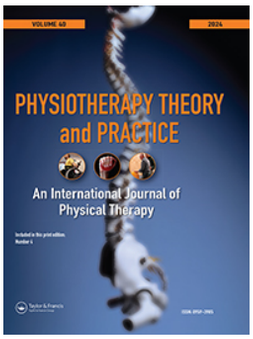

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CASE REPORT



# Perceptions of stigma associated with chronic knee pain: voices of selected women in Thailand and Malaysia

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**ABSTRACT**

**Introduction:** A higher prevalence of knee pain in Southeast Asian countries, compared with non-Asian countries, is an established fact. This article hypothesizes that this fact, combined with personal, cultural, and environmental factors, may influence attitudes toward illness and treatment-seeking behavior and adherence.

**Objective:** This study aimed to determine current attitudes, stigma, and barriers of women to the management of chronic knee pain and treatment in two Southeast Asian countries.

**Methods:** Fourteen semi-structured interviews explored female lived perceptions of chronic knee pain in Southeast Asia. Using a phenomenological reduction process, open-ended questions allowed participants to voice their perceptions of their experience of this knee condition. Particular foci were potential stigma associated with the perceptions of others, health-seeking attitudes, and attitudes toward exercise.

**Results:** The shared experiences of managing chronic knee pain revealed the impact of their condition on participants' normality of life and their struggles with pain, limitations, and fear for the future. Key individual, interpersonal, organizational and community barriers and facilitators impacted the health seeking attitudes and engagement with conservative rehabilitation programmes.

**Conclusion:** Improved socio-cultural competency and consideration for an individuals' intersectional identity and interpersonal relationships are key to designing rehabilitation and conservative management solutions. Co-creating alternative pathways for rehabilitation for individuals that are more distant from health facilities may help reduce socio-cultural barriers at a community level.

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Chronic pain; knee pain; Malaysia; Thailand; stigma

## Introduction

Knee osteoarthritis (OA) is generally understood as a common chronic debilitating disease characterized by joint pain, functional impairment and a significant reduction in quality of life, conferring a significant burden for patients and health care systems (Hunter, Schofield, and Callander, 2014; Safiri et al, 2020). According to a recent (2020) meta-analysis, the global prevalence of knee OA in individuals over 40 years old reached 22.9%, with a higher prevalence noted in females compared to males (Cui et al, 2020; Li, Li, Chen, and Xie, 2020).

Geographic comparisons suggest a higher prevalence of knee OA in Asia compared to the rest of the world (Cui et al, 2020). In Thailand, the prevalence of knee OA has been reported to be between 34.5% and 46.3% (Kuptniratsaikul, Tosayanonda, Nilganuwong, and Thamalikitkul, 2002; Tangtrakulwanich and Suwanno, 2012; Tangtrakulwanich, Chongsuvivatwong, and Geater, 2007). In Malaysia, the prevalence of knee pain reported was between 21.2% and 30.8%, and the estimated prevalence of knee OA was 25.4% for people over 55 years old in the capital (Chia et al, 2016; Mat et al, 2019).

Research has proposed that there are different factors contributing to the higher prevalence in Southeast Asian countries, including the diagnostic criteria used, specific cultural/religious habits, and ethnic, genetic, or environmental factors (Cui et al, 2020; Mat et al, 2019). Malaysia and Thailand are diverse and multicultural countries with various ethnic groups, including Malay, Thai, Chinese, Indian and Indigenous cultures. As such, each ethnic group may have specific cultural and religious practices,

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lifestyle habits, and genetic predispositions that can influence the prevalence and symptomatology of knee OA (Chia et al, 2016; Mat et al, 2019). For example, Malays, who are predominantly Muslim, may perform prayer rituals involving kneeling and prostration several times a day. Similarly, Thai and Chinese individuals are predominantly Buddhist, having the traditional practice of squatting, kneeling and sitting on the floor with legs tucked back to one side (Pattayakorn et al, 2013).

Interestingly, it has been reported that all types of floor activities except kneeling increased the risk of moderate to severe knee OA (Tangtrakulwanich, Chongsuvivatwong, and Geater, 2007), but ethnic Thai Muslims have previously been shown to have a lower prevalence of OA than their Buddhist counterparts (Chokkhanchitchai et al, 2010). Culture and religion often also play a significant role in shaping social structures and support systems, influencing the preference for traditional healing practices, and shaping individual beliefs and attitudes toward illness and treatment-seeking behavior (Che Hasan, Stanmore, and Todd, 2021). Therefore, culture and religion may have a direct impact on subjects' thoughts, life satisfaction and health care practices (Che Hasan, Stanmore, and Todd, 2021; Pattayakorn et al, 2013).

Conservative management is considered as first-line treatment for people with knee OA (Lim and Al-Dadah, 2022). It is believed that surgical intervention should be reserved as a final option for patients that have not responded satisfactorily to less invasive treatments (Hunter and Bierma-Zeinstra, 2019). Core conservative management includes education, exercise, and weight loss (Holden et al, 2023; Hunter and Bierma-Zeinstra, 2019; McAlindon et al, 2014). A well-structured physical therapy program has demonstrated strong evidence supporting its effectiveness in improving pain and function (Olalekan et al, 2014). This article argued that such programs need to consider any potential stigma associated with knee OA, and hence, potential barriers and facilitators to exercise, which are crucial to the implementation of effective adherence strategies (Marks, 2012). Stigma surrounding osteoarthritis could construct barriers that hinder health seeking behaviors to effective treatment and impede the overall well-being of individuals living with the condition (McInnis et al, 2015; Schmitt, Branscombe, Postmes, and Garcia, 2014; Smith et al, 2014a, 2014a).

Research has revealed that a socio-ecological framework has proven effective in categorizing barriers and facilitators that influence health behaviors on multiple levels, including individual, interpersonal, organizational, community and public policy (Baert et al, 2011; Bronfenbrenner, 2005). Similarly, stigma may present on different levels, including the intrapersonal (self-stigma), the interpersonal (person-to-person discrimination), and the structural levels (state-level policies that restrict the opportunities of stigmatized groups) (Hatzenbuehler and Link, 2014). The socio-ecological model can direct the creation of interventions that are more complete, context-specific and that engage with individual perceptions, by explicitly considering interactions from multi-level factors (Hull, De Oliveira, and Zaidell, 2018). Hence, barriers and facilitators to knee OA management have been previously studied (Kanavaki et al, 2017; Marks, 2012).

According to previous studies in various countries (e.g., USA, Spain, France, UK, Singapore, Jordan), the main factors reported include, but are not limited to: patient's health beliefs and personal experiences at the individual level; peer support and cultural attitudes at the interpersonal level; healthcare professional's support and targeted intervention at the organizational level; socio-cultural, environment and accessibility at the community level; and specific healthcare care programmes and recommendations at the public policy level (Al-Khlaifat et al, 2022; Booker, Tripp-Reimer, and Herr, 2020; Carmona-Terés et al, 2017; Darlow et al, 2018; Gay et al, 2018; Hendry et al, 2006; Holden et al, 2012; McKevitt, Jinks, Healey, and Quicke, 2022; Pellegrini, Ledford, Chang, and Cameron, 2018; Yang, Woon, Griva, and Tan, 2022).

Barriers and facilitators differ greatly between individuals according to characteristics such as age, gender, religion, culture and ethnicity (Al-Khlaifat et al, 2022; Baert et al, 2011), and it has been revealed that what some perceived as exercise facilitators, others perceived as exercise barriers (Al-Khlaifat et al, 2022; Gay et al, 2018; Holden et al, 2012). However, there is limited literature specifically addressing the effects of stigma upon people with knee OA (Trojanowski, Davis, Berta, and Weber, 2019), although literature considering the effect of stigma with regard to other conditions exists (Woo, Zhou, and Larson, 2021). Such literature has considered healthcare professionals' attitudes to individuals, based upon their weight or social and cultural habits, for example, smoking (Cavaleri, Short, Karunaratne, and Chipchase, 2016; Woo, Zhou, and Larson, 2021). Stigma around OA has not focused on personal lifestyle history but has been frequently expressed with regard to attitudes toward using a walking aid, being associated with disability and a negative external perception at an individual and interpersonal level (Smith et al, 2014a, 2014b; Yang, Woon, Griva, and Tan, 2022). However, personal lifestyle can be affected by stigma, for example cultural attitudes and beliefs can lead women toward specific stigmatization, for instance, "going to the gym" was

perceived as inappropriate for females in Jordan (Al-Khlaifat et al, 2022).

Research conducted in Malaysia and Thailand reported similarities to previous findings as well as differences, such as faith as a motivator and low levels of education as an obstacle (Ahmad et al, 2018; Aree-Ue, Roopsawang, and Belza, 2016; Che Hasan, Stanmore, and Todd, 2021). Regarding the public policy of Thailand and Malaysia, both Southeast Asian countries hold a universal health care policy, which covers most patients' health care needs, with specific health policy recommendations for patients with knee OA including education about the diagnosis, weight reduction (for obese patients), and exercise/physical therapy (Malaysian Society of Rheumatology, Malaysia AOM, 2013; Sumriddetchkajorn et al, 2019). In contrast, the absence of community or home-based programme alternatives and extra expenses to cover transportation and specific medicines has been highlighted as an obstacle to exercise adherence and knee pain management (Luksameesate, Tanavalee, and Taychakhoonavudh, 2022; Malaysian Society of Rheumatology, Malaysia AOM, 2013), suggesting a socio-economic disparity and increasing the likelihood of health inequality.

Such barriers and influences have only recently been evidenced, and it is unclear whether the management of knee OA amongst women in Thailand and Malaysia is related to the stigma associated with disability. In Malaysia, Che Hasan, Stanmore, and Todd (2021) reported that knee OA patients of both gender experienced shame, inconvenience, and fear of judgment regarding exercise due to societal norms and perceptions of age, which ultimately limited engagement in physical activity (Che Hasan, Stanmore, and Todd, 2021), a key factor within conservative management of OA. Therefore, understanding the stigma associated with the knee OA would help facilitate better, earlier treatment and improve lives, and work accessibility, potentially reducing the financial burden of the disease.

Given the higher prevalence of pain related knee conditions in Southeast Asian countries and the possible differences in personal, cultural and environmental factors, new studies to analyze key determinants of management adherence for this pathology are warranted (Che Hasan, Stanmore, and Todd, 2021; Cui et al, 2020). This study aimed to determine current perceptions and attitudes of women on the management of their chronic knee pain and to explore stigma as a barrier to treatment in two Southeast Asian countries. This information could be useful to inform the design of effective strategic plans to overcome specific population barriers and stigma, and to encourage early interventions for knee pain in countries such as Thailand and Malaysia.

## Materials and methods

This study was approved by the three partner universities' ethics committees: (Approval references: HEALTH0241; 2021310–9942; MU-CIRB 2021/144.2503). Data were collected in accordance with the Declaration of Helsinki (World Medical Association, 2013) and informed consent was obtained from participants prior to completion of the interview.

### *Study design*

This qualitative study used semi-structured interviews to investigate perceptions of female participants' with chronic knee pain in Southeast Asia, undertaking a phenomenological reduction process to maintain a fundamental level of validity (Husserl, 1970). The research involved semi-structured interviews, with open-ended questions, to allow participants to voice their perceptions, as free from researcher bias as possible. Participants' perceptions are shaped by their lifestyle, knowledge, and previous experiences, and this approach enabled the evocation of feelings and descriptive examples associated with chronic knee pain and perceived stigma to arise. The concept of "discrepancies" was not relevant to the research since it sought to enable participants to express their own perceptions.

### *Recruitment and sample size*

Females between the age of 40 and 70, presenting with chronic knee pain (for a minimum 12 months prior to the interview), were invited to participate through the clinics run within the two partner Southeast Asian Universities (Malaysia & Thailand). Exclusion criteria included lower limb orthopedic surgery within the last 6 months, neurological conditions affecting lower limb function, cognitive impairment, and any co-morbidity which would function as a contraindication to engaging with exercise or participation in rehabilitation. Potential participants were provided with a patient information pack which included an invitation to participate, information regarding confidentiality, the contact information of the chief investigator within each country, as well as a consent form to be taken away and considered at home.

Due to the nature of this study, it was determined that a sample of fourteen participants between the two countries would be adequate to generate the required data (Julious, 2005; Lancaster & Dodd, 2004). This is similar to previously published work using this methodology, where authors recruited 16 patients aged between 39–64 with confirmed knee OA to explore

how middle-aged patients conceive exercise as a form of treatment (Thorstensson, Roos, Petersson, and Arvidsson, 2006). It became clear that saturation was reached as the same issues were repeated by many participants, with no new interpretations arising.

### Procedure

Participants who met the inclusion/exclusion criteria were invited to attend a single interview. The interview was anticipated to be between 30–60 minutes. Interviews were conducted by a single interviewer at each location in English, Malay, or Thai according to the participant language needs, and were voice recorded for later transcription. Any interviews not conducted in English were translated by native speakers and verified by the chief investigator within each country. The semi-structured interviews explored four domains: the condition of the individual's knee, the stigma associated with the perceptions of others, the individual's health-seeking attitude, and their attitudes toward exercise. Whilst published literature on phenomenological interviewing techniques recommends that the interviewer take detailed observational field notes during the semi-structured interviews. Due to the exploratory nature of this study, such detail was not included, but it did utilize a phenomenological approach, in that it seeks to investigate female participants' perceptions of chronic knee pain in Southeast Asia, without the use of medical case notes. Due to the additional participant burden, transcripts and analysis were not checked by the participants.

### Data analysis

A combination of phenomenological reduction and thematic analysis was used, providing a comprehensive understanding of subjective experiences of living with knee pain, by revealing both the underlying structures and patterns of experience, as well as the themes and categories that emerge from the data (Sundler, Lindberg, Nilsson, and Palmér, 2019). Phenomenological reduction was used as a preliminary step to identify the essential features of the subjective experiences and to gain a deeper understanding of the structure and meaning of the data, describing them in as much detail as possible, without making any judgments or interpretations. Once the essential features of the subjective experience were identified, the diverse team of researchers used thematic analysis to identify and analyze patterns and themes within the data. The benefit of this approach was to reduce the bias that may occur through solely focusing on the interpretation, privilege or lens of any researcher. Thematic analysis is widely used in qualitative analysis (Braun and Clarke, 2006; Roulston, 2001). Any queries were resolved via discussions with the interviewers in each country. An inductive approach was adopted, allowing the data to generate the themes (Saunders et al, 2018). For this study, the socio-ecological model provided a key framework to explore the multifaceted nature of barriers and facilitators to knee pain management for women in Southeast Asia, exploring how the patients interact and are influenced by multiple levels including individual, interpersonal, organizational, community and public policy (Baert et al, 2011; McLeroy, Bibeau, Steckler, and Glanz, 1988).

## Results

Fourteen female participants completed the study (age range from 40 to 70 years). Participants' demographic characteristics are presented in Table 1. Participants were invited to discuss their experiences of managing chronic knee pain in their own lives, families, and communities. To gain an understanding of their experiences, these findings explore each of the themes through a dichotomy of what prevents them from continuing a normal active life and those behaviors that support and facilitate a normal active life. Within this, consideration has been given to the socioecological model which explores individual, interpersonal, organizational and community factors that inform an individual's psycho-social experience, progression and management of their condition, summarized in Figure 1 (Bronfenbrenner, 2005).

### A normal life

Ten participants discussed how they felt their knee pain affected their normality of life and in part this referred to their particular age. For the participants who felt psycho-socially that it prevented them from continuing their usual daily activities they felt that their experience of developing knee pain from OA at a relatively early age was not normal. This participant, for example, felt it was something that affected her interpersonal and individual identity as she was only 30 years of age at the time,

> At that point maybe, people don't really think knee pain, somebody that they should have the knee pain, so they don't really feel too much. (Malaysia, Chinese, self-employed)

In contrast, other older participants had reconciled that the condition could be quite prevalent at the age of its onset

**Table 1.** Demographic data of the participants ($n = 14$).

| Age (years) | 59.43 (9.31) | Sex | F ($n = 14$) |
|---|---|---|---|
| Height (cm) | 155.00 (5.46) | Weight (kg) | 63.85 (13.74) |
| BMI (kg/m$^2$) | 26.51 (5.09) | Country | Malaysia ($n = 8$) |
| Years with pain | 9.5 (5.3) | | Thailand ($n = 6$) |
| Ethnicity | Thai ($n = 6$) | Religion | Buddhism ($n = 10$) |
| | Chinese ($n = 4$) | | Muslim ($n = 4$) |
| | Malay ($n = 4$) | | |
| Occupation | Retired ($n = 5$) | Education | Bachelor's degree ($n = 7$) |
| | Manager ($n = 3$) | | Master's degree ($n = 3$) |
| | General employee ($n = 3$) | | Grade 12 ($n = 2$) |
| | Self-employed ($n = 1$) | | Grade 6 ($n = 1$) |
| | Legal officer ($n = 1$) | | Unknown ($n = 1$) |
| | Civil servant ($n = 1$) | | |
| Marital status | Married ($n = 7$) | Live with | Family ($n = 13$) |
| | Widow ($n = 3$) | | Alone ($n = 1$) |
| | Single ($n = 2$) | | |
| | Divorce ($n = 1$) | | |
| Knee pain | Unilateral ($n = 5$) | Active in social activity | Yes ($n = 7$) |
| | Bilateral ($n = 9$) | | No ($n = 7$) |

Abbreviations: BMI = Body Mass Index; cm = centimeters; kg/m$^2$ = kilograms per meter squared.


**Figure 1.** Socio-ecological model of barriers to the management of chronic knee pain in women from Southeast Asian countries.

> It is normal: and I accepted it and is a process of aging (Malaysia, Malay, Civil Servant)

> I rarely think about it because I think that I am old and bone deterioration is normal. (Thailand, Thai, general employee)

This perception of "normality" may have encouraged these participants to reconcile their acceptance of the onset of the pain and facilitated a lifestyle that allowed them to undertake as much of normal range of activities as they could.

### Fear for the future

Some of the participants talked about their inhibitions about their knee condition and how the pain may get much worse and led them to a feeling of fear and dread for what may happen in the future.

> You know I'm still not, I still can go along, but you know, after a certain level at this moment, I wouldn't know in the next 10–20 years later, you know, scenario could much change tremendously right. (Malaysia, Chinese, retired)

This feeling of dread prevented some from enjoying their personal and interpersonal lives in the present. This participant explains how their mother had been through the painful and debilitating process of OA and, she knew what to expect.

> *. . . (of her mother) towards her later years of life, you know, it is sort of like, you know, she wasn't having a quality life . . . So that have sort of like, you know, really, you know, sort of like given me a heads up like a hint that probably, you know, it can happen to me as well* (Malaysia, Chinese, Senior manager)

### Degeneration through age

Connected to the fear of the future and a dread of what may come, some participants worried about the perception of physical degeneration that may take place because of the aging process on their bodies.

> *They call it what, I cannot remember the word. It is something to do with some cracking on the bone, some degeneration.* (Malaysia, Chinese, retired)

This perception of physical degeneration affects how participants personally feel themselves and how they are perceived in their wider community. Likewise, this participant explains

*"I feel there is quite a common problem for ageing"* (Malaysia, Chinese, manager)

### Impact awareness – it is quite torturing

Eleven participants discussed the detrimental impact their knee pain had on their daily lives and how it prevented them undertaking daily activities for work or activities that they enjoy. Some participants explained how it negatively affected their ability to undertake everyday activities, for instance, climbing stairs, walking, or sleeping.

> *But bending and stairs, going up and down the stairs is actually, it doesn't make, it is not really conducive for my knees. So, I usually limit my stairs climbing towards once a day. Usually, when I want to go to sleep, I have to go back up, my room is upstairs.* (Malaysia, Malay, Legal Officer)

> *Knee pain affects my life a lot because it stops me from wanting to go outside. Some activities that I used to be able to do, I cannot do anymore.* (Thailand, Thai, retired)

These participants' experience of how it has seriously affected their individual quality of life was representative of all the participants in the study. However, some talked about how it affected not only their individual quality of life, but their interpersonal and organization activities, for instance, work.

> *The pain was bearable, but after a while it became a burden to me because I could not concentrate on working . . . So, it is troublesome in a way but more towards not being able to concentrate on doing my work.* (Malaysia, Malay, manager)

> *It bugs me all the time when I move right now, because of my job it is mainly usually I am sitting at a desk.* (Malaysia, Malay, legal officer)

Another participant's experience chimed regarding the interpersonal and organizational impact on her working life and cost of transportation.

> *It affects my life a lot because I was able to work fine in the past, but now, when I have pain in my knee, I can't work at my full potential, especially regarding travel. I'm not able to get on a bus, I have to change to get in a taxi or on a motorcycle to avoid knee pain which results in higher travelling costs.* (Thailand, Thai, poster worker)

Two participants explained the psycho-social feeling of the disease seriously damaging their everyday leisure and sporting activities. This had an impact on their interpersonal activities with other people

> *It is quite torturing because especially when I want to do some exercise, like running or yoga then it makes me very uncomfortable* (Malaysia, Chinese, manager)

> *I used to think that when I retired, I wanted to go on trips and do some gardening, but when knee pain occurs, it*

*becomes very stressful due to my inability to walk normally.* (Thailand, Thai, state enterprise employee)

### Life changes – it is kind of restrictive

Four participants discussed how it had prevented them from enjoying life in the way that they were used to doing. This participant discusses how it affected their quality of life but implies that she feels that there is a stigma associated with knee pain and by implication being perceived as being disabled, impacting her personal identity and self-esteem.

*Well, modify my way of living is more towards my personal time rather than what others think about me. They don't need me to change anything.* (Malaysia, Malay, employed)

It also stopped her doing most exercise and sporting activities which were central to her interpersonal and social experience

*So, it is kind of restrictive, because right now the only outdoor activities that I am able to do without pain is actually swimming* (Malaysia, Malay, employed)

Likewise, another participant referred to how it resulted in lifestyle changes and identified that the condition had prevented her from continuing interpersonal activities which involved sport.

*"It is only certain exercise. Okay. Like for example, I did do running but I have to stop it and do some you know other activities like swimming or whatever".* (Malaysia, Chinese, employed)

For two participants from Thailand, the life changes were more related to social interaction and responsibilities.

*It affects my life a lot because it interferes with my travelling, especially when travelling with my family.* (Thailand, Thai, retired)

*Knee pain affects my life a lot because I can't do the housework. It is making my life very difficult. I do not go out to meet other people much as I am worried about my knee pain. I am afraid of the difficulties to travel* (Thailand, Thai, general employee)

This demonstrated how chronic knee pain can be seriously debilitating in preventing involvement in interpersonal and sporting activities.

### Support - they feel more empathy towards me

Four of the participants discussed how support from people outside of the family helped facilitate the transition from being fully active to reconciling their experience of knee OA. One participant talked about how they appreciated the empathy shown by someone,

*At work it was okay. I had to quit, I had to leave my job . . . But everybody was actually kind of supportive and they were even like telling me if I wanted to come back after treatment and my medication and things like that.* (Malaysia, Malay, manager)

This participant felt that her work colleagues were very supportive and that this helped her with the transition to coping with chronic knee pain. The feeling of an interpersonal connection with other people within the organizational setting of work made her feel that a fulfilling life was possible, whilst managing the condition.

" *. . .. I think it is the fact that I told them that they feel more empathy towards me.*" (Malaysia, Malay, manager)

This supportive attitude from peers often translated into advice for their medical condition and modification of their activities.

*For my friends, when travelling or going anywhere with them, they will always find a proper seat for me. They always take care of me when I walk. People who see that I have got knee pain recommend me some medications and alternative treatments.* (Thailand, Thai, general employee)

*They often ask if the symptoms are very painful and ask if I have seen a doctor or not. They also ask if my pain is getting better.* (Thailand, Thai, retired)

*I think my brother and my co-workers are sympathetic and worried. My colleagues always recommend that I go to the doctor and recommend other treatments as well.* (Thailand, Thai, state enterprise employee)

However, this empathetic understanding contrasted with two other participants who felt that other people would not understand, unless they had experienced the debilitating feeling of chronic knee pain.

*I think not everybody will understand the effect of the knee pain. Some people may feel the same. But other people may think that actually it is not that bad.* (Malaysia, Malay, Civil Servant)

*For my friends, I think they do not feel anything about it.* (Thailand, Thai, retired)

This lack of understanding is how this participant identified an absence of socio-cultural support from others toward her inhibiting any sense of personal well-being and interpersonal connection with others.

### Familial – sense of community

Six participants from Malaysia discussed how their family and their community within their family enabled

them to learn to cope with the disease. This served as something that prevented them from learning to adjust to their new situation and in other cases facilitated it. This participant felt a sense of foreboding because her father had a similar experience.

> *I feel a bit anxious because I know my dad has osteoarthritis.* (Malaysia, Malay, Legal officer)

Another participant reflected on their experience that their mother had experienced OA.

> *My mum has this problem, I should be more proactive frankly. I should have done my, you know, I should have done my bone density test you know.* (Malaysia, Chinese, Retired)

Interpersonal relationships with their families were key to learning to adapt to living with knee pain. The importance of community of family was evident from most of the participants.

> *Family and friends respond positively and they said is normal.* (Malaysia, Chinese, Self-employed).

This participant's consideration of how their family and friends responded to learning about their knee condition was almost liberatory in its affect. If those in their close family and friends normalized the experience, then there was a genuine reason for hope and optimism for their future lives.

> *I think it is very good sharing. At least my friends or my family they are aware about me and also bring up their awareness.* (Malaysia, Chinese, manager)

The importance of community and family in developing resilience and cultural acceptance for the participants shone through.

### Proactive and preventative treatment

Participants talked about how they should have been prepared for the onset of knee pain because their parents had experienced it.

> *Mum has this problem; I should be more proactive frankly. I should have done my, you know, I should have done my bone density test you know.* (Malaysia, Chinese, retired)

This participant felt that asking for medical support at least enables them to manage the disease.

> *Seeks medical treatment because: At least it is one step ahead instead of we hide the problem.* (Malaysia, Chinese, manager)

Both these quotes perhaps reflect Malay views that it was an individual responsibility to be as preventative as possible to offset the impact of knee OA.

### Treatment - medical or not?

Participants found that individual medical treatment and physiotherapy were beneficial for their knee pain. One participant articulated that their experience of support from medical interventions was helpful.

> *I feel like, whatever health problem we should seek medical advice . . . We try to improve our sickness or the pain . . . At least it is one step ahead instead of we hide the problem. . . . It did help a lot (medical opinion) and also the doctor advised me to do some physio.* (Malaysia, Chinese, manager)

Although, this participant valued medical intervention from professional support, other participants suggested a community-based interventions including exercise and physical therapy was beneficial. Notably, reference is made by this individual to this being an alternative to hiding the problem from the clinician.

> *My knee joints are very painful and swollen, therefore I went to see a doctor and when the symptoms improved, the doctor sent me to get some physical therapy.* (Thailand, Thai, retired)

> *The pain was so much that it was unbearable. Therefore, I had to see a doctor and later I went to see a physical therapist. I thought that if the pain had been treated at its early stage, it would have been better.* (Thailand, Thai, retired)

> *The doctor suggested that I should see a physical therapist.* (Thailand, Thai, retired)

> *And the exercises, therapy that was prescribed was accurate and it helps in terms of my long-term rehabilitation.* (Malaysia, Malay, manager)

> *Other than swimming I think I have done some yoga . . . No exercise on the knee but it did help, and my knee pain has subsided.* (Malaysia, Chinese, manager)

Previous positive experience with physiotherapy was the motive of two participants from Thailand to seek advice on exercise regimen from the physiotherapist.

> *At first, I came to see the clinician because of my wrist therapy, and I found out that it really helped me feel better. Therefore, when I got knee pain, I decided to consult a physical therapist and continued to receive treatment* (Thailand, Thai, general employee)

> *I used to take my mother to get some physical therapy, and she got better, so I believed that it was better to come to get physical therapy myself.* (Thailand, Thai, poster worker)

Then, the importance of facilitating an ordinary life with knee pain was felt to be more valuable by most of the participants. One participant from Malaysia mentioned the use of complementary and alternative interventions focused much more on interpersonal and community remedy and/or a natural treatment to keep an active life.

> *I am thinking occasionally I do take calcium and occasionally I do take fish oil, which is anti-inflammatory, but I have actually stopped taking Glucosamine*. (Malaysia, Chinese, retired)

The focus on community-based interventions with an emphasis on community involvement to facilitate managing knee pain was evident for most participants.

### *Exercise – If it is painful*

All participants were aware of the importance of exercise in maintaining some kind of movement in their knee and how it could help them manage the pain. However, there were limits to how much they felt they were capable of doing.

> *I think if I have no knee pain, I think I will be more active impressive. . . At the moment the knee pain is not very, you know, very obvious or prevalent, so it doesn't really restrict my exercise activities. It is just that I am lazy only frankly*. (Malaysia, Chinese, retired)

This participant reflected the challenge that many women experience in striving to fit exercise into their daily routine, even before they think about the challenge of knee OA. It is a personal challenge that can either facilitate or prevent management of knee pain.

All the five participants from Thailand who stated reasons for not exercising, referred to a lack of time, lack of intrinsic motivation and/or difficulty of the exercises.

> *The reason I don't do it is that I don't have much free time. Some exercises that the physiotherapist suggested as a home program are difficult to do and sometimes it gets too tiring and boring. It's not fun, and I don't have the inspiration to do so*. (Thailand, Thai, general employee)

For several participants it was not individual motivation that prevents exercise it is the actual pain, either before, or during, that inhibits them doing it regularly.

> *If it is painful when I wanted to do the exercises, I wouldn't actually exercise. I would end up resting it, so that means just sitting around or maybe even icing it down* (Malaysia, Malay, manager)

> *The knee whenever strained leads me to (stop other exercise). The pain is first*. (Malaysia, Malay, Civil servant)

Four participants from Malaysia felt that the pain they experienced was preventing exercise and psycho-socially this was quite an individual and personal experience.

### *Exercise – It is for our own health*

Likewise, ten participants felt that that if they could exercise it would facilitate a more active and enjoyable life and importantly enable them to manage the disease. Interestingly, all five participants from Thailand who stated reasons for exercising, referred to the management of pain and function.

> *What encourages me to exercise is the pain, so I want to exercise to relieve it. I also want to recover from having knee pain, so I try to do some exercise.* (Thailand, Thai, retired)

> *I realized exercising is not just for losing weight or anything. It is actually a good thing to know your muscles and also that you can move backwards you know as you grew older . . .* (Malaysia, Malay, manager)

Some participants articulated an understanding of taking control of the knee pain, to a certain extent if she was able to exercise. Making this an individual responsibility and motivation, as they suggested,

> *If there is no pain on the particular time that I want to do exercise or stretches, I would actually just go for it*. (Malaysia, Malay, manager)

> *But what encourages me to do it is the readiness of my body. For example, on the days when I have got enough sleep and do not have any pain, I will want to do it because I feel that when I do it, I can walk better*. (Thailand, Thai, poster worker)

The view that exercise helps with self-management of knee pain was that of most participants and reflects a personal ownership of managing the condition, but also an interpersonal and responsibility to their local community.

> *It is for our own health. This is the main thing. We keep ourselves more flexible and more active and we have to exercise*. (Malaysia, Chinese, manager)

If they could exercise, psycho-socially and physically they could maintain independence. Further, the importance of interpersonal activity and accessibility was suggested by this participant,

> *Mostly I have help from machines, which means I have to go the gym . . . It doesn't hurt the knee but then I mean also the press and the weight* (Malaysia, Malay, civil servant)

The participant suggested that to exercise effectively she needed the use of a gym to do exercises that she was capable of sustaining with knee pain.

In sum, most participants understood the importance of exercise for their own well-being, to facilitate and enhance interpersonal relationships and maintain an active life within their community, whether that is within the workplace or their socio-cultural community.

### Treatment possibilities – losing weight

A key factor for personal responsibility to manage knee pain was for clinicians to encourage participants to lose weight.

> *First thing first is that you know there will be, I think they think I should already learn my lesson that I should bring down my weight. I think that is the first thing* (Malaysia, Malay, legal officer)

This participant's comment can be understood as both a constructive and facilitative intervention because they are personally taking control by trying to manage their weight. Whilst losing weight may often be identified as an individual barrier, it is important to recognize the possible interpersonal, community and organizational influences that may impact stigma, body shaming, and blame around weight loss.

### Stigma and discrimination – "I do not want to burden anyone"

Twelve out of fourteen participants felt that there was a psycho-social burden and cultural stigma with dealing with the disease. The socio-cultural stigma seemed to be prevalent for most participants, as they felt that they did not want their movement or mobility restrictions to become a burden on family, friends, or their local community. It was an interpersonal feeling of stigma,

> *'Slowing people down' and one or two didn't like it. For me it made me feel different".* (Malaysia, Malay, legal officer)

The sensation of feeling different was common among other participants.

> *I am not agile enough to do things that normal people would actually do, you know like sitting on the floor, kneeling down, even praying because, I am actually restricting my pain to sitting down.* (Malaysia, Chinese, manager)

> *I feel very different because I see other people walk normally. I want to walk as actively as I did before.* (Thailand, Thai, retired)

Whilst participants from Thailand reported never feeling different, at the same time they modified their activities or reported hiding. Interestingly, the same three participants mentioned "never been bullied" without prompting, suggesting awareness that bullying does occur.

> *I never feel different because when travelling or going outside, I don't often mention my knee pain. Never been bullied.* (Thailand, Thai, retired)

> *I have never thought or felt any difference. I tend to avoid travelling with other people and try not to cause any difficulties to others. I have never been bullied because of having knee pain.* (Thailand, Thai, poster worker)

> *I have never felt different because when I have to go out or have to walk long-distance, I will prepare myself for it. I also put on a knee support band to avoid causing any difficulties to others. I have never been bullied.* (Thailand, Thai, retired)

This participant explained how she felt knee pain was demonstrating weakness and did not want to be a burden to others in this way,

> *"Sometimes it has been bearable, but if it got worse, probably, I have to tell people my weakness or my problem".* (Malaysia, Chinese, retired)

It was the familial and community stigma that was evident for most participants,

> *I don't want to burden anybody to take care of me.* (Malaysia, Chinese, self-employed)

Whilst many Thai participants appeared especially concerned not to burden others, three participants appeared more resistant to the idea of any kind of stigma. Their answers suggested participant's awareness of potential negative thoughts around knee pain, but they chose to ignore them. Even so, both participants referred to avoiding telling others about their condition and controlling themselves to hide its negative effects.

> *No, as I don't really bother what others might think about me.* (Malaysia, Chinese, retired)

> *No, because like I said I am not really bother about others said . . . I have to control myself and try not to show negative effects so much.* (Malaysia, Malay, Civil servant)

> *I never tell anyone about it because I think that no one would be interested in it . . . I never change according to anyone's complaints.* (Thailand, Thai, state enterprise employee)

Even though all the participants felt that they did not experience discrimination because of knee pain, they all then made comments about restricting activities, adapting their behavior, hiding their condition and focus upon "normality of aging," suggesting the impact of stigma and discrimination upon them.

## Discussion

This study aimed to determine current perceptions and attitudes of women to the management of their chronic knee pain and explore stigma as a barrier to treatment in Southeast Asian countries. Based on the participants' experiences of managing knee chronic pain in their own lives, families, and communities, the study revealed the impact of chronic knee pain on participants' normality of life and their struggles with pain, limitations, and fear for the future. The themes of barriers that prevent women from continuing a normal active life and engaging with formal treatment behaviors to support an active lifestyle are discussed using the socioecological framework (with an individual, interpersonal, organizational & community lens to barriers).

### *Individual barriers*

Individual barriers and facilitators varied greatly across participants, and what was perceived as exercise barriers to some were seen as facilitators to others (Al-Khlaifat et al. 2022; Gay et al, 2018; Holden et al, 2012). Pain and fear Malaysian participants experienced in the present study prevented them from exercising regularly, whilst participants from Thailand, referenced lack of time due to activities of daily living, lack of intrinsic motivation and/or difficulty of the exercises as reasons for exercise avoidance. Previous research regarding chronic knee conditions suggests some participants exercise despite pain, aiming to improve their symptoms, and reduced pain and stiffness by improving strength and joint mobility (Al-Khlaifat et al. 2022; Gay et al, 2018; Holden et al, 2012).

In contrast, other studies have highlighted psychological factors such as avoidance strategies (e.g., Kinesiophobia and fear of pain), which was highlighted as a barrier to exercise where such negative beliefs were associated with pain (Gay et al, 2018; Holden et al, 2012; McKevitt et al. 2022). In contrast, whilst pain-related inhibition places reasoning for avoidance, further studies on participants from UK, Malaysia, and USA, identified that finding time to exercise was a low priority because of individual barriers such as self-claimed "laziness" and lack of motivation (Ahmad et al, 2018; Hendry et al, 2006; Holden et al, 2012; Pellegrini, Ledford, Chang, and Cameron, 2018).

Most individual barriers (Figure 1) relate personal identity, and experiences based on individual beliefs, values, or lenses; people evaluate and cope with situations with different degrees of stress (Carmona-Terés et al, 2017). Patient attitudes to rehabilitation and exercise in the present study created barriers to treatment commitment which may be linked to their understanding of their condition (Hurley et al, 2018). Similarly, unfavorable views on exercise could be connected to a variety of attitudes and experiences, such as a lack of pleasant physical activity memories or references, safety concerns, and unfavorable opinions of gyms and exercise programs (McKevitt et al. 2022). Some participants would stop exercising for fear of exacerbating their condition (Al-Khlaifat et al. 2022; Gay et al, 2018; Holden et al, 2012). Such misconception may be further confounded by the belief that knee pain is an inevitable age-related condition, thus limiting exercise to prevent perceived increase in damage (Holden et al, 2012, Hurley et al, 2018; Ahmad et al, 2018). Negative acceptance in this study placed knee pain as an inevitable consequence of the normal aging process, further implying powerlessness over the pain and self-management behavior (Booker, Tripp-Reimer, and Herr, 2020). As such, participants were not inclined to participate in physical activity to relieve current symptoms or prognosis, believing declining health and quality of life was inevitable (McKevitt et al. 2022).

The attitude an individual adopts has previously been associated with education (Che Hasan, Stanmore, and Todd, 2021). A study in Malaysia identified education as a significant barrier toward health seeking behavior, similarly, some of the Southeast Asian participants in the present study were unable to read or write and appeared less able to find coping mechanisms for concerns compared to patients with a higher educational background (Che Hasan, Stanmore, and Todd, 2021). Further research exploring the intersectional experience of individuals may help to further unpick possible strategies for overcoming some of the highlighted individual barriers.

### *Interpersonal barriers*

Whilst elements of social activities are often viewed as interpersonal relationships, individual barriers can often lead to social isolation and emotional disengagement (Che Hasan, Stanmore, and Todd, 2021). This may compound through individuals hiding their condition, not wanting to become a burden, assuming their condition as a sign of weakness (Holden et al, 2012, McKevitt et al. 2022; Che Hasan, Stanmore, and Todd, 2021). Interpersonal barriers reported by participants, included the absence of socio-cultural support, negative family medical history, negative impacts of pain on social activities, reduced social connections, and the lack of desired empathy and social or motivational support from close ones (e.g., during exercise).

Whilst discrimination was not explicitly reported, signs of discrimination were notable in some answers and behavior. There were indications that weight loss played an important role in decision making attitudes. It is important to realize the potential impact of positive awareness raising campaigns and media and the potential influence this may have on changing attitudes at an individual, interpersonal, and community level (Selensky and Carels, 2021). The presence of social stigma and fear of discrimination amongst the women was implied by participants reporting hiding their medical condition from others, feeling responsible for their condition, and fear of becoming a burden to the society around them. These findings are congruent with previous work exploring the stigma of chronic illness such as knee OA and the connection between mobility aids and feelings of shame in Asian societies like Singapore (Yang, Woon, Griva, and Tan, 2022). Some of the cultural and social challenges facing Malay females in engaging with exercise and managing knee pain, have previously included feelings of shame about doing exercises and fear of making a bad impression on their community and family (Che Hasan, Stanmore, and Todd, 2021). The findings of the present study suggest the barrier of stigma associated with disability in SE Asia requires further attention.

### Organizational barriers

Lack of healthcare professionals' support or stigmatization by staff has been described as a barrier to knee pain management in other countries (McKevitt et al. 2022; Nyvang et al. 2016, Al-Khlaifat et al. 2022; Cavaleri, Short, Karunaratne, and Chipchase, 2016; Woo, Zhou, and Larson, 2021). The primary organizational barrier found in this study was the lack of support from medical professionals which has previously been described as the main facilitator to exercise-based treatment regimens in Malaysia (Che Hasan, Stanmore, and Todd, 2021). It is important to note that previously documented stigma associated with health care professionals may also explain the suggestion some people hide information from clinicians (Cavaleri, Short, Karunaratne, and Chipchase, 2016; Woo, Zhou, and Larson, 2021).

Whilst in the workplace interpersonal barriers may impact individuals in managing their knee pain, the negative impact of pain experiences may also impact people at an organizational level, impacting their job functions and performance. The effect of chronic knee pain on the work environment has received little attention in the literature since it has been considered as an age-related condition (Darlow et al, 2018). This study is the first to highlight the relative importance of assessing barriers at work for women with chronic knee pain in SE Asia when considering rehabilitation regimens.

### Community barriers

For the present study, reduced access to public transport, reportedly hindered access to knee rehabilitation. This agrees with previous research that reported distance, transportation availability, and prohibitive cost of travel as the primary community barriers for older individuals with knee OA in Malaysia and England (Che Hasan et al, 2021; McKevitt et al, 2022).

### Limitations

As this study focused purely on a sample of women from Malaysia and Thailand, there are limitations in terms of the validity or transferability of the findings to women in other spaces. Though this study explores stigma amongst women of color in SE Asia, this study did not consider the possible influence of post-colonial lived experience on data or analysis. The qualitative semi-structured interviews employed for this study limit the voices and opinions shared. Whilst this study included site specific translators and multiple researcher agreement between countries on the identified themes, the authors acknowledge the potential limitation of not seeking thematic agreement with participants or obtaining detailed field notes. Further studies may adopt a mixed method approach to add further depth and understanding of where tangible changes are needed to improve the experience of Southeast Asian women.

## Conclusion

This study is the first to explore perceptions and experiences of knee pain in Southeast Asian countries using the socio-ecological model as a framework for identifying the key barriers associated with the management of women with chronic knee pain. The study highlights the need to employ socio-cultural competency and consider an individuals' intersectional identity and interpersonal relationships when designing rehabilitation and conservative management solutions. Improved support from healthcare practitioners and understanding the barriers related to the workplace for those with chronic pain may also help to develop appropriate regimens that help maintain financial and physical independence. Finally, co-creating alternative pathways for rehabilitation for individuals that are more distant from health facilities may help to reduce socio-cultural barriers at a community level.

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