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# Perceived factors contributing to the care provided by informal (family) and formal caregivers of older adults with noncommunicable diseases in rural communities: A qualitative focus group study

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## Abstract:

**BACKGROUND:** Informal and formal caregivers of older adults with noncommunicable diseases (NCDs) are important in every aspect of current caregiving for older adults by understanding reality specific to direct experiences perceived by each person in caring for older adults in order to develop nursing knowledge and using knowledge to plan care for older adults with NCDs to have a good quality of life. The current study aimed to investigate the points of view on factors concerning the care provided by informal and formal caregivers providing care for older adults with chronic diseases in the community.

**MATERIALS AND METHODS:** This study was conducted with a qualitative design. The sample was 5 informal and 20 formal caregivers providing care for patients with chronic diseases, namely hypertension and diabetes mellitus. Furthermore, a qualitative approach was used with four focus groups (FGs) with 25 informants. Data were collected during March–August 2021 in rural communities of Nakhon Phanom Province, Thailand. Finally, the qualitative analysis used content analysis; FG data were analyzed using content analysis in which a preliminary set of codes was determined according to other documented experiences of patients.

**RESULTS:** The findings revealed three main themes emerging in the data obtained on the perceived factors contributing to the care provided by informal and formal caregivers: “caregivers’ knowledge,” “factors related to caregivers” and “community factors.”

**CONCLUSION:** Points of view on the factors correlated with the care provided by informal and formal caregivers of older adults with chronic diseases that explain and confirm the findings can be used to plan care with effects on quality of life among older adults with chronic diseases.

## Keywords:

Formal caregivers, informal caregivers, noncommunicable diseases, rural communities

## Introduction

Noncommunicable diseases (NCDs), or chronic diseases, are medical conditions that are time-consuming and may be caused by several factors such

as genes, physiology, environment, and behavior. Examples of NCDs include cardiovascular disease (heart attack, stroke), cancer, chronic respiratory diseases (chronic obstructive pulmonary disease, asthma), and diabetes mellitus.<sup>[1]</sup> NCDs account for

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70% of mortality in the world's population, while 16 million people with NCDs die before 70 years of age and 82% of these premature deaths due to NCDs occur in low- to middle-income populations. The rise in chronic disease is primarily attributed to the following four risk factors: smoking, lack of exercise, alcohol consumption, and malnutrition.<sup>[1]</sup> The incidence of chronic disease among older persons tends to relatively increase, partly due to advanced age and poor self-care management.

Chronic disease renders older adults vulnerable to disability or death. According to the NCD office,<sup>[2]</sup> the chronic diseases accounting for death in Thailand include heart attack and stroke (58.6%), ischemic heart disease (18%), stroke (25.1%), hypertension (7.1%), and diabetes mellitus (11.3%). Chronic disease in older adults causes them to experience physical and emotional stress and economic burden, while having an older adult with a chronic disease also affects family members, communities, and health, particularly in countries where patients have difficulty accessing qualified medical care with prompt diagnoses and treatments. On the other hand, countries with advanced health-care systems have been reported to have higher survival rates due to earlier detection and effective, prompt treatment.<sup>[1]</sup> There are different ways of providing care for patients with NCDs, including screening, treatment, and palliative care. Importantly, preliminary self-care is likely to promote early detection, thereby reducing complications, duration of treatment, and treatment costs. Patients undergoing a prompt, effective treatment may prevent early loss of life.<sup>[1]</sup>

In addition to age itself, this group of patients suffers also from the reduced role in society, increasing cost of living, and lack of caregivers.<sup>[3]</sup> Indeed, not only the patients themselves but also communities and those giving care to older adults, including family members and caregivers, affect the progression of the disease pertaining physical, psychological, and socioeconomic aspects. In a community, a caregiver covers both formal and informal (family) caregivers. By definition, formal caregivers are individuals who work for hospitals and have no personal relationships with patients, while informal caregivers are usually family members bound together either through marriage or blood ties and are not paid for doing the job.<sup>[4]</sup> Both formal and informal caregivers play key roles in providing care for older adults with chronic disease, and their knowledge and attitudes affect treatment outcomes. This was consistent with the findings of Machado *et al.*<sup>[4]</sup> who studied quantitative and qualitative research and strategies for coping with problems in the daily lives of family caregivers with chronic diseases and found that strategies for coping with problems among the participants were the accomplishment of "pleasurable

activities, spirituality and informal social support." Therefore, in the present study, we used qualitative methods with focus groups (FGs) by emphasizing data intensity to describe the core of phenomena and factors related to the care provided by caregivers of older adults by understanding reality specific to direct experiences perceived by each person in caring for older adults in order to use this understanding to develop nursing knowledge and using knowledge to plan care for older adults with noncommunicable chronic diseases to have a good quality of life.<sup>[5]</sup> The objective of this research was to study the points of view on factors concerning the care provided by informal and formal caregivers providing care for older adults with chronic diseases in the community.

## Materials and Methods

### Study design

The current study was a qualitative approach was employed to explore attitudes, beliefs, and points of view on their jobs using FG discussions.

### Study participants and sampling

The informants were selected by convenience sampling. They were caregivers of older adults with chronic diseases dwelling in 11 communities of rural Thailand. The informal caregivers comprised either children, grandchildren, relatives, friends, or neighbors who had not been paid for any caregiving and had experience in providing care for older adults for a minimum of 1 year ( $N = 5$ ). The chronic diseases included hypertension, type 2 diabetes mellitus, or pulmonary disease. The formal caregivers comprised caregiving volunteers, professional caregivers, professional nurses, or health-care team members who were constantly engaged in organizing activities for the elderly ( $N = 20$ ). Any candidates who were illiterate in Thai were excluded from the study. In this study, a total of 25 persons were selected as the study subjects, this study had four FGs with 5–7 informants per group consisting of 5 informal caregivers and 20 formal caregivers (nurses = 2, caregiving volunteers and caregivers = 18). The study was conducted from March to August 2021.

### Data collection tool and technique

The questionnaire on the personal information of the subjects covered demographic information and illness information, including age, gender, marital status, education level, occupation, family income, duration of caregiving to older adults with chronic disease, training participation concerning chronic diseases in older adults, and problems faced by the caregivers.

The questions for the FG discussions with the informal caregivers covered experience in caregiving, attitudes,

points of view on giving care, approach to caregiving, caregiving outcomes, and related factors.

The questions for the FG discussions with the formal caregivers (caregiving volunteers, caregivers, and public health personnel from health promotion hospitals) covered policies and plans to provide care for patients with chronic diseases based on current practices and decisive factors of achievement. A recording form for the FG discussions and an observation form were used to record observation of the subjects' activity participation.

The instruments used to collect data included a questionnaire on personal information and a question guideline for the group discussion using semi-structured interviews. Content validity was verified by three experts, including two nursing instructors and one professional nurse specializing in chronic disease. Reliability was tested when data recordings were transcribed for peer debriefing by two qualified experts, who tested data reliability, and member checking by bringing interpreted or theme-organized work to informants to read and check again in order to have understanding matching meanings related by informants.<sup>[6]</sup>

### Data collection

After the ethical committee approved the study (Code: NKP REC NO 005/64) at the first stage, the researcher contacted the health-care personnel at the health promotion hospital, caregiving volunteers, caregivers, and related informants for help in screening the population eligible for the study. The samples were informed of the study's objectives and rights protection before giving consent for research participation. The questionnaires on personal information were distributed and completed by the subjects, which took approximately 10 min. Afterward, to collect data from four FGs who represented family caregivers, caregiving volunteers, caregivers and medical personnel from the health promotion hospital, the researcher conducted 60–90 min FG interviews and group discussions.<sup>[6]</sup>

### Data analysis

Personal data were analyzed using descriptive statistics consisting of frequency distribution, percent, mean, and standard deviation. FG discussions were then transcribed, summarized, and coded by the researcher who was trained in qualitative analysis.<sup>[6]</sup> FG data were analyzed using content analysis in which a preliminary set of codes was determined according to other documented experiences of patients. Next, the researcher added new codes as needed for data analysis and to identify emerging themes.<sup>[7]</sup>

## Results

This study was conducted with the objective of studying the points of view on factors concerning the care provided by informal and formal caregivers providing care for older adults with chronic diseases in the community. The findings were divided into the following two parts: (1) sociodemographic characteristics and (2) perceived factors contributing to the care provided by informal and formal caregivers providing care for older adults with chronic diseases in the community (FGs) were as follows.

### Sociodemographic characteristics

#### *Formal caregivers*

The personal data characteristics of 20 subjects showed that subjects consisted of males (4.8%) and females (95.2%). Most of the subjects were aged 40–49 years (49.8%) (mean = 43.24). The subjects were married (68.8%) and had secondary levels of education (66.9%). The subjects worked as caregiving volunteers and caregivers (90.4%) with income under 10,000 baht per month (90.4%). Furthermore, the subjects had cared for older adults for more than 60 months (49.5%). The subjects were involved with older adults through the performance of tasks involving older adults (76.2%) and had training in the care of older adults (100.0%). Most of the caregivers had problems related to problems from older adults with comorbidities (74.8%) in Table 1.

#### *Perceived factors contributing to the care provided by informal and formal caregivers providing care for older adults with chronic diseases*

According to the FG interviews with 5 informal caregivers and 20 informal caregivers, the following three themes emerged in the data obtained: caregivers' knowledge, factors related to caregivers, and community factors, as shown in Table 2.

#### *Theme 1: Caregivers' knowledge*

Analysis of individual questions and from FGs of formal and informal caregivers had three subthemes consisting of dietary management, abnormal symptom observation, and medication administration.

#### *Dietary management*

Knowledge about food preparation found among the informal caregivers consisted of appropriate food selection for diseases and food preparation for patients according to the following statements:

"When preparing food, I know which foods are right. I prepare at least one meal with protein to give my mother energy."

#### *Observation of abnormal chronic disease symptoms*

The formal and informal caregivers had to be trained to observe abnormal symptoms of patients specific to the

**Table 1: Number, percentage, and personal characteristics of informal and formal caregivers**

Characteristics	Informal caregiver (n=5), n (%)	Formal caregiver (n=20) (health-care professionals=2, caregiving volunteers and caregivers=18), n (%)
Gender		
Male	-	1 (4.8)
Female	5 (100)	19 (95.2)
Age (years), mean (SD)	51.11 (11.67)	43.24 (9.27)
18-29	-	3 (15.6)
30-39	1 (4.8)	4 (19.0)
40-49	3 (90.4)	10 (49.8)
50-59	1 (4.8)	3 (15.6)
Marital status		
Single	1 (4.8)	3 (15.6)
Married	4 (95.2)	14 (68.8)
Widowed/divorced	-	3 (15.6)
Education		
Primary	4 (95.2)	4 (19.0)
Secondary	1 (4.8)	13 (66.9)
Bachelor	-	3 (15.6)
Occupation		
Farmers	5 (100)	-
Civil servants	-	2 (9.6)
Caregiving volunteers and caregivers	-	18 (90.4)
Income		
<10,000	5 (100)	18 (90.4)
10,001-20,000	-	2 (9.6)
Duration of caregiving (months)		
<30	-	4 (19.0)
30-60	1 (4.8)	6 (29.5)
>60	4 (95.2)	10 (49.5)
Relationships with care recipients		
Daughter	5 (100)	-
Sibling	-	5 (23.8)
Performance of tasks involving older adults	-	15 (76.2)
Training in the care of older adults		
Absent	-	-
Present	5 (100)	20 (100)
Perception of news		
Absent	-	-
Present	5 (100)	20 (100)
Mode of receiving news/information		
Authorities	5 (100)	18 (90.4)
Caregiving volunteers and caregivers	5 (100)	2 (9.6)
Caregivers' problems		
Absent	-	3 (15.6)
Caregivers' expenses	5 (100)	-
Underlying disease	5 (100)	-
Older adults with comorbidities	-	15 (74.8)
Caregivers' health	-	2 (9.6)

Four focus group: Informal caregiver (n=5), health-care professionals and caregiver (n=6), caregiver and caregiving volunteers (n=7), caregiver and caregiving volunteers (n=7). SD=Standard deviation

disease. Formal caregivers who were professional nurses learned about each chronic disease and provided regular training for volunteer caregivers. Furthermore, formal caregivers used knowledge to advise informal caregivers in the care of patients and in observing abnormal symptoms. Caregivers were able to observe abnormal

symptoms from observing symptoms of patients with hypertension and diabetes according to the following two statements:

“I have methods for observing abnormal symptoms. If my mother begins to ask questions or if she’s blurring,

**Table 2: Themes and subtheme from focus group interviews**

Themes	Subthemes
Caregivers' knowledge	Dietary management Abnormal symptom observation Medication administration
Factors related to caregivers	Caregivers' income Older adults with comorbidities Difference of caregivers' chronic diseases Fatigue Pride
Community factors	Community organizations Training courses

slowing, feeling dizzy or numb, I make preparations for her to be checked out at the THPH in the morning. Before we leave, I also get her to fast."

"I visited homes for one hour/case on a weekly basis. I measured blood pressure every time. If blood pressure was abnormal, I'd ask patients about their past activities that may have caused blood pressure to be high. I'd measure again. If the blood pressure was still high after measuring for the second time, I give them advice and send them to the THPH."

Furthermore, in the area of caregivers' knowledge, qualitative data on drug administration knowledge was found.

Knowledge about drug administration was mostly found among informal caregivers who cared for patients at all times, managed drugs for patients according to time, and had knowledge about each type of drug prepared for patients including drug activation mechanisms.

"I prepared the drugs myself by putting them in cups and telling my mother to take it after she was done eating. This was so that her phosphorus won't be high when she's on dialysis."

### *Theme 2: Factors related to caregivers*

Analysis of individual questions and from FGs of formal and informal caregivers had five subthemes consisting of caregivers' income, older adults with multiple illnesses, caregivers' chronic diseases, fatigue, and pride.

#### *Caregivers' income*

In the area of based on the personal data of the informal caregivers, most of the caregivers' problems were found to be related to caregivers' expenses (100%). The incomes of informal and formal caregivers were under 10,000 baht per month (100% and 90.4%, respectively). This was consistent with the qualitative data. The informal caregivers had to have more knowledge about practices than patients and higher care-related expenses according to the following informal caregivers' statement:

"I work alone at home. Someone who has kidney disease needs to have a properly modified room. Funds are difficult."

#### *Older adults with multiple illnesses*

Most of the caregivers' care problems were found to be concerning problems of older adults with multiple illnesses (74.8%). This was consistent with qualitative data in regard to problems of caregivers of older adults with multiple illnesses from how older adults had confidence, exchanged knowledge, and believed friends with chronic diseases from having more knowledge of self-care behaviors, multiple chronic diseases, and repeated monthly treatments according to the following three statements:

"Some patients know what they will be examined for and refuse blood pressure tests and blood glucose tests in addition to not following recommendations."

"Patients understand and believe each other easily when they talk among themselves. If you tell them that taking a lot of drugs will make them have kidney failure, they will stop taking drugs. This is the main problem."

"Diabetic and hypertensive patients will not eat sweet, fatty or salty foods for 3 days before being examined. They know that this will prevent their blood sugar from being high when they are examined. Some of them don't eat at all."

#### *Caregivers' chronic diseases*

Most of the caregivers were found to be related to older adults as children (100%). DM and hypertension are genetic diseases. Therefore, many informal caregivers who had the same diseases as parents were found. Consequently, knowledge about diseases in self-care and care for patients was correlated with chronic diseases in line with qualitative analysis. Furthermore, genetics, dietary lifestyles, and living in families and communities were correlated with caregivers' chronic diseases according to the following two statements from family caregiver FGs:

"Genetics, lifestyle, living together and partying. Whoever wants to eat something brings it and cooks it to eat together. Eating sweet things gives you energy."

"I just found out that my mother is diabetic because my mother's sister is also diabetic, but she went into shock and died at the age of only 39 years."

#### *Fatigue*

The factors stemming from the physical aspects of providing care for patients were fatigue and other physical risks found in caregivers.

“Sometimes, patients refuse to listen to their relatives or other people in their households, so the burden falls on us, so we feel tired to have to provide care and do everything.”

“It’s risky every time we make a home visit. Some houses have really mean dogs and we can’t even get inside the house, even when we’ve notified them ahead of time about the day we’re going to visit. They don’t help or put the dogs in a cage.”

### *Pride*

In addition, the mental aspects of working as a caregiving volunteer can result in pride in providing care for patients.

“I’m proud to be a caregiving volunteer. I get to help patients in my community.”

### *Theme 3: Community factors*

Social support from the related agencies in the community such as local administrative organizations, village leader groups, village headmen and health personnel have different roles in assisting and providing care for patients with chronic disease as shown in the following two statements by formal and informal caregivers:

“For the care of patients, we make home visits on schedule at 3 months, 5 months and 9 months. According to the CPG, we screen for complications and provide care based on treatment plans...”

“We’ve got TAO leaders and people in the community who helped construct a kidney dialysis room for us where we can help one another provide care. It’s lucky that we’ve helped other people in the community before, so they’re helping us.”

Based on the data obtained on personal characteristics, most informal caregivers had received news and information (100%). The modes through which they received news and information were authorities, other caregivers, and caregiving volunteers.

### *Training courses*

Community factors included a health-care system to support training courses for formal caregivers on a regular basis, so they would receive knowledge and make suggestions to older adults with chronic disease.

“Every year, I attend training courses about providing care for patients with chronic disease. Every time, here are other agencies there who arrange academic conferences. Once nurses have been trained, they become the trainers for caregiving volunteers and CGs.”

“As caregiving volunteers, we receive instruction and training from doctors and nurses. We practice until we

understand. Then we can take care of patients at another level.”

The above findings correspond with the personal data on both the informal and formal caregivers who have training in the care of older adults at a rate of 100%.

## **Discussion**

According to the findings, the personal data of informal and formal caregivers of older adults showed most of the subjects to be aged 40–49 years. The subjects at those ages were of working age with greater care and attention for older adults than other ages. This was similar to Martins *et al.*<sup>[8]</sup> who found informal and formal caregivers aged 40–49 years to have strength and energy. Most of the formal and informal caregivers were married women. This was consistent with previous findings revealing married women to perform caregiving activities better than single or divorced people.<sup>[9,10]</sup> Female caregivers cared for parents as another duty through beliefs or culture. Most of the caregivers were related to patients as children with the primary duty of caring for parents. This was consistent with the study which found most of the caregivers to be children or relatives who had to provide care to repay gratitude.<sup>[8,11]</sup> In addition, informal and formal caregivers cared for older adults for more than 60 months. This was consistent with the study which found 60% of informal caregivers to have provided care for more than 3 years.<sup>[4]</sup>

According to the analysis of caregivers’ knowledge, the caregivers possess observations of abnormal symptoms, drug administration, and dietary management. The findings were also similar to a study conducted by Liu *et al.*<sup>[12]</sup> who found caregivers’ experience to have effects on stroke knowledge with statistical significance. In addition, based on the literature review, it was found that caregiver facilitation of health care is positively correlated with personal and/or social resources as well as workload or burdens. As long as caregivers have adequate access to the necessary resources, the burden and quality of care provided can be balanced. In this regard, the key essential resources include health-care provider support and perceived caregiver confidence.<sup>[13]</sup> The above findings correspond with the culture of instructing informal caregivers, which is the role of formal caregivers and is believed to ease the burden of providing care.<sup>[14]</sup>

Caregivers’ income – Concerning the findings revealed most of the care-related problems encountered by family caregivers regarding caregivers’ problems with expenses. This was consistent with the study, in the area of burdensome experiences among the formal and informal caregivers of older adult patients with broken

hips, qualitative research findings revealed informal caregivers' financial factors to include payment of expenses that cannot be disbursed by the government.<sup>[14]</sup> Moreover, the findings showed most of the older adult patients to be unemployed or retired, causing problems with expenses and subsequent effects on caregivers.<sup>[15]</sup>

Among older adults with comorbidities, formal caregivers' problems were mostly found to be regarding problems of older adults with multiple illnesses. This was consistent with a study conducted by Sareeso *et al.*<sup>[16]</sup> who studied the situations, health problems, and care needs of older adults with chronic diseases and found the first problem of older adults to be health problems from physical deterioration and chronic diseases. Furthermore, knowledge about self-care in various areas was found to be similar to studies on self-care behaviors among older adults, which found patients to have less cooperation with treatment when symptoms improve, causing patients to stop taking medications and treating themselves.

Given, chronic diseases of both types of caregivers, formal caregivers were found to have reported lower back pain (38.5%), while informal caregivers reported hypertension (40%), which was consistent with the findings of Diniz *et al.*<sup>[17]</sup> who analyzed reports from formal caregiver and informal caregiver reports.,

As for fatigue of caregivers, several studies confirm that caregivers' physical factors particularly fatigue and insomnia affect the quality of care.<sup>[17,18]</sup> Furthermore, the findings revealed physical impacts on caregivers to be more than 40% of the specified theme.<sup>[15]</sup>

### Pride

Adequate family care and support yields positive results in the care of older adults. This type of support is particularly beneficial when enhanced by good caregiver–older adult relationships. Thus, arrangements can be made for the care of older adults living in communities through partnerships and participation between families of older adults and community agencies.<sup>[19]</sup>

### Community factors

Apart from the physical factors, mental and family factors of older adults, social and community factors are important. Community acceptance of patients with chronic diseases leads to more efficient care further resulting in a better quality of life for patients.

Strong communities can provide support for self-care and health management among patients with chronic diseases. This community factor is deemed fundamentally essential in community accountability with cooperation and collaboration in finding the most effective means

for surveilling community health issues in addition to mitigating the health issues of individual members of the community.<sup>[20,21]</sup> The above findings correspond with the findings of a study that found “communities can create environments that support caregivers in areas such as social participation, social inclusion, and community support and health services.”<sup>[22]</sup>

To raise caregiver competence and patient safety, training courses are required to develop their essential skills concerning specific tasks.<sup>[23]</sup> Furthermore, problem-solving skills are required. Caregivers need to learn evidence-based curriculum in these courses, while instructional courses or workshops on specific topics can be offered by agencies or nurses in communities. Examples of these topics include appraisal, pharmacological, and nonpharmacological, all of which can contribute to improvements in caregiver attitudes and knowledge concerning the behavioral management in difficult patients as a means of building caregiver confidence in addition to arming caregivers with fundamental activity and coping skills.<sup>[20,21]</sup> In addition to the three main themes in health care: caregivers' knowledge, factors related to caregivers, and community factors, we recommend that factors in health system and policies related to caring for the elderly with chronic diseases. It plays an important role in the quality of life of the elderly so that the elderly can live with chronic diseases happily and in good health.

## Conclusion

Qualitative discoveries from studying the points of view on the factors correlated with the care provided by informal and formal caregivers of older adults with chronic diseases in the community were explained and confirmed. The findings cover three main themes in health care, including caregivers' knowledge, factors related to caregivers and community factors on providing care for older adults with chronic diseases. This study was limited by having a small sample and lacking in-depth interviews of individuals. In the area of future implementation of the findings, additions should be made regarding the sample size and the study area should be expanded to cover many communities.

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## Conflicts of interest

There are no conflicts of interest.

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