with chronic illnesses at home. The burden on families in undertaking caregiving for the elderly with chronic illness that requires long-term care, economic limitations, and limited knowledge of the treatments for elderly patients, will impact the emergence of uncomfortable feelings for caregivers. These need to be considered because it is crucial in determining the caregivers' interventions, recommendations, and nursing care. Therefore, the researchers want to know more about the family's burden in treating the elderly with chronic illness.

Methods

1. Aim

This study used a phenomenological qualitative design which incorporated the COREQ (Consolidated Criteria for Reporting Qualitative Studies) research reporting checklist [14]. Individual semi-structured interviews were conducted to ascertain the families' perception of the burden of undertaking caregiving for the elderly with chronic illnesses.

2. Study design

The researchers used Colaizzi's phenomenological method to

qualitatively analyze the experience of family caregivers undertaking caregiving for the elderly with chronic illness. The Colaizzi data analysis method is a rigorous and powerful qualitative method used by researchers to discover, understand, describe, and define respondents' experiences and reveal emerging and intertwining themes [15]. This scientific approach guarantees the authenticity of the experiences of the caregivers to comply with scientific standards.

3. Setting and participant

This research involved participants in the work area of Bengkulu City Public Health, Indonesia, and was conducted from July to August 2022. Purposive sampling techniques were used in this qualitative study, and qualitative samples were taken to answer the research objectives. The researcher met the person in charge of the elderly program at the community health center and selected respondents according to the inclusion and exclusion criteria. Home visits had been made to potential respondents who fit the criteria. Also, willing potential respondents had their residences visited for interviews. The study consisted of 12 respondents (n = 12). The subjects were caregivers who met specific criteria, including participants were the primary caregivers in families caring for the elderly with a chronic illness that had a total degree of dependence; caregivers understand Indonesian; caregivers and the elderly live in the same house or live nearby; the caregiver is willing to become a participant by giving consent through informed consent; and able to tell their experience as a caregiver who cares for the elderly with chronic illness. All caregivers who met the inclusion criteria and gave consent were participants.

4. Ethical considerations

This research has received ethical approval number 271/UN9.FKM/TU.KKE/2022 from the faculty of public health Sriwijaya university. Participants gave their written consent to participate, evidenced by signing the informed consent. Before the interview, the participants were informed that participation in the interview was voluntary and that they could resign at any time.

5. Data collection

The first author (NY) conducted face to face in-depth interviews with 12 respondents to facilitate caregivers in expressing their experiences. The interviews were conducted using topic guidelines and audio recorded in Indonesian. An interview guideline (Table 1) was adopted from The Zarit Burden Interview and panel discussions among the researchers including a

Table 1. Interview question guidelines

Interview Questions
- Please tell me about the current state of health of the elderly.
- According to you, how much is the dependency of the elderly? Please explain!
- What is your state of health since caring for the elderly?
- Do you feel still capable of caregiving for your own elderly, or will you leave the responsibility to the other sibling? Explain why!
- How do you feel while undertaking caregiving for the elderly? Are there feelings of stress, anger, fear, tension/discomfort? Can you explain?
- Do you feel a loss of self-control while caring for/dealing with elderly illnesses?
- Are you unsure about the care you have given the elderly?
- What is your hope for the elderly? Is there a feeling of wanting to do anything for the health of the elderly?
- Let's talk about whether, since caring for the elderly, you feel that you do not have time to do other activities, such as free time for yourself, other families or friends?
- Is there a feeling of shame and discomfort in making friends with others because there is an older person who is sick?
- Can you explain, does taking care of the elderly interfere with relationships with other families?
- How is the economic condition of your family since caring for the sick elderly? Is there an elderly's need that requires additional funds?

principal investigator (with expertise in qualitative research methods and community nursing) [16].

The first (NY) and second (TA) authors inspected and refined the question and organized them into a logical flow from a broad to specific focus. During the interviews, several questions were modified or added to clarify important content arising in the earlier interviews. The interviews were undertaken primarily at the caregiver's home, but some wanted to be at their workplace for approximately 90 - 120 minutes per interview. Data collection ceased once data saturation was reached and no new themes were emerging from the interviews. In-depth questions were also applied to obtain richer data and begin with preliminary questions that include initials, age, education, occupation, income, relationship with the sick elderly, period of caregiving for the sick elderly, chronic illness suffered by the elderly, and the age of the elderly then followed by the main question, as described in Table 2 below.

6. Data Analysis

The audio recordings were transcribed verbatim by the first (NY) and second (TA) authors. Two researchers (TAU and MM) were checked for the accuracy of the transcripts and then stored in the computer software program NVivo 12 (QRS International Pty.Ltd). Thematic analysis was carried out using the Colaizzi method [17]. Within 24 hours of each interview, the tape was transcribed and analyzed by Colaizzi's method of phenomenological analysis. To ensure that optimal analytical rigour was practised, the data were analysed and coded independently by researchers (TAU and MM), any discrepancies were resolved through a consensus discussion with a third researcher (NY).

NVivo 12 was used to organise the analytical process, particularly to facilitate the tagging of text segments and groupings of code labels. Reliability was checked by examining response and content consistency across the interviews. Themes were checked by three researchers (NY, TAU, MM) to reduce investigator bias.

7. Trustworthiness

The four aspects of trustworthiness in qualitative research, credibility, transferability, dependability and confirmability [18] have been recognized and utilized in this study. Data were collected in the form of interviews, audio recording and confirmation of findings were confirmed with member checking throughout the interview. Field notes were taken to reveal any biases, and audio recordings were transcribed verbatim in addition to performing an inter-rater reliability analysis. We used intercoder reliability (ICR) to measure of the agreement between different coders (TAU and MM) regarding how the same data should be coded [19]. Cohen's kappa formula used to calculate the agreement among coders [20]. Similar to correlation coefficients, it can range from - 1 to +1. Of the 12 transcripts, 14 major codes were selected for ICR assessment. The overall kappa coefficient for all 14 codes was 0.67.

Results

1. Characteristics of the Participants

Twelve caregivers agreed to share their experiences caring for the elderly with chronic illness. The characteristics of the participants are described in Table 2.

Table 2. Participant's demographic data (N=12)

Elderly age (years)	Gender of the elderly	Diseases suffered by the elderly	Period of the illness	Caregivers' age (years)	Caregivers' education	Caregivers' work	Relationship with the elderly
66	F	Stroke, paralysis from the waist down	5 years 9 months	68	Undergraduate	Retiree	Husband
80	F	Osteoporosis	3 years 6 months	88	Senior Secondary	Retiree	Husband
87	F	Hypertension, paralysis	6 years	52	Senior Secondary	Housewife	Biological children
78	F	DM, stroke	6 months (lying down), 12 years sick	37	Senior Secondary	Entrepreneur	Biological children
69	F	Hypertension, stroke	5 years	32	Undergraduate	Self-employed	Biological children
60	F	Stroke	6 years	32	Senior Secondary	Housewife	Biological children
90	M	Stroke	3 years, 1-year total care	32	Undergraduate	Housewife	Daughter-in-law
66	M	Stroke	3 years	63	Elementary	Housewife	Wife
83	F	Heart disease	4 years	56	Diploma	Civil servant	Biological children
80	F	Stroke	3 years	42	Undergraduate	Civil servant	Biological children
62	F	CKD, DM	6 years, lying 4 months	32	Undergraduate	Housewife	Biological children
78	F	Stroke	6 years	46	Senior Secondary	-	Biological children

M = Male, F = Female.

2. Theme

The interview analysis contained four themes: The physical burden of caregivers in the care of the elderly with chronic illness; The psychological burden of caregivers in the care of the elderly with chronic illness; Obstacles of the caregivers in the care of the elderly with chronic illness; The state of caregivers who carry out the care of the elderly with chronic illness. Excerpts related to these themes are attributed to participants in parentheses in the text below. Dots in quotes indicate pauses. In Table 3, examples of categories, codes, and all categories for one of the themes are displayed.

2.1 Theme 1: Physical burden of caregivers in undertaking caregiving for the elderly with chronic illness

The theme of "Physical Burden" relates to all the limitations experienced by the elderly that affect the physical aspects of caregivers. Physical disturbances are intended in the form of social activity disturbances such as activities in the work environment and home environment, rest disturbances and fatigue, and other activity disturbances such as vacations, me time, and work disturbances.

"I can't go to the community anymore. In the past I could join community activities, or visit other families. But now, I can't... who's waiting for mom when I go?" (P1)

"I sometimes complain because I feel tired, taking care of my mother's defecation and urination" (P5)

In addition, this theme also explains the various dependencies

Table 3. Themes and Categories

Theme	Category
Caregiver Physical Burden in Caring for Elderly with Chronic Illness	- Activity Disturbances - Elderly Care - Elderly Dependence - Disease History - Fatigue
The psychological burden of caregivers in caring for elderly people with chronic diseases	- Psychological Burden - Caregivers Hope
Barriers of caregivers in caring for elderly people with chronic illnesses	- Economic Barriers - Help Needed - Lack of Family Involvement - Time Constraint
The condition of caregivers who care for elderly people with chronic diseases	- The caregiver's economic situation - Roles and activities - Caregiver Perceptions

of the elderly, from partial to total, the occurrence of immobility, the duration of dependency, and the inability and non-participation of the elderly in the decision-making process, so that the needs for daily living activities require assistance from caregivers, which of course becomes a burden for the caregiver. The existence of cognitive and physiological decline is unique and different from that of patients with other chronic diseases. The condition of decline in the elderly is actually a physiological condition that naturally occurs, such as decreased memory, decreased com-

munication skills, emotional changes, and other changes that make elderly caregivers experience their own difficulties in dealing with patients.

“Anxious, often unclear what he says, sometimes unclear meaning, sometimes remember he is still young his children are still small like that, more to the past again” (P7)

This theme also discusses elderly care, which usually requires many things to support daily living activities such as mobility assistance, oxygen assistance, elimination, routine medication, bathing assistance, as well as various treatment efforts, which of course are pursued by caregivers in maximizing the care process. The physical burden felt by caregivers has been summarized in this theme, showing that in caring for elderly people with chronic illnesses, aspects of the physical burden on caregivers must also be considered and minimized, considering that the physical burden expressed affects all aspects of life for individuals.

2.2 Theme 2: The psychological burden of caregivers in undertaking caregiving for the elderly with chronic illness

The theme of the psychological burden felt by caregivers in caring for elderly people with chronic illnesses summarizes various caregiver perspectives regarding feelings related to the emotional aspects felt by caregivers. The psychological burden includes feelings of anxiety, anger at the circumstances and situations that force the caregiver to care for the elderly with an uncooperative attitude, and fear of death of the elderly.

“No stress because I have to take care of my mother, but sometimes angry words appear because I'm tired when I drop, others don't care even though there are many children. Sometimes I often blame the mother's condition but don't want to treat it” (P12)

Various hopes were also expressed, including the caregiver's desire to provide the best support and care and hopes related to the recovery of the elderly, but some respondents had also surrendered to fate. For them, recovery is not always a happy ending, but if indeed death is the best thing for the patient, then they have accepted that as the best decision and are willing to do whatever is best so that the elderly can die in good condition.

“I don't know what it's like, the important thing is I've taken care of it. I have treated it, I have been given medicine, I have been to the hospital, where do I take the treatment. So far, not much has changed.” (P3)

2.3 Theme 3: Obstacle of caregivers in undertaking caregiving for the elderly with chronic illness

Various things expressed by respondents as caregivers became obstacles in the process of caring for elderly people with chronic diseases. The first obstacle relates to the help needed by caregivers, but it is rare and very difficult to obtain. This assistance includes care assistance. This occurs because there are no other families, other families are busy, and other families are unable to provide care, so caregivers are the only caregivers who are able to provide care. Lack of family support is also a barrier. Families who do not understand will consider the care process trivial, not care about the caregiver's responsibilities in carrying out care, and lack involvement in helping the process of caring for elderly people with chronic illnesses.

“But sometimes we still need someone's help, if for example we can't lift it ourselves, right, then our role for treatment is to decide to call someone... in treatment we take them to the hospital” (P7)

Furthermore, caregivers face challenges in maintaining routine control of elderly people with chronic diseases due to a lack of visits from health workers. Economic barriers and time constraints were also revealed to be the main obstacles in the treatment process, given the role or role activities that caregivers have in carrying out their functions as healthy individuals.

2.4 Theme 4: The state of caregivers who undertake caregiving for the elderly with chronic illness

The fourth theme summarizes the various circumstances of the family caregivers who are the respondents in this study. The caregiver's economic situation varies; caregivers who have enough money will do various things, such as provide care that includes the facilities needed and the recommended routine treatment budget. The second situation relates to the roles and activities of the caregiver to meet the needs of the household as the mother and head of the family, the health condition of the caregiver himself, the management of the time needed to carry out his activities, the prevention of conflicts related to care, and the role of the family caregiver in work that is also important to become a source of daily livelihood. The caregiver's perceptions have been summarized into the reasons expressed for carrying out the treatment, the sincerity of being a family caregiver, adaptive coping, care experience, and the psychological condition of the family caregiver itself.

“No, if that's the problem, my husband understands, understands

the consequences if I move here and what the consequences will be, yes, because it was he who told me to come here again at the suggestion of my husband. Because I really understand I'm the oldest child" P6

Dicussion

This study described the participants' experiences as caregivers for the elderly with chronic illness. The depth and richness of the conversation suggest that caregivers in this study were able to describe the experience of caregiving for the elderly with chronic illness. Interpretation of the interview revealed four themes of participants' descriptions of their experiences.

Family caregivers take care of the elderly with chronic illness [21]. A family caregiver is a person who always accompanies and cares for patients with chronic illness. As for the duties of caregivers, in addition to being a family that helps patients in their daily activities, they also help in terms of reminding patients to routinely go to the hospital, reminding to take medicine regularly, reminding to adhere to the diet that must be followed, and so on [22,23].

In Indonesia, family caregivers most required health information regarding caring for the elderly with chronic illnesses in order to fulfill their roles and maintain their quality of life [24,25]. Unfortunately, many programs in Indonesia, such as POSBIN-DU and PROLANIS, did not offer family caregivers with learning on caring for patients with chronic illnesses [26].

Caregiver burden is a multidimensional response to negative assessments and stress from caring for sick people [24]. While treating patients, caregivers can experience difficulties due to the burdens that must be borne physical, psychological, social, and financial burdens [25]. Some factors that affect caregivers' burden include age, gender, income, education level, employment status, marital status, family relationships, and family support [26,27].

1. Physical Burden of Caregivers in Undertaking Caregiving for the Elderly with Chronic Illness

Caregivers have a physical burden because they must take care of patients on an ongoing basis, starting from the need for treatment or control and daily needs, such as eating, self-care, supervision, and others [28]. This study found that the physical burden felt by caregivers when caring for the elderly was fatigue, and in accordance with previous studies that stated the physical burden felt by caregivers can influence the caregiver's health condition, including fatigue, sleep disturbances, no appetite, headaches, high blood pressure, and stomach ulcers [29]. Caregivers

who are at high risk of having a low quality of life spend more time and energy caring for chronically ill patients [30].

With age, the health of the elderly deteriorates, functional abilities generally decrease, and they become dependent on others in their daily activities [30]. Therefore, caregivers take more responsibility and provide more help. Caregivers are also burdened with various medical services such as primary daily care like cleaning wounds, administering medicines, providing physical therapy, coordinating medical examinations, providing transportation, and assisting with nutritional needs. Caregivers bear a greater responsibility and commitment to providing daily assistance with special care, especially for the elderly with dependence. Caregivers who served the elderly longer than 14 hours reported higher levels of physical burden than those with shorter caregiving hours [30].

In this study, it is initiated that caregivers had difficulty making time to do social activities because of their busy life in caring for the elderly. Previous research stated that the elderly with chronic pain need more attention, where caregivers become more focused on the patient's condition so that they interact less with others and do not participate in social activities [31]. Providing care to the elderly can cause difficulties in finding time to socialize with the community and recreation.

2. Psychological Burden of Caregivers in Undertaking Caregiving for the Elderly with Chronic Illness

The results of this study show that caregivers experience various psychological problems while treating patients. Psychological conditions that affect caregivers' burden are emotional states, including stress, anxiety, and worry about the patient's condition. Previous research suggests that four of ten caregivers felt unable to cope with their anxiety about the patient's condition [31]. In addition, they also experienced fatigue from caring for the patients and even depression [32]. One-third of caregivers experienced sleep deprivation because they felt worried, stressed, and depressed [33].

Psychological disorders in facing problems such as interpersonal problems, role conflicts, stress, and constant anxiety in life, have an impact on the high burden of caregivers. In addition, along with the patient's health problems, caregivers are also required to support the emotionally ill elderly and take responsibility for the activities of their daily lives, which can aggravate their burden. Caregivers with a higher caregiving burden tend to sacrifice their quality of life [34]. Caregivers feel more responsible for caring for the patients, thus experiencing higher stress levels and tension [35].

The emergence of various burdens or problems in treating patients depends on the coping strategies caregivers use in treating patients, and the quality of life of caregivers also affects the emergence of burdens for caregivers [36]. The weight of the burden experienced by the caregiver depends on the coping strategy used by the caregiver. The more positive the coping strategy the caregiver has, the better the caregiver's way of overcoming his problem [36]. Caregivers use various coping strategies during caring for elderly patients, namely with positive emotions such as affection, hope for a better future, getting closer to God, participating in religious activities, helping others who have the same problem, consulting with experts, and accepting the disease suffered by the patient [37]. In this study, most respondents accepted the condition suffered by the patient as a form of coping and drawing closer to God.

3. Obstacles of caregivers in undertaking caregiving for the elderly with chronic illness

The results of this study show that caregivers need assistance in caring for the elderly such as assistance for caregiving, family support, family involvement, and health facilities. Based on previous studies, patients with chronic disorders can reduce their level of dependence on caregivers through self-care and control of the symptoms of their illness [38,39]. In this study, patients with diabetes mellitus were able to do self-care and control the symptoms of their disease by regulating their diet and doing glucose checks every day. In contrast, patients with stroke could not do self-care or control the symptoms of their disease. So that caregivers for stroke patients need help treating clients when transferring patients and installing pampers. This result is the same as previous studies that stated that patients with diabetes had the lowest care load value [40].

The results of this study show that most caregivers did not get families' support and involvement. The caregiver's responsibility for patient care leads to limited caregiver time for family and friends, resulting in tension in the family and friend relationship [33]. Caregivers who have family support and involvement in providing care to the elderly have a higher spirit than respondents who do not get family support. This because caregivers feel that the burden of caring for the elderly is felt by all family members, while caregivers who take care of the elderly alone feel that they have no other choice but to take care of the patient. However, both caregivers with family support and involvement provide maximum care. Previous research suggests that family support and involvement are coping sources for caregivers caring for the elderly with chronic it [40]. Caregivers who have their family,

friends or social relationship who provide emotional support to others or their spouses, have better health and are satisfied with their quality of life [41].

In addition to the lack of family support, in this study, it was found that there were caregivers who experienced economic barriers. This is because caregivers only rely on their income to treat patients, but caregivers have their spouses' support to finance patient care. Family caregivers are the backbone for the elderly with chronic illness because they provide most of the care and social support for their loved ones [42]. Families who have family members with chronic illness can affect the family's psychological and emotional functioning, disruption of leisure activities, interpersonal relationship and financial resources, where there will be an increase in the needs and financial burdens in the family [43]. Respondents with sufficient financial support reported better health satisfaction. These findings are consistent with previous literature reporting that financially healthy caregivers have less workload and a better quality of life [30,44].

4. The state of caregivers who carry out caregiving for the elderly with chronic illness

Family caregivers will be faced with the number of hours of caring for patients, shouldering a heavy burden, and physical, psychological, and financial problems, which can also influence their health problems [21,22-46]. Undertaking caregiving for the elderly at home can burden caregivers externally and internally. External burdens can arise from other work that caregivers must do and the behaviour of the elderly who are being cared for. Internal burdens one of them is the physical and psychological burdens or emotions [46]. Caregivers can also play a dual role, and it is possible that they also have other family members who need to be taken care of or may also have a partner who lacks support for caregivers in caring for the elderly. Caregivers find it very helpful if there is a burden sharing in the family. The elderly can get a good quality of life if the family can play an optimal role in their caregiving for the elderly. Together, families must collaborate so that when problems arise for the caregiver can be handled and managed correctly, it has an impact both physically and psychically [47].

The financial condition of caregivers in this study consists of the upper middle and lower middle. Respondents with a stable economic state can choose the best medical care. They can also have access to a wide range of treatment options. In addition, caregiving does not burden their finances, and they have a high sense of accomplishment because it does not burden a person. On the contrary, caregivers with limited financial resources find it difficult

to cover patients' medical expenses while at the same time supporting their families. This can jeopardize their quality of life and increase the burden on the caregivers [48]. Health insurance can help alleviate long-term medical expenses, effectively reducing the burden on caregivers and health care costs [29]. Patients seek treatment in two ways: by paying in cash and not paying. Patients who do not pay come from underprivileged communities using the JAMKESMAS, JAMKESDA, or JAMKESKOT CARDS and guarantees from ASKES (for civil servants or retirees) [28].

The results of this study revealed that even though caregivers have physical, psychological, and economic obstacles, they still carry out maximum care for the elderly because the elderly are family members they care about. Respondents also expressed satisfaction with their current health. Previous research suggested that nearly half of caregivers reported being satisfied with their overall health and having a good physical health status [49]. In this study, caregivers did not feel burdened with the patient's disease. However, some caregivers show difficulties in the division of caregiving roles, especially when they have high burdens and family problems, thus developing the guilt of feeling unable to perform the role properly.

The majority of caregivers today reveal that undertaking caregiving for the elderly is their obligation. This finding is in accordance with the existing literature, which states that social norms and responsibilities reflect the general expectation that family members are especially needed by the elderly with chronic illness [49]. Nearly a third of caregivers did not experience adverse health effects due to the role of caregivers. Caregivers often find positive aspects of their experiences while caring for the elderly, although their burden is also constantly increasing. This in line with previous studies that revealed that the caregiving experience gives them purpose and meaning in life, makes them feel good about themselves, allows them to adapt to situations, and strengthens their relationships with others [50,51]. Supporting or helping others in health is as beneficial as receiving help [30].

Limitations of this study

The first limitation of this study is that most of the participants were biological children. This is because in Indonesia, biological children are the dominant family caregivers, whether it be caring for elderly, and whether they are healthy or sick. Based on this biological children-dominant factor in the participants, this study cannot be generalized considering that the experiences of family caregivers caring for sick elderly are not necessarily the same as the experiences of wife or husband caring for sick elderly. The

second limitation of this study is that the most respondents were diagnosed with stroke, and therefore this study cannot be generalized considering that the experiences of family caregivers caring for sick elderly with non-communicable disease might be different from the experiences of those caring for elderly with other conditions such as diabetes, pulmonary, kidney and cardiovascular disease. Another limitation is that while caring for chronic illness must be unforgettable and deeply remembered by the family caregivers, the recall bias could be possible with the passage of time since the moment of loss.

Conclusion

The experience of caregivers in undertaking caregiving for the elderly with chronic disease has many obstacles, such as physical, psychological, and economic burdens. However, they still carry out maximum care for the elderly because the elderly are a family member they care about. Caregivers often find positive aspects of their experiences while caregiving for the elderly, although their burden also constantly increases. The caregiving experience for the elderly gives them purpose and meaning in life, makes them feel good about themselves, allows them to adapt to situations, and strengthens their relationships with others. This study expected that health facilities could pay serious attention to family caregivers and facilitate programs that can help reduce the burden on family caregivers. Further research is needed to explore the experiences of family caregiver burden on broader family roles. The study that highlights the caregiving role and patients' quality of life is also needed to investigate whether or not caregiver burden affects them.

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Conflict of interest

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Authors' contributions

Nova, Yustisia contributed to conceptualization, data curation, data collection, formal analysis, funding acquisition, methodology, project administration, writing - original draft, review & editing, investigation, and resources. Titin, Aprilatutini contributed to data collection, writing- original draft, and data curation. Angriani, Utama, Tuti contributed to supervision, validation, methodology, formal analysis, and writing-review & editing. Mahmasoni, Masdar contributed to formal analysis, software, and visualization.

Data availability

Please contact the corresponding author for data availability.

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