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Family Caregivers of Older Adults with Physical Disabilities in Rural Thailand

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Abstract

Thailand is one of many countries experiencing changes in the demographics of its population. People are living longer and having fewer children resulting in an increasing percentage of older adults in the general population. This presents a challenge in providing care for older adults, especially in countries where there is a culture of family caregiving. This study aims to investigate the experience of family caregivers, exploring the problems of caring for older people with physical disabilities and the needs of family caregivers. This is done to better understand ways to support caregivers. Using a descriptive qualitative approach, 15 family caregivers were enrolled who provide care to older adults with physical disabilities in a rural community in Northern Thailand. The interviews were conducted face-to-face and were analyzed by thematic analysis. Findings showed two main categories from the data: problem areas and needs. The "problem area" themes are low-income households, management of activities of daily living, and access to resources. The "needs" themes are home modifications and adaptive equipment and development of a support system. The identified themes provide guidance for long term care, home adaptation, and assistive products. Future research can be done into the impact of these interventions.

Keywords

caregiver burden, descriptive qualitative research, older people, physical disability, rural

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Family Caregivers of Older Adults with Physical Disabilities in Rural Thailand

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Thailand is one of many countries experiencing changes in the demographics of its population. People are living longer and having fewer children resulting in an increasing percentage of older adults in the general population. This presents a challenge in providing care for older adults, especially in countries where there is a culture of family caregiving. This study aims to investigate the experience of family caregivers, exploring the problems of caring for older people with physical disabilities and the needs of family caregivers. This is done to better understand ways to support caregivers. Using a descriptive qualitative approach, 15 family caregivers were enrolled who provide care to older adults with physical disabilities in a rural community in Northern Thailand. The interviews were conducted face-to-face and were analyzed by thematic analysis. Findings showed two main categories from the data: problem areas and needs. The "problem area" themes are low-income households, management of activities of daily living, and access to resources. The "needs" themes are home modifications and adaptive equipment and development of a support system. The identified themes provide guidance for long term care, home adaptation, and assistive products. Future research can be done into the impact of these interventions.

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Introduction

In 1980, the global population of people 60 years or older was 382 million (World Health Organization, 2021). That number has more than doubled to one billion as of 2020. The population of older adults is expected to double by 2050 to two billion (United Nations, 2019). Developing regions contain two thirds of the world's older people and that is expected to increase to 80% by 2050 (Balachandran et al., 2020). Not only are there an increasing number of older adults globally, but countries are also seeing greater percentages of their population being composed of older adults (Anderson et al., 2012; Puts et al., 2017). Thailand is no exception, having an increasing number of older adults in the country, but also having the older adults making up a larger percentage of the population.

Thailand uses the cut off of 60 years and older as the definition for older adult (or senior citizen) in government pensions and government publications (Ministry of Social Development and Human Security, 2003). An "aged society" is one in which 10.0-19.9% of the population are aged 60 or older, a "complete-aged society" is where more than 20% of the population are aged 60 or older and a super aged society is one in which 28% of the population are aged 60

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or older. In 2017, Thailand had eleven million older adults, out of a total population of 65.5 million. This is an older adult population percentage of nearly 17%, putting it near the upper end of being an aged society. From 2017 to 2022, it is expected that Thailand will surpass the 20% of older adult population to be classified as a "complete-aged society." Thailand is predicted to soon have more than 20 million older adults in its population with those 80 years and older more than doubling. In 2017 there were 1.5 million older adults over age 80, and within the next 20 years it is expected to double to 3.5 million (National Committee for the Elderly, 2017). In 2018, there were 616,365 older adults with physical disabilities (National Association of the Deaf in Thailand, 2018).

The shift towards a "complete aged" society can be attributed to two main causes: the increasing life expectancy and the declining birth rate. In 2009, the life expectancy in Thailand was 70 years old; in 2019, it had increased to 77.2 years old (Vollset et al., 2020). The average number of children per family was seven in 1974, but declined to less than two in 2000, reducing the total population growth rate (Foundation of Thai Gerontology Research and Development Institute, 2019). These factors are important to consider when looking at familial caregiving.

It is important to consider the cultural factors around older adults in Thailand. There is an established expectation that families will provide assistance for their older family members (Wongsawang et al., 2013). Children, spouses, and relatives feel a duty to care for older family members (Limpawattana et al., 2013; Tamdee et al., 2019). Women are most often the family members to take on this role (Knodel & Chayovan, 2009). They provide care for spouses, parents, parents-in-law, and children. Ninety percent of both older adults and those with disabilities receive daily familial care (Knodel & Chayovan, 2009); this leaves the significant responsibility of caregiving on family members, especially women. Younger people are moving from rural areas to more urban cities leaving fewer family members available to assist in caregiving or support the caregiver (Knodel & Chayovan, 2009). It is preferable that older adult care in Thailand is operated and delivered by family and community to produce best results for the older adult (Rittirong et al., 2014). Living with family in familiar surroundings as well as receiving support from their families enhance the older adult's quality of life (Shrestha et al., 2012). Having an increasingly aging population, slowing population growth, and geographic changes of families, Thailand will see an increase in the need for familial caregiving in the coming years.

Providing care to a family member is not without its own difficulties. Caregiver burden is the physical, financial, and psychosocial hardships of caring for a loved one who struggles with a medical condition (Limpawattana et al., 2013; Zarit et al., 1980). To better support caregivers it is important to have a thorough understanding of caregiver burdens and their causes and impact. In addition to experiencing emotional and psychological stress, caregivers can also feel worry, confusion, and boredom while caring for older adults. This makes them unsure of how to proceed and may cause them to lose confidence and worry about caregiving. This is especially true when a caregiver provides care to older adults with physical disabilities (Yodpet, 2009). Establishing standards for their wellbeing and determining how they want to be supported is an important step in future research (Chen & Chunharas, 2009).

This study was conducted in OnTai, Sankampaeng District, Chiang Mai Province, Northern Thailand. OnTai is a rural sub-district with the main source of income being farming (Griffiths et al., 2020). Twenty-six percent of the community are considered an older adult (Health Promotion Hospital, 2017). Of the 26%, 100 (7%) are registered as having a physical disability. The government has tried to meet the challenges of caring for older people in rural communities. Community health promotion hospitals are established with nurses and health volunteers to coordinate the care of the villagers. They carry out monthly home visits for older

people with physical disabilities and their families, although this has been impacted during the COVID-19 pandemic (Ontai Health Promotion Hospital, 2021).

Internationally, there is significant research related to caregiver burden. A lot of this research is quantitative trying to find associated factors with caregiver burden for either the care recipient or the caregiver. Previous studies have looked at caregiver burden with specific diagnoses such as mild cognitive impairments, dementia, and Alzheimer's (Griffiths et al., 2020; Tamdee et al., 2019). There is limited research looking at older adults with physical disabilities and the resulting caregiver burden (Clyburn et al., 2000; Haley et al., 2003). This warrants further investigation. Caregiving is different across different cultures. The cultural component of caregiving is important as caregivers in Asian countries experience different expectations from community and family. Differences between rural and urban caregivers also need to be considered when looking at previous research (Watanabe et al., 2019; Zhong et al., 2020). Taking a qualitative approach of listening to those who are directly impacted may offer a different, human experience answers to the challenges facing caregivers to assist policy, laws, and healthcare professionals in helping.

This research investigates: (1) the problems of caring for older people with physical disabilities, and (2) the needs of caregivers, and ways to support them.

The researchers involved in this study are all occupational therapists that have worked with older adults with physical disabilities. When working as occupational therapists, we saw firsthand the difficulties caregivers experienced when caring for their family members with physical disabilities and wanted to better understand their lived experiences.

We are hopeful that by understanding this underserved population, we can share how they can be more appropriately supported through education, community, and governmental support.

All three researchers worked together on a quantitative project looking at the predictors of caregiver burden within the same population, but we felt qualitative input was needed.

Method

This was a descriptive qualitative study investigating the problems and needs of caregivers of older people with physical disabilities. According to Merriam (2019, p. 7), a descriptive qualitative approach seeks "to discover and understand a phenomenon, a process, the perspectives, and worldviews of the people involved or combination of these." This study was determined by the theoretical positioning of the researcher, the alignment of methodology and methods, the strategies to establish rigor, and the analytical lens through the data (Caelli et al., 2003).

Participants

The research was conducted in OnTai community in Chiang Mai province. The municipal office records show that there were 1,435 older people registered at the start of the research. Of the 1,435, 100 are also registered as having a physical disability. Purposive sampling was used for selecting participants. The inclusion criteria were: 18 years or older, willing to participate in research study, caregiver of someone with a physical disability 60 years and older, caregiver for at least two years, family member of care recipient, and provides physical care. Exclusion criteria were unable to tolerate being interviewed and unable to communicate. Selected participants who were willing were interviewed at home in a face-to-face individual interview.

There were 69 eligible caregivers of older people with physical disabilities. Participants were interviewed until data saturation occurred, 15 caregivers were included for this study

(Hanson et al., 2011). All the participants were female, with 14 being currently married and one widowed. Nine lived with extended family, with six living with a nuclear family. The age range of the participants was 53 to 78 years old with an average age of 62.87 years old. Among the participants, two completed their middle school education. Thirteen participants had an elementary school education with ten making less than \$145 USD a month.

The care recipients were made up of seven females and eight males. The age range of the care recipients was 63 to 92, with an average age of 79.4 years old. Based on independence with activities of daily living (ADLs), eight were considered homebound, with seven being bed bound. Eight of the care recipients were parents of the caregiver, five were spouses, one was a sibling, and one was a father-in-law.

Data Collection

The study was conducted during the month of March 2022. Due to COVID-19 concerns, all interviews were conducted outside at the participant's or care recipient's home, masks were worn, and hand sanitizer was made available. The interviews were conducted away from the care recipient to allow for the most authentic and accurate responses. Prior to the interviews, consent forms were signed and participants made aware that the interviews would be recorded for later analysis. The recordings lasted for between eight to 30 minutes, with an average length of 13 minutes. Data were collected through semi-structured interviews conducted by two native Thai speakers with the same northern dialect as the participants who are familiar with the culture. The questions were designed by discussion among the researchers. Nine open ended questions were asked (Table 1).

Table 1

Example interview questions

Questions		
•	What are the problems you are experiencing in helping your family members?	
٠	Explain the largest problem you experience. To reduce this problem, what can be	
	done to help you?	
•	What do you need to be able to better take care of your family member?	
•	What devices, adaptive equipment, or environmental modifications may be helpful	
	and what if any do you currently have?	

The interview recordings were transcribed by two separate non-authors who are native northern dialect Thai speakers and occupational therapists. Literal transcribing was used with instructions to write exactly what they hear. Instructions were given to the transcribers that they were not to attempt analysis or further interpretation of the interviews. The transcripts were reviewed and checked for accuracy.

Data Analysis

Inductive thematic analysis was used for data analysis of the transcribed interviews following Braun and Clarke's six step guide to analysis (Braun & Clarke, 2006): 1. Familiarizing yourself with data was accomplished by having two Thai researchers conducting the interviews and reading the transcribed interviews numerous times. The audio recordings were available to both authors conducting the data analysis if needed during this process so they could clarify emotion expressed during the interview. 2. After thorough review of the data, the Thai researchers separately began to generate initial codes. Semantic data was coded due

to the explicit nature of the interviews. 3. The coded data was then collated to start the process of identifying overarching themes. 4. The identified themes were then compared to the data codes that had been generated. After the Thai researchers had separately done the four previous steps, they met with the first author to complete the fifth step. 5. All of the authors met to "refine and define" the themes, making sure they are agreed upon. After the themes were agreed upon in Thai, the authors then collaborated to translate the themes to English. Translation was done to prevent the loss of meaning and maintain the importance of the themes. During this time, quotes were identified by the Thai researchers. Translation was also used for the quotes with a discussion among the authors for each quote. 6. The translated quotes and themes were used for the completion of this manuscript.

Trustworthiness of the Study

The credibility, transferability, dependability, and confirmability were assessed using the criteria proposed by Hanson et al. (2011). Several techniques were used to ensure credibility was met. Triangulation was used by having 15 participants interviewed, allowing a range of perspectives to be shared. The interviews were conducted by Thai researchers following interview guidelines. For the first three participant interviews, all researchers were present; this was to establish a consistent process for the remaining interviews. The remaining interviews were completed with two researchers present. Both Thai researchers reviewed all 15 transcripts collected during data analysis. The interviews provided detailed data as saturation occurred after 15 interviews. Both interviewers are occupational therapists with years of experience. Interviewing patients is a skill taught during occupational therapy training and is used regularly. Both have prior qualitative research experience, they used open-ended questions during the semi-structured interviews which led to a skillful interview technique. Transcripts in the native northern Thai language were analyzed word-for-word and then translated into English (Twinn, 1997). These transcripts were checked by two academics fluent in both Thai and English. While translating and analyzing the data, we considered the challenges of translating. To maintain semantic equivalence with realistic and textual meanings, linguistic differences were considered.

Transferability has been met by providing a thorough description of the sample population, the setting, interview questions asked, and results. Further information is always available should future researchers request it by contacting the corresponding author.

Dependability was established by having multiple researchers complete the data analysis. Also, peer debriefing occurred after each interview as the first author discussed with the interviewing author emerging insights during the data collection process. Finally, member checking occurred as the researchers returned to meet with participants after data analysis had identified themes to confirm that the themes align with their experience and capture what they were trying to convey. All participants confirmed that the challenges and needs themes identified were accurate.

Confirmability was completed by having all interviews recorded and transcribed. The meeting between the two researchers to discuss coding and themes was also recorded. The meeting among all researchers for a final decision on themes and the translation process from Thai to English was also recorded. By doing this, external researchers will be able to follow our line of reasoning.

Ethics Consideration

Ethical approval for the research was given by the Ethics Committee, Faculty of Associated Medical Sciences, Chiang Mai University, study code: AMSEC-64EX-122

number: 21/2022. All participants were given verbal and written information regarding the research project; verbal and written consent was obtained, with the understanding that they could end their participation in the research at any time. Participants were made aware of the use of recording devices for the purpose of researcher transcription. The names and private information of participants were kept confidential.

Results

Based on the completed data analysis, this study showed five themes. Three themes have been identified as problem areas, with two themes for areas of need. The "problem area" themes are low-income households, management of activities of daily living, and access to resources. The "needs" themes are home modifications and adaptive equipment and development of a support system. The identified themes relate to the participants' views, experiences, and the burden of caregiving with older adults with physical disabilities. Each of the five themes are presented and illustrated with example quotes from the interviews (Table 2).

Table 2

Summary of themes

Categories	Themes
Problem Areas	Low-income households
	Management of Activities of Daily Living
	Access to Resources
Areas of Need	Home Modifications and Adaptive Equipment
	Development of a Support System

Themes of Problem Areas

Low-Income Households

Thai pensions are 600 baht per month for those 60–69 years old, 700 baht for those 70– 79 years old, 800 baht for those 80–89 years old and 1,000 baht for those over 90 years old. Those registered as having a disability also receive an additional monthly pension. The monthly pensions from older people are used to contribute to family expenses. For caregivers who are unemployed or underemployed, these monthly pensions become essential parts of their income but may not meet their financial needs. Participant #10 said:

The financial assistance from the government is not enough; the disabled pension is 800 baht (\$23 USD) per month. I am 60 years old, and I just get 600 baht (\$17 USD) a month.

Many participants said that the monthly government pension is inadequate. They shared that they spend a lot of money buying items to support the care recipient. The item that most participants shared as a problem was buying diapers. The cost and frequency of use made this a topic shared by nearly all participants. Participant #1 stated:

I receive 800 (\$23 USD) baht a month, but it isn't enough. A package of diapers is over 400 baht (\$11 USD), I don't have money to pay for that. I use a wet cotton ball...

Participant #1 mentions using cotton balls to help with toilet hygiene instead of diapers because of the cost. This is a cultural norm and used instead of toilet paper when a parent wipes a child because of the soft nature of cotton balls. Caregivers and families have to find alternative means to meet their needs when there are limited resources. Participant # 5 states this:

I don't have money to pay for everything...Since I have to look after him it is very difficult, I have nothing, no money or valuables. I have to borrow money from other people every month at 10%-20% interest, but I still don't have enough to buy everything.

She is taking loans from her community with very high interest rates to make ends meet. Some participants manage the difficult financial situation with working, leaving the care recipient alone for extended periods of time. Being able to leave the care recipient alone for part of the day depends on the independence level of the care recipient, and the need of the caregiver to work and make money. Participants #14 and #1, respectively, spoke to how they manage the situation:

While I am at work sorting tobacco leaves, he sits and lies down at home and doesn't do anything.

and

Before I go to work in the morning, I put breakfast and lunch next to his bed, and I turn the TV on for him.

This extended time alone with limited support is not the best for the care recipient, but necessary in certain situations. As seen by the generally low monthly income of the participants, it is understandable that financial burden is a theme. The use and cost of diapers and time commitment of being a caregiver restricting working adds to the financial challenges. The government pension for older people and people registered as having a disability is not enough as stated by the participants.

Management of Activities of Daily Living.

Older adults with disabilities must still complete most ADLs. Dressing, bathing, toileting, grooming, transferring, and eating were completed by most of the care recipients with the assistance of the caregivers. The participants spoke generally regarding the difficulty of helping their family members with ADLs. The tasks around toileting and transfers were mentioned frequently by the caregivers as a major problem they face in providing care. When speaking of transfers, Participant #1 said:

I am 53 years old. I cannot lift him up on my own, I am getting older, and it is too much.

Participant #6 shared the same sentiment and said:

I have back pain when I get him up, he is big and heavy. He is 68 years old, and I am 4 years younger.

Alternative means of transfers are attempted, but there are still problems faced by the caregiver and care recipient as shared by participant #14.

When I am not home, he can't use the wheelchair so he scoots to the toilet, but then he can't get onto the toilet.

Participant #11 said this about transferring their family member to the toilet:

To get him to the toilet, we have to place him on a cloth and then drag him into the bathroom.

The difficulty experienced by the caregiver is not isolated to the actual transfer to the toilet; Participant #3 also expressed difficulty when completing toileting activities or dressing in bed:

He is heavy. It is difficult to turn him over. I have to call people to help.

The caregivers also spoke of the time commitment of helping others with ADLs. Feeding is typically three times a day activity, not including meal preparation time. Participants #15 and #5, respectively, stated this:

I feed him on the bed, I roll him over and change his pampers, I make the bed and stretch him.

and

I do everything for him, it is difficult for me. I have to get him up and feed him. He can use only 1 hand. I have no time for resting.

For the quality of life of the care recipients to be maintained, ADLs must be completed. The care recipients are at various levels of independence and thus require different assistance from the caregivers. All caregivers expressed difficulty in the management of ADLs and many specifically related to toileting. Their own physical limitations along with those of the care recipient all were part of the challenge. They adapted as best they could, and still identified many related problems.

Access to Resources

The caregivers were asked what current resources they are using from the government and local municipality. This sparked a discussion where it was revealed that many participants were either not aware of different resources, or there has been a delay due to COVID. In Thailand, those with physical disabilities are eligible to have a home assessment done with improvements made of up to 40,000 Baht (\$1162 USD). According to Participant #4, she spoke of her feeling about the difficult time, as shown in the following section:

A company said they were going to come and place cement to make the floor flat. But, because of covid, they haven't come back since they had a lot of people get COVID. No one has come to look at my home for modifications due to COVID.

Participant #4 shared that someone has been in contact with her, but there has been a long delay due to COVID. This participant was at least aware of the program, while Participant #5 and others first heard about it from the question that was being asked by the researcher.

I don't know what to do. He hasn't received any therapy. I am old myself. I don't have money to take him to the hospital. No one has come to do a home assessment. I don't know anything about financial support from the government for home modifications.

This participant is quoted previously when she speaks to the financial challenges she experiences. The government assistance for home modifications would be substantial to her, as she makes less than 1,000 Baht (\$29 USD) per month. Participant #5 was not the only participant that was not aware of home modifications. Participant #1 was also not aware of the home modification grant, but also was not aware of the disability pension. Care recipients registered with a physical disability are granted 800 baht (\$23 USD) per month as a pension.

No one has come to tell me how to apply for a grant to make modifications. I wasn't told of the rights of older adults and the extra money.

The resources available are not equitably distributed due to a lack of awareness. Even though all caregivers were providing care for more than two years as part of the inclusion criteria, COVID-19 may be one reason for the delay in accessing resources. The care recipient might have been more functionally independent in the beginning of COVID-19, and only during the pandemic did they require more assistance.

Themes of Needs Identified

Home Modifications and Adaptive Equipment

None of the homes of the participants are the same, but there are some commonalities. It is important to note that these are rural homes of caregivers with often limited resources. It is typical in rural Thailand for the bathrooms to be towards the back of the house, often a separate building. As seen with the challenges related to toileting, the caregivers expressed a lot of needs related to bathroom and other home modifications. Participant #10 stated:

The most difficult thing is taking him to the toilet. The toilet is far away... We brought him to the bathroom in a wheelchair, but when he went to transfer sit on the toilet, the floor was slippery, and he fell. Since the fall he has had difficulty getting up...

Participant #1 shared this regarding the environment of the bathroom:

I have a squat toilet, I need a regular toilet. My mom has fallen because of it. The bathroom is narrow, so my mom has to shower outside. The modifications and equipment available to participants is varied. Some have access to equipment through various sources; some adapt and make do the best they can with the situation. Participant #15 stated:

Before [the disability] he stayed on the second floor, now I modified a room downstairs for him...The room is smelly. I want to have a bigger room with good ventilation for my dad. At the moment, there is no air conditioning, just a fan.

Participants #3 and #12, respectively, shared a simple list of needs that would help address the problem areas identified.

I need a transfer commode chair to get him on the toilet and into the shower. I also need diapers and catheters.

and

I want a bed that lowers, so when I move my mother it would be easier. When I transfer her, I have back pain, because my mother resists and is scared.

The participants identified needs of home modifications and adaptive equipment. A lot of the commented items were toilet and transfer related which aligns with previous results. Participant #1 shared how she was able to learn through observation in the absence of professional instructions.

I observed while I was at the hospital how the room was set up and how to use the wheelchair. When I came home, I modified the home like the hospital with handrails and ramps... If I didn't modify the house I wouldn't be able to take him to the toilet.

Development of a Support System

The development of a support system is an important need for many of the caregivers. They expressed a need to have a family, community, and government support system. As with the other themes, the current support systems of the caregivers are unequal. By having an adequate support system, it could help address financial, time consumption and psychological burden experienced. A quote shared by Participant #13 expresses the isolation from family some caregivers experience:

I feel sad because no family came to help.

She is not the only caregiver that expressed this. Others, such as Participant #5, also shared the sentiment with longer descriptions of their needs and how they are receiving support.

My step-son and family don't care. My step-son has a family and stays in Bangkok. He doesn't come to look after his dad. We live in a poor house with a plastic wall, the community members came together to help build a new wall.

The researchers returned to this participant's home after the initial interview and analysis as she was one of the participants contacted to ensure dependability. We were able to confirm that

the wall she was speaking about in the previous quote was made of cardboard with bamboo weaving. While we were there, there were also community members helping to repair and build out more roofing segments. This participant expressed a need for family support, but showed she has community support. Participant #12 spoke about their own needs and the cumulative impact of extended caregiving without support.

I have to look after my mom all day. I cannot go anywhere. It is like my mother is attached to me, she doesn't want to be left on her own. She is scared, if I go out, she will ask for me all of the time or she calls me. I am tired. My son is 15 years old now; I haven't had a chance to take him to the ocean yet.

Without the support system to care for her mother, this participant shares the negative impact on her own children. Participant #15 spoke about how they are caregivers for multiple family members.

Every day I am responsible for looking after everyone in the family. My mother is old. My sister had a motorcycle accident and has a brain injury and my brother had a high fever in his brain when he was young. I have to take care of them all.

With both her brother and sister care recipients too, this leaves this participant with few options and a great need for support. Participant #15 spoke previously and Participant #10 shares below that this is an everyday endeavor.

I have looked after him for 14 years. I am 65 years old now. He yells at night, causing me to get up two to three times. I don't get enough sleep at night. Sometimes I'll be almost ready for bed, turning off lights and he yells for me, and I have to get up and help him.

When caregivers are isolated from family and community, they express a need for support. Some caregivers experienced a support system in their family but feel it lacking in other areas. Caregivers spend significant time with the care recipients making physical and family sacrifices.

Discussion

The hours of interviews of the caregivers sharing their experiences provide answers to the research question. Both challenges and needs of the caregiver were able to be identified with consistent answers from the participants. The participants' responses and the corresponding themes can be compared to findings from previous qualitative studies.

The problem area themes are low-income households, management of activities of daily living, and access to resources. A previous study found that caregivers that are unemployed reported higher levels of caregiver burden than those who are employed (Bekdemir & Ilhan, 2019). This goes beyond employed and unemployed because another study found the expenses of being caregivers such as medical appointments and equipment to be a burden (Muller-Kluits & Slabbert, 2018). This is in line with the results from this study that financial insecurity is a problem area. There is the opportunity cost associated of being a caregiver and not being able to work or working less. There are also the associated costs related to caring for older adults; this was expressed in our participants with concerns for the costs of diapers and home modifications.

The management of ADLs was reported as a problem area. Many of the discussed ADLs require lifting and transferring which was difficult for the older and female caregivers. A study found that caregivers reported ADLs as a difficult problem to tackle in caring for older adults (Robinson et al., 2005). This is consistent with another study that found that functional ability of care recipients significantly affects the well-being of caregivers (Rattanasuk et al., 2013). Two other studies found the same results, that as functional independence increased caregiver burden decreased (Nelson et al., 2008; Pucciarelli et al., 2017).

The needs of the caregivers identified in this study of home modifications and development of a support system are also noted in other studies. Another Thai study found results that were in conflict with this study. They found that caregiver hours did not significantly affect the well-being of the caregiver. They used the culture of caregiving, generosity, and good wishes as a way to explain this (Rattanasuk et al., 2013). This is inconsistent with many of the caregivers as they reported the difficulties in the lack of assistance from family and the long hours. Other studies found that caregiving hours did impact caregiver burden; this is most aligned with the results from this study (Clyburn et al., 2000; McCullagh et al., 2005).

The results from the research suggest areas for interventions and future studies focused on the identified themes along with actions of impact for the municipal government. This is an area of concern that the Thai government and local municipal offices should investigate. There is a need to help older adults and caregivers access resources such as assistive technology and products. This study found that caregivers needed assistive products that were inaccessible due to resources. This finding resonates with those of other studies related to low- and middleincome countries. A study found that assistive products in low-income countries had limited access and that it led to stagnation of rehabilitation (Eide & Øderud, 2009). The provision of assistive devices and resources for older adults needs to be improved.

Many of the caregivers noted the cost of diapers as being a point of burden. They reported paying between 250-400 Baht (\$7-11USD) per package. This is further exacerbated with the caregiver's low monthly income. There are a few options we propose to solve this issue. One way is to work with local community hospitals and try to organize bulk purchasing of diapers at a wholesale hospital cost. This would allow the caregivers to keep using the products that they know at a reduced price. We know from our research that Thailand has community hospitals with health volunteers that liaison to the different villages. The health volunteers would make this proposal more possible. It would require an initial investment from the community hospital and staff to manage the program, but it is an option to relieve a concern reported by caregivers.

Another option to reduce the cost associated with diapers is through the intervention of occupational therapists. Occupational therapists can help address the independence related to activities of daily living. Toileting (clothing management and hygiene), toilet transfers, bowel management, and bladder management are all within the scope of practice for occupational therapists. An example of an intervention could be recommending a bed-side commode, completing transfer training with the caregiver, or helping set up a bowel/bladder schedule. This option could require more assistance from the caregiver but will reduce the use of diapers in the long term, and thus the cost.

A final challenge identified by the caregivers as a theme was the time commitment that was required of them. The time commitment is likely higher with care recipients with greater disability/lower independence with activities of daily living and instrumental activities of daily living. A way to reduce the time commitment experienced by the caregivers interviewed is to advocate sharing the work with family or hiring a local paid caregiver. The free option of having family help would allow the primary caregiver to focus on themselves or complete needed chores. The cost of hiring a paid caregiver as previously mentioned may not be possible

for all families but is an option for some. The municipal hospital could also become involved; they could train and compensate local community members to help the family caregivers. Finally, depending on mobility of the care recipient, a community approach may be done by having an organized "Older Adult Day Care Services" where the care recipients along with other community dwelling older adults could spend the day with trained staff at a facility, allowing the caregivers time to work or complete other activities. The previously mentioned municipal paid caregivers could also care for those not mobile enough for the "Older Adult Day Care Services."

The caregivers of this study identified challenge areas and areas of additional needs. Through hours of interviews with the research participants, a lot of impactful quotes were shared. The 15 interviews were analyzed into five themes: low-income households, management of activities of daily living, access to resources, home modifications and adaptive equipment, and development of a support system. Further research in interventions aiming to reduce caregiver burden guided by the answers from the caregivers would be beneficial.

References

- Anderson, L. A., Goodman, R. A., Holtzman, D., Posner, S. F., & Northridge, M. E. (2012). Aging in the United States: Opportunities and challenges for public health. *American Journal of Public Health*, 102(3), 393-395. <u>https://doi.org/10.2105/AJPH.2011.300617</u>
- Balachandran, A., de Beer, J., James, K. S., van Wissen, L., & Janssen, F. (2020). Comparison of population aging in Europe and Asia using a time-consistent and comparative aging measure. *Journal of Aging and Health*, 32(5-6), 340-351. https://doi.org/10.1177/0898264318824180
- Bekdemir, A., & Ilhan, N. (2019). Predictors of caregiver burden in caregivers of bedridden patients. *The Journal of Nursing Research*, 27(3), e24-e24. https://doi.org/10.1097/jnr.00000000000297
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. <u>https://doi.org/10.1191/1478088706qp063oa</u>
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2), 1-13. https://doi.org/10.1177/160940690300200201
- Chen, H., & Chunharas, S. (2009). Introduction to special issue on "Population Aging in Thailand". Ageing International, 33(1-4), 1-2. <u>https://doi.org/10.1007/s12126-009-9029-4</u>
- Clyburn, L. D., Stones, M. J., Hadjistavropoulos, T., & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 55(1), S2-13. <u>https://doi.org/10.1093/geronb/55.1.s2</u>
- Eide, A. H., & Øderud, T. (2009). Assistive technology in low-income countries. In M. MacLachlan & L. Schwartz (Eds.), *Disability & international development* (pp. 149-160). Springer. https://doi.org/10.1007/978-0-387-93840-0_10
- Foundation of Thai Gerontology Research and Development Institute. (2019). *Situation of the Thai Elderly*. Nakhon Pathom: Institute for Population and Social Research, Mahidol University.
- Griffiths, J., Thaikruea, L., Wongpakaran, N., & Munkhetvit, P. (2020). Prevalence of mild cognitive impairment in rural Thai older people, associated risk factors and their cognitive characteristics. *Dementia and Geriatric Cognitive Disorders Extra.*, 10(1), 38-45. <u>https://doi.org/10.1159/000506279</u>

- Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine*, 6(2), 215-224. <u>https://doi.org/10.1089/109662103764978461</u>
- Hanson, J. L., Balmer, D. F., & Giardino, A. P. (2011). Qualitative research methods for medical educators. *Academic Pediatrics*, 11(5), 375-386. <u>https://doi.org/10.1016/j.acap.2011.05.001</u>
- Knodel, J., & Chayovan, N. (2009). Older persons in Thailand: A demographic, social and economic profile. *Ageing International*, *33*(1-4), 3-14. <u>https://doi.org/10.1007/s12126-009-9025-8</u>
- Limpawattana, P., Theeranut, A., Chindaprasirt, J., Sawanyawisuth, K., & Pimporm, J. (2013). Caregivers burden of older adults with chronic illnesses in the community: A crosssectional study. *Journal of Community Health*, 38(1), 40-45. https://doi.org/10.1007/s10900-012-9576-6
- McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*, 36(10), 2181-2186. <u>https://doi.org/10.1161/01.STR.0000181755.23914.53</u>
- Merriam, S. B., & Grenier, R. S. (2019). *Qualitative research in practice: Examples for discussion and analysis.* John Wiley & Sons.
- Ministry of Social Development and Human Security. (2003). *The Act on the Elderly B.E.* 2546.
- Muller-Kluits, N., & Slabbert, I. (2018). Caregiver burden as depicted by family caregivers of persons with physical disabilities. *Social Work*, 54(4), 493-502 <u>https://doi.org/10.15270/54-4-676</u>
- National Association of the Deaf in Thailand. (2018). *Report on disability situation in Thailand* 2561. NADT. https://nadt.or.th/en/stat61.html.
- National Committee for the Elderly. (2017). *Situation of the Thai Elderly*. <u>https://thaitgri.org/?wpdmpro=situation-of-the-thai-elderly-2017</u>
- Nelson, M. M., Smith, M. A., Martinson, B. C., Kind, A., & Luepker, R. V. (2008). Declining patient functioning and caregiver burden/health: the Minnesota stroke survey--quality of life after stroke study. *Gerontologist*, 48(5), 573-583. <u>https://doi.org/10.1093/geront/48.5.573</u>
- Ontai Health Promotion Hospital. (2021). Older people with physical disability care report. Sankamphaeng, Chiang Mai.
- Ontai Health Promotion Hospital. (2017). Older people population report in Ontai. Sankamphaeng Chiang Mai.
- Pucciarelli, G., Vellone, E., Savini, S., Simeone, S., Ausili, D., Alvaro, R., Lee, C. S., & Lyons, K. S. (2017). Roles of changing physical function and caregiver burden on quality of life in stroke: A longitudinal dyadic analysis. *Stroke*, 48(3), 733-739. <u>https://doi.org/10.1161/strokeaha.116.014989</u>
- Puts, M. T. E., Hsu, T., Szumacher, E., Sattar, S., Toubasi, S., Rosario, C., Brain, E., Duggleby, W., Mariano, C., Mohile, S., Muss, H., Trudeau, M., Wan-Chow-Wah, D., Wong, C., & Alibhai, S. M. H. (2017). Meeting the needs of the aging population: The Canadian network on aging and cancer—report on the first network meeting, 27 April 2016. *Current Oncology*, 24(2), e163-e170. <u>https://doi.org/10.3747/co.24.3455</u>
- Rattanasuk, D., Nantachaipan, P., Sucamvang, K., & Moongtui, W. (2013). A causal model of well-being among caregivers of people with spinal cord injury. *Pacific Rim International Journal of Nursing Research*, 17(4), 342-355. <u>https://he02.tci-thaijo.org/index.php/PRIJNR/article/view/8713</u>
- Rittirong, J., Prasartkul, P., & Rindfuss, R. R. (2014). From whom do older persons prefer

support? The case of rural Thailand. *Journal of Aging Studies*, 31, 171-181. https://doi.org/10.1016/j.jaging.2014.10.002

- Robinson, K. M., Buckwalter, K. C., & Reed, D. (2005). Predictors of use of services among dementia caregivers. Western Journal of Nursing Research, 27(2), 126-140. <u>https://doi.org/10.1177/0193945904272453</u>
- Shrestha, B., Sermsri, S., & Hongkrailert, N. (2012). Self-efficacy, family support and physical-social functioning activity among Thai elderly under a community QOL program, Kanchanaburi province, Thailand. *Journal of Public Health and Development*, 10(3), 3-16. https://he01.tci-thaijo.org/index.php/AIHD-MU/article/view/4671
- Tamdee, D., Tamdee, P., Greiner, C., Boonchiang, W., Okamoto, N., & Isowa, T. (2019). Conditions of caring for the elderly and family caregiver stress in Chiang Mai, Thailand. *Journal of Health Research*, 33(2), 138-150. <u>https://doi.org/10.1108/jhr-07-2018-0053</u>
- Twinn, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing*, 26(2), 418-423. <u>https://doi.org/10.1046/j.1365-2648.1997.1997026418.x</u>
- United Nations. (2019). *World population ageing*. Department of Economic and Social Affairs. https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldP opulationAgeing2019-Highlights.pdf
- Vollset, S. E., Goren, E., Yuan, C.-W., Cao, J., Smith, A. E., Hsiao, T., Bisignano, C., Azhar, G. S., Castro, E., Chalek, J., Dolgert, A. J., Frank, T., Fukutaki, K., Hay, S. I., Lozano, R., Mokdad, A. H., Nandakumar, V., Pierce, M., Pletcher, M., . . . Murray, C. J. L. (2020). Fertility, mortality, migration, and population scenarios for 195 countries and territories from 2017 to 2100: A forecasting analysis for the Global Burden of Disease Study. *The Lancet*, *396*(10258), 1285-1306. <u>https://doi.org/https://doi.org/10.1016/S0140-6736(20)30677-2</u>
- Watanabe, O., Chompikul, J., Kawamori, M., Pimpisan, N., & Visanuyothin, S. (2019). Predictors of family caregiver burden in caring for older people in the urban district of Nakhon Ratchasim a province, Thailand. *Kokusai Hoken Iryo (Journal of International Health)*, 34(4), 217-228. <u>https://doi.org/10.11197/jaih.34.217</u>
- Wongsawang, N., Lagampan, S., Lapvongwattana, P., & Bowers, B. J. (2013). Family caregiving for dependent older adults in Thai families. *Journal of Nursing Scholarship*, 45(4), 336-343. <u>https://doi.org/10.1111/jnu.12035</u>
- World Health Organization. (2021, 4 October 2021). Ageing and Health. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health
- Yodpet, S. (2009). Family and the elderly. In C. Vitchawut, N. Chayowan, Y. Wongchai, P. Intarasombat, & N. Thamanawat (Eds.) *Review and synthesis of Thai elderly knowledge*, 2002–2007: A research plan for improving the quality of life of the Elderly (pp. 193-226). Foundation of Thai Gerontology Research and Development Institute. (in Thai).
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20(6), 649-655. <u>https://doi.org/10.1093/geront/20.6.649</u>
- Zhong, Y., Wang, J., & Nicholas, S. (2020). Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: The mediating role of caregiver burden. *BMC Geriatrics*, 20(1), 3. https://doi.org/10.1186/s12877-019-1403-9

Author Note

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