Original Research

IJNHS

Quality of Caregiver Services and Quality of Life among Chronic Illness Undergoing Home Care in Katingan Districts, Central Kalimantan, Indonesia

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Article info

***Article history*:**
Received: February 10th, 2022
Revised: March 03th, 2022
Accepted: April 10th, 2022

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International Journal of Nursing and Health Services (IJNHS)
Volume 5, Issue 3, June 20th, 2022
DOI: 10.35654/ijnhs.v5i3.575
E-ISSN: 2654-6310

Abstract

Background: The chronically ill person often gets late treatment because there is a lack of family preparation to deal with the chronic disease process, resulting in a heavy burden on the community, family, and quality of life of persons with chronic diseases in the Katingan District. **Objective:** The study aimed to examine a relationship between caregiver services and quality of life in a chronically ill person undergoing home care. **Methods:** The research method used is correlational design. Participants were randomly selected: 187 chronically ill persons receiving care at home in six subdistricts in Katingan District, Central Kalimantan. The participants in this study had at least been suffering from chronic illnesses for more than three months during their home treatment. **Results:** there is a significant relationship between caregiver services for chronically ill persons and the quality of life of chronic sick persons ($r = 0.471$ and $p = 0.00$). **Recommendation:** The finding of this study be utilized as a guideline to the policymakers, community health canter, health workers, nurses, educators, family, and researchers to determine areas to improve caregiver services, which could translate into a significant improvement in the quality of life chronically ill persons.

Keywords: caregiver, chronically ill person, quality of life, level of care services.

INTRODUCTION

Indonesia is one of the countries with the highest mortality rate due to chronic diseases(1). Compared to other Asian countries, Indonesia ranked second after Sri Lanka and seventh in the world, along with China, India, Brazil, Russia, the United States, and Mexico (2). Taking into account all Indonesian hospitals in 2009, the national rate of inpatients with chronic disease was 29.2%, and that of outpatient was 28.37% (3). Data from inpatients and outpatients with chronic diseases throughout the provinces in Indonesia in 2010 show that Central Kalimantan had one of the highest percentages: 47% inpatient clients and 60% outpatients (4).

The data revealed that chronic disease burden is a reality in many provinces and districts, one of which is the Katingan District. In 2012, Katingan District was one of the significant contributors to mortality and morbidity in Central Kalimantan, based on reports from the hospital and the community health center of Katingan District (5). However, although the Posbindu-PTM program has been working to reduce mortality and morbidity, until 2017, the number of persons with chronic diseases in Central Kalimantan is still increasing yearly (6). The Central Kalimantan Health Department noted that the increase in the number of persons with chronic diseases was attributed to the unhealthy lifestyle of the people, and there are still many districts that do not receive good health services, including Katingan District (5).

Chronically ill persons' unstable condition, easily infected with other diseases, requires intensive therapy, and a complex of needs often causes families and chronically ill persons to be unprepared for the changes that occur in their lives (7)(8). In addition, the lack of knowledge of family and chronically ill persons causes the quality of life to be received with deficient attention when a person has a chronic disease(9). This disrupts various aspects of their lives, such as their spiritual, physiological, social interaction, self-concept, and economic elements (7)(10). The government made efforts to reduce the number of people with chronic diseases by activating the Integrated Non-Communicable Disease Development Program (Posbindu-PTM) in each alert village in Central Kalimantan (11). However, although the Posbindu-PTM program has been working to reduce mortality and morbidity, until 2017, the number of persons with chronic diseases in Central Kalimantan is still increasing yearly (6).

The Central Kalimantan Health Department noted that the increase in the number of persons with chronic diseases was attributed to the unhealthy lifestyle of the people, and there are still many districts that do not receive good health services, including Katingan District (5). In 2012, Katingan District was one of the significant contributors to mortality and morbidity in Central Kalimantan, based on reports from the hospital and the community health center of Katingan District (5).

Everyone hopes to have a good quality of life and die with dignity. However, even now, in Katingan District, many chronically ill persons still have not received proper care and treatment (4). It has been observed that health workers in Katingan District have given less attention to the aspects of the quality of life of chronically ill persons. Besides that being a low priority, many health workers or family members who provide care have insufficient knowledge in caring for chronically ill persons.

The chronically ill person often gets late treatment because there is a lack of family preparation to deal with the chronic disease process, resulting in a heavy burden on the community, family, and the persons with chronic diseases in the Katingan District. As a result, all aspects of the family life of chronically ill persons are disturbed, including spiritual, physiological, social interactions, self-concept, and economic (12). Therefore, as a clinical decision-maker and an advocate for chronically ill persons, a health provider must pay attention to family preparedness and the well-being of chronically ill persons in dealing with the adverse effects of chronic disease processes and complex care(13).

OBJECTIVE

The study aimed to examine the relationship between caregiver services and quality of life among chronically ill people undergoing home care in Katingan Districts, Central Kalimantan, Indonesia.

METHODS

Design

This study applied the correlational design to determine reciprocal relationships between caregiver services and quality of life in a chronically ill person undergoing home care.

Sample size and sampling technique

The population of this research was 187 chronically ill persons undergoing home care in Katingan District, Central Kalimantan. The sampling technique used was simple random sampling. The researcher selected six sub-districts of the 13 sub-districts in the Katingan District for males or females diagnosed with chronic diseases, at least three months or longer (age ≥ 18 years old).

The instrument for data collection

Data was collected using a questionnaire comprising three instruments. First, the researcher used a demographic data questionnaire consisting of gender, age, civil status, health problems, caring for chronically ill persons at home, and duration of providing care services to chronically ill persons at home. Second, the researcher modifies the care practices profile of chronically ill persons by the Family Caregiver Alliance (2006)(14). The level of caregiver services consisted of 25 items and was measured using a 5-point Likert scale with the following ranges: The higher the total score, the higher the level of care services provided. These scores are interpreted as 1.00 – 1.79 = 100% assistance, 1.80 – 2.59 = 75% assistance, 2.60 – 3.39 = 50% assistance, 3.40 – 4.19 = 25% assistance, and 4.20 – 4.99 =0% no assistance.

Third, the researcher adopted the World Health Organization Quality of Life (WHOQOL)-BEFF developed by the World Health Organization (2004)(15). the World Health Organization Quality of Life consisted of five parts, with 31 items. A 5-point Likert scale was used to determine the quality of life: self-concept, economic aspect, and spirituality. These are interpreted as 1.00 – 1.79 extremely poor, 1.80 – 2.59 poor, 2.60 – 3.39 slightly poor, 3.40 -4.19 not so good, and 4.20 – 4.99 good.

The questionnaire was faithfully translated into the Indonesian language and back-translated to English text for accuracy. The translated questionnaire was pretested through a study in Central Java, Indonesia, with 30 participants with chronic illness and 30 caregivers. Validity and reliability tests resulted in a Cronbach's alpha = 0.971 for the care practices profile of chronically ill person questionnaire and a Chronbach’s alpha for the quality of life of sick chronically person questionnaire of 0.962.

Data collection process

The data were collected in August 2020 using a structured questionnaire. The researcher collected data from six subdistricts in Katingan District. The six subdistricts were Katingan Hilir, Tewang Sangalang Garing, Pulau Malan, Central Katingan, Sanaman Mantikei, and Katingan Hulu. The data collection in each district was done after obtaining a research permit from the Development of Regional Development Planning Research and Strategies of Central Kalimantan Province, Development of Regional Development Planning Research and Strategies of Katingan District, and the Department of Health Katingan District.

The researcher used the data of chronically ill persons from the Community Health Center as guidelines to select patient and carer participants. Before data collection, the researcher asked permission from participants and gave them information about this study, such as the potential benefits and risks to the participants. A contract time to meet the participants and the place to meet was set in the process of collecting data.

Data analysis

Profiles of chronically ill persons and their caregivers are presented in percentages. The quality of life of chronically sick persons is demonstrated through their mean values as a measure of central tendency. To determine if a significant relationship exists between the level of care services rendered by caregivers. For the quality of life of chronically ill persons, the Pearson Product-Moment correlation analysis was used at a 0.05 level of significance.

Ethical consideration

This research was carried out according to the code of ethics applicable at the Silliman University research ethics committee. Human dignity was ensured by obtaining the participants' consent to participate in the study using informed consent. Participants joined the study voluntarily and were informed of their right to withdraw participation at any time. The right to fair treatment and participants' privacy was also ensured by maintaining data confidentiality and anonymity through coding.

RESULTS

Table 1. Characteristic chronically ill persons

Characteristic	**Number of Respondents (N=187)**	
	Number of Carers of Chronically Ill Persons	**Percent**
Gender		
Male	94	50.3
Female	93	49.7
Age, years		
30-45	15	08.0
46-55	36	19.2
56-65	87	46.5
66-75	39	20.8
76-85	10	05.4
Civil Status		
Single	6	03.2
Married	141	75.4
widow/Widower	32	17.6
SeparatedDivorced	7	03.7
Health Problems		
Heart trouble	3	01.6
High blood pressure	64	34.2
Cancer	1	00.5
COPD	1	00.5
Stroke	7	03.7
Diabetes mellitus	86	45.10
Chronic kidney failure	1	00.5
Tuberculosis	2	01.1
Asthma	22	11.8
Caring for chronically ill persons at home		
Friend	1	0.05
Spouse/Partner	60	32.1
Children	2	01.1
Parent	91	46.7
Sibling	33	17.6
Duration of providing care services		
<1 year	40	21.4
1-2 year	81	43.3
>2 year	66	35.3

Based on the results of this study, shown in Table 1, of the people with chronic diseases in six subdistricts in the Katingan District, 50.4% (94 people) are male, and 49.7% (93 people) are female. The highest percentage of chronically ill persons in the Katingan District is experienced by persons aged 56 to 65, with a percentage of 46.5% (87 persons). Regarding civil status, the majority (75.4%) of respondents with chronic illness in the Katingan District are married, 3.2% are single, and 3.7% are separated/divorced. The most common disease of participants was diabetes mellitus, noted in 86 people (45.1%), the second most common was hypertension, indicated in 64 people (34.2%), and asthma ranks third as a disease among 22 participants (11.8%).

This study shows the relations of carers with chronically ill persons (Table 1): 91 carers (46.7%) provide care for their parents, 60 carers (32.1%) provide care for their spouses, 33 carers (17.6%) provide care for their siblings, and two carers (01.1%) provide care for their children. In this study, the carers have provided complex care for chronically ill persons for a long time: 40 carers (21.4%) have provided chronically ill persons care for almost one year; 81 carers (43.3%) treated chronically ill persons for 1 to 2 years, and 66 carers (35.3%) treated chronically ill persons more than two years.

Table 2. Quality of Life of Persons with Chronic Illness

Aspects	**Mean Score**	**Interpretation**
Physiological	2.4298	Not So Good
Social Interactions	4.0845	Good
Self-concept	2.7594	Slightly Poor
Economic	2.0254	Poor
Spiritual	4.4519	Good
Respondents' Quality Of Life: Slightly Poor		**3.1502**

Based on the survey data in Katingan Districts (Table 2), the quality of life of chronically ill persons in Katingan District is slightly poor, with a mean score of 3.1502. Can be seen in The physiological aspects of sick chronically persons in Katingan Districts are "not so good," with a mean overall score of

2.4298, have a slightly poor self-concept, with a mean overall score of 2.7594, economically poor, with a mean overall score of 2.0254, but they have good social interaction aspects, with a mean overall score of 4.0845, and have an excellent spiritual part, with a mean overall score of 4.4519

Table 2.1 Frequency and Percentage Distribution of Chronically Ill Persons' Perceived Quality of Life

Quality of Life	Number of Chronically Ill Persons	Percent
Extremely poor	0	00
Poor	58	31
Slightly poor	104	56
Not so good	25	13
Good	0	00
Total	**187**	**100**

This study shows that chronically ill persons in Katingan District have a slightly poor quality of life, with the highest percentage of 56% (104 sick). Meanwhile, there are 58 people with chronic diseases with poor quality of life and 25 persons with chronically ill with not-so-good quality of life.

Table 3. Frequency and Percentage Distribution Level of Caregiver Services Provided for Chronically Ill Persons

Level of Rendered Care Services	Number of Carers of Chronically Ill Persons	Percent
100%	58	31
assistance	52	28
75% assistance	29	16
50% assistance	40	21
25% assistance	8	04
No assistance		
Total	187	100

The results of this study (Table 3) record the level of care services rendered to chronically ill persons in the Katingan District. Among the participants, 58 (31%) chronically ill persons received 100% care services, 52 (28%) received 75% care services, 25 (16%) received 50% care services, 40 (21%) received 25% care services, while 8 (4%) received no assistance.

Table 4. Tests for Significance of the Relationship between Two Variables

Paired Variables	Statistical Treatment	Interpretation at α = 0.05
Caregiver services and quality of life	r = 0.471 p-value = 0.0000	Significant

Based on data in Table 4, there is a significant relationship between the quality of life of chronically ill persons and the level of care services for chronic sick persons (r = 0.471 and p = 0.0000).

DISCUSSION

The findings of this study addressed a significant relationship between the quality of life of chronically ill persons and the level of caregiver services for sick chronically persons at home. A total of 25 (13%) (Table 2.1) sick chronically persons have a "not so good" quality of life. Chronically ill persons often suffer (physically) pain, and mostly, they have difficulty handling any pain or discomfort and difficulty performing their routine activities because of disease.

This study shows that chronically ill persons in Katingan District have a slightly poor self-concept, with a mean overall score of 2.7594 (Table 2). In Katingan District, most chronically sick persons have chronic diseases that cause other conditions such as damage to the integrity of the skin due to bed rest, diabetic wounds, breast cancer wounds, decreased motor system function due to stroke, and so on. This supports the study conducted by Lcsw & Licsw (2017)(16), which shows that self-image is how a person values himself and how others think of others. Belil, Alhani, & Ebadi (2018)(17) point out self-efficacy is one's coping ability in certain situations, related to the mindset, behavior, and emotions at various levels of experience. Someone with good self-efficacy can control their emotions, manage themselves, and have good quality and mental health. However, when someone is sick, this aspect becomes disturbed. In a study by Lucykx (2016)(18), chronically ill persons will constantly adjust themselves during the disease process. Individuals with a good self-concept have a positive attitude in managing emotions, can deal with changes in their lives, and have relatively low-stress levels.

On the other hand, chronically ill persons who do not have a good self-concept have difficulty controlling their emotions and feel depressed at any time, which impacts the loss of quality of life. Considering that most chronically ill persons in Katingan District are 65 years or older. Age is one of the factors that can reduce the quality of life of chronic sick persons because the more senior the chronically ill person, the more the rate of/her life decreases, and the younger the sick chronically persons, the better their quality of life (19).

Meanwhile, when viewed from the gender aspect, Herwana (2006)(20)found no significant difference between the quality of life of men and women when they had a chronic illness; both had a low quality of life. Vlassoff (2007)(21) points out that men and women have different responses regarding receiving the care given, seeking treatment, and changing responsibilities at home when they suffer from chronic illness. According to him, women tend to have more negative coping than men, such as withdrawing, protesting, and self-isolation. In contrast, men think more about the effects of chronic diseases on their freedom of activity.

Maslow's hierarchy of needs also shows that physiological conditions are one of the highest basic needs that must be met. When someone is chronically ill, their physiological needs are disrupted because of the symptoms such as pain, fatigue, mood disorders, changes in body image, decreased range of motion, and disability. Hickman (2011)(22) shows that when someone gets a chronic illness, physiological aspects affect the psychological condition of the chronically ill person and family, which causes depression, anxiety, worsening of the health condition of chronically ill persons, and difficulties in making decisions in the family. Caregivers must help chronically ill persons regain their quality of life through the care services they provide.

The results of this study are consistent with research by Collins et al. (2011)(23), which shows a significant relationship between the level of caregiver services and improving the quality of life of people with chronic illness. A caregiver who gets psychoeducation, skills training, therapeutic counseling, appropriate information, and support from community health workers has better skills and knowledge than caregivers who do not. These caregiver skills help improve the quality of chronically ill persons and reduce the burden on the caregiver. Hickman (2011)(22) shows that the level of care services and the quality of life of chronically ill persons can be disrupted because of the psychological awkwardness of the family due to complex disease processes. The uncertainty of chronic diseases causes families of chronically ill persons to experience higher psychological pressure. This psychological pressure affects the family in making rational decisions in providing nursing care to the chronically ill person, resulting in a decrease in the quality of life of chronically ill persons. Another study with a larger sample size on the same population should be conducted to confirm this research finding. The result of this study is that there is a significant relationship between the level of caregiver services and the quality of life of chronically ill persons. It is recommended that professional health care in the community should continuously improve their knowledge and share that knowledge with family members who provide care services for the chronically ill family member. Sharing the knowledge can improve carer and sick chronically persons' knowledge about the nature of the diseases, diagnosis and findings, and how to perform personal care.

Conclusion

This study shows a significant relationship between the quality of life of chronically ill people and the level of caregiver services for chronically ill persons, with r = 0.471 and $p = 0.0000$. It means a decrease in the quality of life of sick and chronically persons can occur due to the provision of inadequate care services. This study has several limitations. The research was supposed to be conducted in seven sub-districts in Katingan District, but the researcher was only able to collect data from only six sub-districts. This is due to the considerable distance to one sub-district, and the researcher is less familiar with the place. The researchers did not visit the area due to difficulty contacting local health workers because there was no telephone or internet access.

Acknowledgment

The deeper gratitude and sincere appreciation to all significant contributors who, in one way or another, have made this study so meaningful. Thank you so much To Prof. Theresa A. Guino-o, Dean College of Nursing, Silliman University, Dumaguete City, the Philippines, who independently supervised, supported, and encouraged me throughout this research work. I am very thankful to the Satya Wacana Christian University's Faculty of Medicine and Health Sciences for providing the opportunity and financial and moral support for me to be able to finish this research. My warmest thanks to all the nurses, patients, and their families for their time, effort, assistance, and contribution throughout the research process.

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