

ORIGINAL ARTICLE

Understanding the Family Involvement in Caring Older People with Chronic Musculoskeletal Pain in the Community.

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ABSTRACT

Introduction: Worldwide, the family unit serves as the main social framework, and older people predominantly depend on their relatives for healthcare and support. However, there are other facets of issues related to the strain of caregiving. This study aimed to investigate the health beliefs, experiences, expectations, cultural and religious beliefs of family members of older people with chronic musculoskeletal pain in managing symptoms and supporting older people in the community. **Method:** A qualitative study using purposive sampling methods was applied, resulting in 11 family caregivers from the Malay, Indian, and Chinese communities. A semi-structured interview was conducted based on a subject guide, and the data were analysed using thematic analysis. **Results:** The study revealed that family caregivers felt accountable for providing care but faced several responsibilities. Caregivers utilise many coping strategies to deal with pain, influenced by cultural and belief differences, including complementary alternative medicine (CAM). **Conclusion:** Healthcare in Malaysia should prioritise addressing the challenges experienced by caregivers and enhance cultural sensitivity in delivering care to the older people. The results will help evaluate the needs of caregivers in providing care. In the future, we will enhance our healthcare services by focusing on cultural sensitivity.

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INTRODUCTION

Family is the main social institution responsible for the well-being of older people. Family caregiving is an informal care arrangement when family members provide assistance to older people relatives (1) and is widely practised around the world as elderly individuals are more prone to chronic pain because of their age and other health issues such as diabetes, hypertension, and bone disorders, older persons were at risk of developing chronic musculoskeletal discomfort which

can impair their ability to do daily activities. Multiple ethnic groups had important cultural responsibilities to provide care, including Asian caregivers. Self-care and informal caring present several safety issues across different dimensions: physical, emotional, cognitive, instrumental, economical, social, environmental, technological, and cultural (2). Despite the burden, the caregivers expressed a strong sense of filial obligation that motivated them to continue caring. Moreover, family carers view providing care as significant and fulfilling since it allows them to bond, attach, and support one another especially the carers who were grounded in Muslim and Christian principles, which enabled them to persevere, be resilient, and find meaning in caring. A family caregiver's approach to routine care is influenced by acquired knowledge and experience, reflecting the caregiver's cultural background, family dynamics, and

environment (3). Malaysian healthcare professionals should also consider family caregivers' burdens and beliefs. They must also be aware of and sensitive to cultural disparities among family caregivers, as these affect the way care is provided. The study aimed to explore the health beliefs, experiences, expectations, cultural and religious beliefs of family members of older people with chronic musculoskeletal pain regarding symptom management. It also examined how family members assist older people in managing chronic musculoskeletal pain in the community.

MATERIALS AND METHOD

This study was conducted utilising a qualitative research design underpinned by phenomenology provides insights into the subjective experiences of individuals, aiming to uncover the fundamental aspects of their lived experiences and the meanings they attribute to them. The interview was carried out at their home specifically at a locality adjacent to Kuantan. Interviewers include those who are well-trained in the field of the study and constantly supervised by experts. Malay, Indian, and Chinese subjects were recruited using purposive sampling methods and were approached by face-to-face and phone calls before conducting the interview. Additionally, participants will receive an information sheet detailing the study and the researcher to ensure transparency and empower them to make well-informed decisions in taking part in the research. The duration of semi-structured interview was thirty minutes to an hour and adhered to the pattern of the topic guide, using open-ended and probing questions. Topic guide and questions were pilot tested with small sample of participants who are similar to the target population. The researcher used an audio recording to collect the data and field notes were made during and after the interview. The interviews were conducted until data saturation was reached which means the data from the previous interviews were repeated and no new themes occurred in the analytical process. Before proceeding, approval was obtained from the Kulliyah of Nursing Postgraduate Research Committee (KNPGRC) (Ref No.:IIUM/313/G/14/3/1) and the International Islamic University Malaysia Research Ethics Committee (IREC) (Ref No.: IIUM/504/14/11/2/IREC2022-KON). Thematic analysis was employed to evaluate and analyse the data. It is commonly used as a crucial element in advanced qualitative procedures and methods, and it is acknowledged as an appropriate approach for exploratory qualitative research. (4).

RESULTS

The study received eleven responses from family caregivers (five Malays, three Chinese, and three Indians). The emerged themes are 'sense of responsibility', 'challenges with older people with musculoskeletal pain', and 'coping with pain'.

Table I: Summary of themes and subthemes

Themes	Subthemes	Example
	Filial piety	"Even when I was a child... she took care of me. So, this time whatever she does, we must take care of her as well." (PI3)
Sense of responsibility	Need division of responsibility	"Support from the family, for example, if we want to go on holiday, she stays at my brother's house or my nephew's house." (PM1)
		"If I'm not there, my younger brother will be the one with her" (PC1)
	Time-consuming for social activities	"It's just a little problem when we go out... if the place has stairs, she can't go up." (PM1)
Challenges with older people with musculoskeletal pain	Financial issues	"If my mother is sick, if possible, we will take emergency leave..." (PI2)
		"I need everything because I only use his pension money. It's not enough." (PI1)
	Lack of knowledge	"We don't know much; we must ask him if it's okay to hold it like this." (PM4)
		"I'm didn't know either, I just do it." (PI3)
Coping with pain	Practising CAM	"I think support is necessary because otherwise we don't even know what's wrong." (PM5)
		"My grandma very traditional person. She doesn't trust doctors... she'd rather go to a Chinese shop" (PC1)
		"We call a masseuse if her feet are numb. My mother said that she boiled and drink... kulim fruit... she felt relieved." (PM3)
		"...She makes herbs... There are 'semambu'(neem) leaves... We have Indian oil... She warmed herbs, put it in the cloth and tied it at her feet." (PI3)
		"She always gets her medicine and herbs from the Chinese shops, and we have one tool she believes it will absorb the pain... so, she always uses that to massage at pain area... every night my grandma boils herbs ... it is effective" (PC1)

Sense of responsibility

Family members felt responsible to caregiving. Participant expressed their experience in fulfilling the acts of filial piety.

"Even when I was a child... she took care of me. So, this time whatever she does, we must take care of her as well." (PI3)

Sometimes, they need to hand over responsibility to other family members as they also have other commitments in their life.

“Support from the family, for example, if we want to go on holiday, she stays at my brother’s house or my nephew’s house.” (PM1)

“If I’m not there, my younger brother will be the one with her” (PC1)

Challenges with older people with musculoskeletal pain

Caregivers has limited social activity due to caregiving responsibilities. Participant mentioned that they are not being able to leave their home to be involve in social activities.

“It’s just a little problem when we go out... if the place has stairs, she can’t go up.” (PM1)

Caregivers’ working time were interrupted as they are constantly ‘on-call’ for their parents. Their working productivity may also be affected which may lead to financial issues to the caregiver as their job is one of their sources of income.

“If my mother is sick, if possible, we will take emergency leave...” (PI2)

“I need everything because I only use his pension money. It’s not enough.” (PI1)

Some participants admit that they require education, and support from healthcare personnel about the disease and how to provide appropriate care.

“We don’t know much; we must ask him if it’s okay to hold it like this.” (PM4)

“I’m didn’t know either, I just do it.” (PI3)

“I think support is necessary because otherwise we don’t even know what’s wrong.” (PM5)

Plus, a Chinese caregiver also shared that she is uncertain in seeking medical treatment among older people which prevent them going to healthcare facilities.

“My grandma very traditional person. She doesn’t trust doctors... she’d rather go to a Chinese shop” (PC1)

Coping with pain

Caregivers also stated that they use complementary and alternative medicine (CAM) according to their own respective culture to manage their loved one’s pain. Massage, oils, and herbs are the common practices used. “We call a masseuse if her feet are numb. My mother said that she boiled and drink... kulim fruit... she felt relieved.” (PM3)

“...She makes herbs... There are ‘semambu’(neem) leaves... We have Indian oil... She warmed herbs, put it in the cloth and tied it at her feet.” (PI3)

“She always gets her medicine and herbs from the Chinese shops, and we have one tool she believes it will absorb the pain... so, she always uses that to massage at pain area... every night my grandma boils herbs ... it is effective” (PC1)

DISCUSSION

Family caregivers from all races are aware of their own responsibilities and felt compelled to fulfil the obligation since it is one of the actions of filial piety to return parental services the elderly or parents who have reared them from childhood. This might be explained due to caregivers who were rooted in Christian and Muslim values were tough, endured, and found meaning in their caring responsibilities (5). The burden was said to be generated by cultural differences in how individuals perceive disease and what it means to care for others (6). The carers also felt bound to their parents until they needed to divide their responsibilities in caring for older people among other family members. Division of responsibilities among family member needed to allow them to take care of themselves and recuperate the energy used when caring for the other (3).

Caregiving was perceived as demanding because the caregiver had restricted social interactions for themselves and their family as a result of caregiving responsibilities. According to a study, caregivers’ dedication to their responsibilities prevents them from engaging in meaningful social interactions with their spouses or children (2), leading to a decrease in social connections and an increase in caregiver isolation (7). Plus, they also being interrupted during working will affect the carer’s sourced of income due to reduced working productivity. Working carers who provided considerable support with health care tasks experienced three times more job productivity loss. (8). They also need knowledge to provide care to the elderly, but they did not get the chance to be involved in care resulting in increased burden on the caregiver. Once they were given a role, they felt threatened by their lack of knowledge or skills (3). Furthermore, phrases used by healthcare providers are complicated and the information offered is insufficient Thus, sufficient education and support are needed to ensure positive outcome and prevent uncertainty in seeking medical treatment. Positive lived experiences may be created through increasing caregiver education, increasing awareness of the caregiver position in society, particularly among healthcare professionals (9).

Musculoskeletal pain poses prolonged pain to the older people, and they struggle to manage the pain by their

own using various alternative. Caregiver mentioned that they have been practising complementary alternative medicine (CAM) in managing the symptoms. Four Traditional Chinese Medicine (TCM) therapies - acupuncture, moxibustion, herbs, and massage - effectively reduce inflammation and can be considered as supplementary pain management treatments for knee osteoarthritis (10). Caregivers are practicing CAM according to their culture. Massage was frequently used as a coping strategy in Malay culture (11) but other culture also has been practicing massage to alleviate the pain (12). However, to avoid complications in the older people, the safety of adopting other options should be highlighted.

Therefore, it is crucial to improve the healthcare services and policy to ensure that a proper plan for the patient, health education, and information regarding musculoskeletal care of the elderly are given to the family caregiver prior to discharge. This can be achieved by involving family caregivers in the discharge process and assessing the requirements of older people at home might provide older individuals with greater possibilities to master life at home following discharge, easing the burden on family caregivers to reduce hospital readmissions. Plus, offering family carers a course on caring for families at home, as well as a training on improving cultural competency for medical staff.

CONCLUSION

Family caregivers face a variety of challenges when caring for older people with musculoskeletal pain, including a lack of time, financial constraints, and knowledge gaps. Caregivers also helped manage pain by using culturally appropriate coping strategies. Healthcare professionals in Malaysia may need to place a greater emphasis on the caregiver's burden and be more culturally sensitive when caring for the older people. It is hoped that cultural sensitivity is embedded while providing health-related services.

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