

Care Giver Lived Experience in Caring for Elderly with Palliative Conditions

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ABSTRACT

Introduction: Elderly is the final stage of the human development cycle. Every year the number of elderly people increases in Indonesia in the Bali area based on the population census. The prevalence of the number of elderly people from 2021 to 2022 increases. According to a survey by the Indonesian Medical Gerontology Association (PERGEMI), as many as 24.6% of the elderly population (seniors) in Indonesia have a history of chronic disease. In the condition of the elderly who are unable to take care of themselves fully, they need a caregiver or companion who is often called a caregiver, the role of a caregiver is as a provider of nursing care to the patient. Objectives: This study aims to describe of the care giver's experience in caring for elderly people with palliative conditions.

Methods: This research uses a qualitative research method with a descriptive phenomenological approach. The sample in qualitative research is called participants. The method of selecting participants in this research is not directed at numbers but is based on the principles of suitability and adequacy until data saturation is reached, meaning that sampling of participants will be stopped if those collected have experienced saturation. The instrument used in this research is the researcher. as the main instrument that has a special role when carrying out interview activities; The interview guide was carried out using a semi-structured interview question method; Field notes are carried out by preparing document sheets (field notes) where the researcher as an instrument will write nonverbal data during the interview process; A voice recorder is a recording device used as a tool to assist the interview process. Data analysis in the research was carried out using the Colaizzi 7 step process method.

Results: The results of this study by using interviews and observations from 4 participants, 4 themes were obtained that show the Care Giver's experience in caring for the elderly with palliative conditions, namely: (1) End Stage of Life Phase (2) Routine Care (3) Psychological Support (4) Spiritual Support.

Conclusions: The description of the Care Giver's experience is considering palliative conditions as conditions in the End Stage of Life Phase; Daily care focuses on Routine Care; Psychological support is really needed; Spiritual support is really needed. Based on the research results, it can be concluded that elderly people in nursing homes in the final phase of their lived experience worsening conditions between life and death and all their needs are assisted by caregivers. In palliative conditions, all daily needs are fulfilled by the caregiver. The main focus of care for elderly people with palliative conditions is providing psychological support and spiritual supported.

Keyword : Care Giver, Lived Experience, Elderly, Palliative

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Introduction (Cambria Bold 12 pt)



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Elderly is the final stage of the human development cycle where individuals will enter the age range starting from 45 years and above. At this stage, individuals hope to be able to live their lives calmly and peacefully with their families full of love (Amelia, 2019).

Every year the number of elderly people increases in Indonesia in the Bali area, based on the population census, the number of elderly people from 2021 to 2022 increases, the number of elderly people aged 60-64 years in 2021 is 199.9 thousand and in 2022 it is 208.2 thousand. thousand people, elderly people aged 65-69 numbered 152.2 thousand people in 2022 there were 157.9 thousand people, elderly people aged 70-74 numbered 104.4 thousand people in 2022 there were 109.8 thousand people, elderly people aged over 75 years old numbered 122.2 thousand people and in 2022 there will be 127.0 thousand people.

According to a survey by the Indonesian Medical Gerontology Association (PERGEMI), as many as 24.6% of the elderly population (seniors) in Indonesia have a history of chronic diseases.

Chronic diseases tend to cause permanent damage which shows a decrease in the ability to carry out various body functions, such as musculoskeletal and sensory organs. Chronic disease problems can affect older people throughout their lives (Dihni, 2022).

In the condition of the elderly who are unable to take full care of themselves, they need a caretaker or companion who is often called a caregiver. Caregivers act as providers of nursing care to patients. The role played by caregivers includes helping the elderly with mobilization, communicating with the elderly, assisting with Activity Daily Living (ADL) needs. A caregiver must be able to balance the role of responsibility towards the elderly. Especially the elderly in nursing homes (Airiska, M., Winarni & Ratnasari, 2020)

A nursing home is a home for caring the elderly. Social welfare services for the elderly through the Bali Province Social Services UPT home are a form of social responsibility and solidarity from the government. This is done to anticipate various social problems experienced by the elderly. Apart from that, in order to improve the dignity of the underprivileged and neglected elderly in accordance with the concept of local Balinese wisdom, namely Tri Hita Karana (Dihni, 2022).

Based on the results of a preliminary study conducted by researchers at PSTW Wana SRaya, there were four caregivers caring for 11 elderly people with palliative conditions, where the elderly were cared for in the isolation care room at PSTW. From the results of interviews conducted by caregivers, they said that they do not yet have a special expertise certificate in caring for them, but they always learn to update information through seminars or information from students who practice at PSTW. Participants in caring for the elderly said they learned to be patient, steadfast and sincere in caring for them. Another participant said caring for the elderly was a form of *sradha bhakti* in carrying out life's karma.

The caregiver's experience in caring for the elderly in palliative conditions at PSTW forms the basis of knowledge in providing palliative care for the elderly. An individual's experience of a phenomenon is called phenomenology. Phenomenology itself is a scientific approach that aims to examine and describe a phenomenon as the phenomenon is experienced directly by individuals in their daily lives. The aim of this research is to describe the experience of caregivers in caring for elderly people with palliative conditions. Based on the background above, researchers are interested in knowing "Care giver experiences in caring for elderly people with palliative conditions"



Methods

This study was a qualitative research method with a descriptive phenomenological approach with semi-structured interview questions. The participants in this study were care givers who had experience caring for elderly people with palliative conditions at Panti Sosial Tresna Wredha (PSTW). The inclusion criteria for this study are as follows: 1. Care givers who have experience caring for elderly people with palliative conditions at PSTW; 2. Able to communicate in expressing his experiences; 3. Willing to be a participant. The exclusion criteria for this study are as follows: 1. Participants who withdrew during the data collection process; 2. Participants who were sick during data collection (interview); 3. Uncooperative participants. Participants were taken using purposive sampling technique. Purposive sampling is selection based on the researcher's objectives. The sample used total sampling, namely 4 caregiver participants at the Tresna Wredha Wana SRaya social institution. The instrument used in this research is the researcher. as the main instrument that has a special role when carrying out interview activities; The interview guide was carried out using a semi-structured interview question method; Field notes are carried out by preparing document sheets (field notes) where the researcher as an instrument will write nonverbal data during the interview process; A voice recorder is a recording device used as a tool to assist the interview process. Data analysis in this research used the Colaizzi 7 Step process technique, namely (1) Collecting data and making data transcripts; (2). Read the transcript several times; (3). Grouping data into a category; (4). Categories are grouped into sub-themes and into potential themes; (5). Describe data and analysis results; (6). Confirm or verify themes with participants; and (7). Combine additional data into a final description of the theme .

Ethical approval was provided by the ethics committee of the Health Research Ethics Commission, STIKES Wira Medika Bali Letter number: 99/E1.STIKESWIK/EC/III/2023. All participants were asked to fill out an informed consent form and sign it voluntarily after receiving information about the study and their right to participate or not in the study. The researcher assured their privacy and confidential information with utmost security. The data collection instrument in this study was using face to face individual in depth interviews. Data collected in April 2023. All participants were given information about the purpose and stages of this study and asked to fill out an informed consent form. In the process of collecting data, researchers carry out bracketing, namely placing in brackets all the assumptions and presumptions of the researcher about the object being studied. Bracketing aims to obtain information originating from natural stories or expressions from participants about various experiences experienced without being influenced by assumptions, knowledge and beliefs.

Results

| Characteristics | | Total | Percentage(%) |
|-----------------|------------|-------|---------------|
| Age | 30-40 Year | 2 | 50% |
| | 40-50 Year | 2 | 50% |
| Marital Status | Married | 4 | 100% |



| | | | | |
|----------|--------------------|-------------------|---|-----|
| Table 1. | Level of Education | Elementary School | 3 | 75% |
| | | Bachelor | 1 | 25% |
| | Length of Work | 5-10 Year | 3 | 75% |
| | | 11-15 Year | 1 | 25% |

Participant Characteristics Based on Age, Education Level and Years of Work

Characteristics of participants based on education level: 75% elementary school education, with 100% married with 75% work experience between 5-10 years.

Participant 1

Participant 1 is a caregiver who worked as a caregiver at PSTW Wana Sraya for 3 years, the participant is a graduate of Engineering. Participants said that working as a caregiver is a form of sincerity in carrying out a routine, where what we do is a reflection of us in our old age. As a caregiver who works to care for the elderly at PSTW, of course the participant hopes that no children will put their parents at PSTW, as long as there are children or families. Participants said that caring for the elderly at PSTW as caregivers must instill a spirit of sincerity and patience, we must not be provoked by the psychological situation of the elderly we care for. Especially caring for the elderly in palliative situations, what we can do is accompany them patiently and provide support both psychologically and spiritually. In essence, we help the elderly to remain calm and accept their condition.

Participant 2

Participant 2 is a caregiver who worked as a caregiver at PSTW Wana Sraya for 5 years, the participant is an elementary school graduate. The participant stated that working as a caregiver is a self-defined obligation, for him it is a way of life, a job that must be loved and carried out sincerely. Participants stated that even though they were elementary school graduates, they felt very grateful to be able to gain knowledge informally from PSTW and from nursing students who practice at PSTW. The activities carried out focus on meeting the daily needs of the elderly. Participants said that the main thing that must be possessed in caring for the elderly is patience and sincerity, where we must be patient when listening to complaints and be patient. Participants said that what they do when an elderly person is in death is to accompany and provide support, essentially it is hoped that the elderly person will be ready and accept their condition sincerely.

Participant 3

Participant 3 is a caregiver who worked as a caregiver at PSTW Wana Sraya for 11 years, the participant is an elementary school graduate. Participants said that working as a caregiver is a form of sincerity in carrying out a routine, where what we do is a reflection of us in our old age. As a caregiver who works to care for the elderly at PSTW, of course the participant hopes that no children will put their parents at PSTW, as long as there are children or families. Participants said that caring for the elderly at PSTW as caregivers must instill a spirit of sincerity and patience, we must not be provoked by the psychological situation of the elderly we care for. Especially caring for the elderly in palliative situations, what we can do is accompany them patiently and provide support both psychologically and spiritually. In essence, we help the elderly to remain calm and accept their condition.

Participant 4



Participant 4 is a caregiver who worked as a caregiver at PSTW Wana Sraya for 4 years, the participant is an elementary school graduate. The participant stated that working as a caregiver is a self-sufficient obligation that has been outlined, for him it is a way of life, a job that must be loved and carried out sincerely. Participants said that even though they were elementary school graduates, they felt very grateful to be able to gain knowledge informally from PSTW and from nursing students who practice at PSTW. The activities carried out focus on meeting the daily needs of the elderly. Participants stated that the main thing that must be possessed in caring for the elderly is patience and sincerity, where we must be patient when listening to complaints and be patient. Participants said that what they do when an elderly person is in death is to accompany and provide support, essentially it is hoped that the elderly person will be ready and accept their condition sincerely.

Based on the results of interviews and observations from 4 participants, 4 themes were obtained that show the Care Giver's experience in caring for the elderly with palliative conditions, namely: (1) End Stage of Life Phase (2) Routine Care (3) Psychological Support (4) Spiritual Support

End Stage of Life Phase

In my opinion, an elderly person who is between life and death, ma'am, is experiencing a worsening condition (P1, L3-L5) (P1,L3-L5)

The condition of the elderly in the final phase of their life, who need help, are already weak in all conditions, so they depend on the help of other people (P2, L2-L4)

Routine Care

Elderly people who are no longer able to meet their living needs; can no longer be independent; can't walk anymore (P3, L3-L5)

Elderly people who are no longer able to carry out activities must have all their needs met with assistance from us (P4, L3-L5)

Psychological Support

We always accompany and pray and provide support to remember the family and be sincere (P1, L13-L15)

Sometimes when I'm in the final phase, I always support and give prayers, do whatever I want, provide comfort to the elderly so that I'm sincere, and I'm ready for overtime (P2, L18-L22)

Spiritual Support

The elderly who I usually accompany in the final phase also give prayers so that the elderly can calm down (P3, L20-L22)

I usually accompany the elderly to support them with prayer and accompany them to provide a sense of calm and comfort (P4, L22-23)

DISCUSSION

This finding of this study has four main themes. The themes identified are: (1) End Stage of Life Phase (2) Routine Care (3) Psychological Support (4) Spiritual Support Fase End Stage of Life



(1) End Stage of Life Phase Based on interviews that have been conducted, it is known that elderly patients with palliative conditions are in the "End Stage of Life" condition, namely the condition of elderly people in the final phase of their life, where they experience conditions that get worse in the middle of their lives. and death and all its needs are assisted by a caregiver. According to Campbell (2013) terminal illness is a condition experienced by individuals who undergo a medical condition and ultimately ends in death within a very limited time. Treatment of terminal illness patients aims to prevent and reduce the patient and provide something useful to the patient so that the patient obtains quality of life. which is good regardless of stadium or other therapeutic needs. A terminal condition is also a condition experienced by a person while undergoing medical treatment which results in death within a relatively short time. Terminal illness can occur in individuals who suffer from a disease that threatens the patient's life without any medicine to cure it. Sufferers of terminal conditions experience a decrease in quality of life, namely experiencing physical disorders such as pain, being unable to actualize themselves due to helplessness, psychological disorders such as anxiety due to actions, feeling inner suffering because they are unable to carry out activities. carry out their religious duties optimally (Ghaljeh, dkk 2016). Based on the results of existing research and theory, researchers argue the opinion that palliative conditions are conditions where patients are nearing death where the patient is in the final phase of his life.

(2) Routine Care

Based on interviews that have been conducted, it is known that care givers in caring for elderly people with palliative conditions focus on "Routine Care" care. Meeting the needs of the elderly requires knowledge or cognitive abilities and attitudes that can influence the behavior of the elderly (Surti, Candrawati & Warsono, 2017). ADL (Activity Daily Living) is the activity of carrying out daily routine work and is the main activity for self-care. ADL is a measuring tool to assess a person's functional capacity by asking about daily life activities, to find out elderly people who need help from other people in carrying out daily life activities or are able to do them. Dependence on the elderly is caused by the condition of the elderly who experience many disorders. Physically and psychologically, if the elderly do not receive support from the family, the elderly will have difficulty carrying out daily activities due to lack of ability and lack of physical immobility, problems that are often encountered in the elderly as a result of various physical, psychological and environmental problems experienced by the elderly. Immobilization can cause complications in almost all organ systems. The mental health condition of the elderly shows that in general the elderly are unable to carry out daily activities (Suci & Jepisa, 2020). Based on the results of existing research and theory, researchers argue the opinion that the focus of elderly care focuses on daily needs, the condition of the elderly with decreased physical function makes the elderly have total dependence on fulfilling daily needs such as eating, bathing, toileting and dressing, which of course these needs becomes a care routine carried out by the caregiver.

(3). Psychological Support

Based on interviews conducted by care givers in caring for the elderly in palliative conditions, they focus on psychological support by providing assistance and trying to provide comfort to the elderly. Older people live old age in different ways. There are elderly people who are able to see the importance of old age in the context of human existence, namely as a period of life that provides opportunities for them to grow and develop. There are also elderly people who view old age with attitudes that range between resignation and rebellion, denial and despair. These elderly people become locked in on themselves, thereby accelerating the



process of physical and mental decline (Anggarawati & Sari, 2021). Elderly people who received psychological support had a greater average MMSE score than elderly people who did not receive psychological support. The results of this study are in accordance with the results of Zulfutri and Miller's research in (Emilia & Tarigan, 2022) which found a significant relationship between emotional support and the behavior of elderly people with hypertension. Forms of emotional support for the elderly can be in the form of comfort, maintaining communication, and giving each other affection. The results of other research state that health services and the togetherness of the elderly in the family give rise to a high enthusiasm for life in the elderly, increase calm in life, a sense of happiness, affect physical and mental health, thereby influencing the emotions of the elderly. elderly to increase positive attitudes and behavior in the elderly, including elderly with dementia (Emilia & Tarigan, 2022). Based on the results of existing research and theory, researchers believe that psychological support is the main focus of caregiver care. Psychological support is needed to provide psychological support to elderly people in PSTW who are far from their families and feel lonely.

(4). Spiritual Support

Based on the results of the interview, it is known that caregivers in caring for the elderly in the final stage of palliative conditions provide spiritual assistance to accompany the elderly and pray for the elderly to remain calm and sincere. Elderly life is the final part of a life cycle which is accompanied by a decline in various physical, psychological, social and spiritual functions. with the emergence of various chronic diseases, apart from that, other problems that arise in the elderly are psychosocial problems such as depression, anxiety and spiritual pressure. Spiritual well-being plays an important role in having a positive impact on health and can help elderly people who experience depression and health problems to face problems in their lives (Elmaghfuroh, Febriansyah, & Agustini, 2022). Spiritual understanding can help elderly people reach their potential and improve their quality of life, so that the spiritual health of elderly people is said to be good if they fulfill several spiritual characteristics, namely: relationship with oneself, namely strength from within, namely who they are, what they can do, and also their attitudes. which relates to belief in oneself, a harmonious relationship with nature, relationships with other people where these relationships consist of harmony and disharmony, and relationships with God which include prayer and supplication, participation in worship activities (Ilham, 2020). Based on the results of existing research and theory, researchers are of the opinion that elderly people in the final phase of their lives experience increasingly deteriorating conditions between life and death and all their needs are assisted by caregivers. The main focus of care for elderly people with palliative conditions is to provide psychological support and spiritual assistance. Spiritual assistance in elderly care is carried out to provide the elderly with readiness to accept their condition.

Conclusion

Based on the results of research that has been carried out, it was found that care givers' experiences in caring for elderly people with palliative conditions resulted in four main themes. The themes identified are: (1) End Stage of Life Phase (2) Routine Care (3) Psychological Support (4) Spiritual Support. it can be concluded that elderly people in nursing homes in the final phase of their lives experience worsening conditions between life and death and all their needs are assisted by caregivers. In palliative conditions, all daily needs are fulfilled by the caregiver. The main focus of care for elderly people with palliative conditions is providing psychological support and spiritual support. Based on the findings of this study, the recommendation for further research is to conduct For further research, it is hoped that research can be carried out with a larger number of participants and not just at one nursing home. This will provide stronger data and increase the generalizability of the findings.



Ethics approval and consent to participate

Research ethical permission in this study was through the Stikes Wira Medika health research ethics commission team with permission issued No: 99/E1.STIKESWIK/EC/III/2023

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