

'Grandchildren are like my medicine': Practices and expectations of South Asian individuals and their families for digitally enabled and carer supported pain self-management in the United Kingdom

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Abstract

Background

Chronic pain affects South Asians disproportionality in the United Kingdom. Self-management is an essential part of living with chronic pain, with families playing an important role in the process. This study explored chronic pain self-management practices of South Asian individuals and their families for pain self-management and examined the potential for digitally enabled and carer supported pain self-management.

Methods

This narrative study involved interviewing families, including individuals living with chronic pain and their family members. South Asian adults living with chronic pain and receiving support from family members were considered eligible. Semi-structured interviews were conducted with families in Punjabi, Urdu and English. Interviews were audio-recorded and transcribed verbatim. Anonymised transcripts were coded, analysed and interpreted.

Findings

Ten individuals and twenty-five family members participated in ten family interviews. We developed three themes capturing how chronic pain is experienced and managed within social and cultural contexts. Firstly, we found that self-management decisions were largely family-led and shaped by experience with healthcare system, treatment expectations and online information. Secondly, variations in self-management strategies and treatment expectations (e.g., pain reduction vs function improvement) were influenced by socio-cultural and family dynamics, particularly the degree of reliance within families. Thirdly, dissonance between clinical advice and families' social realities perpetuated distrust in healthcare system. Participants perceived treatments to be pharmacological in nature and found advice related to non-pharmacological aspects (such as diet and physical activity) impractical and culturally irrelevant. Digital pain self-reporting tools and simple pain visualisations were seen as valuable for supporting pain self-learning and improving self-management, particularly by enabling proxy access and shared learning from others' experiences of pain management.

Conclusion

Pain self-management practices are diverse and shaped by social, technological, cultural, and family contexts. Family dynamics and treatment perception guided people's treatment expectations, which are primarily focused on pharmacological interventions.

Introduction

Chronic musculoskeletal pain is a major public health challenge in the United Kingdom, affecting at least one in four adults (Fayaz et al., 2016; NHS England, 2026). This condition has a profound impact on daily function, psychological wellbeing and overall quality of life (Public Health England, 2017; Versus Arthritis, 2024). Effective pain management requires a person-centric and collaborative care approaches (Hutting et al., 2022), and a significant proportion of pain management occurs outside formal clinical settings. The National Institute for Health and Care Excellence (NICE) recommends pain self-management approaches (NICE, 2021) that can improve the ability of an individual to '*manage symptoms, treatment, physical, psychosocial consequences, and lifestyle changes*' (Miles et al., 2011).

Evidence suggests that self-management not only fosters patient autonomy but also mitigates the pressure on health care systems by reducing the frequency of clinical interventions (Cohen et al., 2021). To facilitate the process of self-management, NICE recommends person-centred assessments of the causes and effects of pain that can inform care plans (NICE, 2021). However, doing such person-centred assessments well is far from straightforward, since perceptions of causes and effects of pain are not universal but deeply influenced by cultural frameworks (Rogger et al., 2023). For instance, research indicates that some Black African communities may conceptualise pain as an emotional burden intertwined with social stigma and disability, while South Asian populations often identify dietary factors as primary triggers for chronic pain (Ali, Lee, et al., 2023). These variations underscore the complexity as well as the significance of understanding the social context in which pain experiences are shaped, which shapes how pain is communicated and managed.

Despite the evidence of the impact of cultural factors on pain perception, existing pain self-management interventions often overlook the complex realities of culturally diverse communities (Maricar et al., 2024). South Asians, as one of the largest ethnic minority groups living in the UK, are disproportionately affected with chronic pain, experiencing a higher prevalence of the condition, inequities in access to services and poor clinical outcomes (Ali et al., 2024). Among South Asians, the beliefs about illness and care socially constructed, whereby intergenerational and cultural views are shaping and guiding their self-management practices (Burton et al., 2019; Clarke et al., 2023). These culturally informed

understandings of illness and care have profound implications for how self-management is organised within South Asian families as support is often shared among family members (Kimmitt et al., 2025).

Current research on familial support focuses on a primary caregiver (Botas et al., 2025; Liu et al., 2024), which fails to consider the relational nature of self-management within South Asian families (Dilla et al., 2020), where multiple family members perform interconnected roles ranging from supporting medication adherence, preparing culturally appropriate healthy meals, encouraging physical activity and facilitating the use of lay remedies. While, the involvement of multiple family members in caregiving task-sharing is acknowledged, evidence beyond primary caregivers is limited (Lim-Soh et al., 2024).

The relational nature of self-management becomes particularly significant in the context of the growing use of digital health technologies for accessing health services and managing long-term conditions. While such tools offer opportunities for real-time monitoring and personalised feedback to support self-management, they risk exacerbating existing pain inequities and challenges if they are not designed to accommodate the needs of culturally diverse communities (Farre et al., 2023; World Health Organisation, 2022). Although family members often act as digital "enablers" (Whitehead et al., 2023), they may also support the use of digital health technologies for better pain monitoring (Ali et al., 2024; Ali & van der Veer, 2025) and supporting its management (Schulman-Green, Feder, Dionne-Odom, et al., 2021; Whitehead et al., 2018). Therefore, this study aimed to understand the role of family members in supporting self-management and how digital could support this role. Specifically, this will contribute to enhancing the potential of digitally enabled and carer supported pain self-management within South Asian community in the United Kingdom.

Methods

Study design

We employed a narrative study design, using a family interviewing approach, to explore the lived experiences of South Asian individuals and their family members in relation to pain self-management practices. A narrative approach was selected as it enables an understanding of how individuals construct and ascribe meaning to their illness and care experiences through personal narratives (Finlay & dela Cruz, 2023). The focus on family enabled us to provide an in-depth exploration of how participants make sense of their condition over time and within their specific social setting.

Owing to the cultural heterogeneity among South Asian communities, this study focused specifically on the Pakistani community living the UK, who experience more severe chronic pain (Health Survey for England, 2017; The Health Foundation, 2025).

We reported our study in accordance with Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) (annexure A).

Participant eligibility and recruitment

We used a combination of purposive and snowballing sampling techniques to identify and recruit at least three members of a family, including the person living with chronic pain.

Adults aged 16 years and above, self-identified of Pakistani heritage or background, either living with a chronic pain condition or providing care for a family member with such a condition, and willing and able to provide written informed consent for an audio-recorded family interview were considered eligible for this study.

Recruitment and data collection was facilitated by two community-based organisations working with South Asians living in a large city region in the North West of England. These organisations promoted the study through their regular activities and (digital) networks. Initial screening was conducted by a community volunteer, followed by a second screening by the lead researcher, who explained the study and answered questions before scheduling a family interview. Family interviews were conducted in English, Punjabi, or Urdu (languages commonly spoken among British Pakistani communities) at a time and location convenient for all family members. All eligible people provided written consent and were compensated for their time.

Data collection

Following written consent, basic demographics and related information were captured using an online questionnaire. We adopted a family interviewing approach rather than using focus groups, where participants typically do not know one another. In contrast, family interviews involve individuals with pre-existing relationships and shared caring responsibilities. Given that pain self-management within South Asian communities is often relational, this approach enabled us to capture how family members jointly interpret, negotiate, manage, and coordinate care and care needs; processes that would be difficult to reproduce within a focus group setting (Eggenberger & Nelms, 2007).

We developed a topic guide (annexure B) for semi-structured family interviews that was informed by the existing literature on the role of family carers and self-management (Ali et al., 2024; Boon et al., 2023; Chi et al., 2020; Kang et al., 2024; Mann et al., 2013; Schulman-Green, Feder, Dionne-Odom, et al., 2021), theories of self- and family management framework (Schulman-Green, Feder, Montano, et al., 2021) and relational autonomy (Oshana, 2020). Drawing upon the literature, topic areas such as lived experience, current pain management practices, self-management and role of family carers, needs and expectation regarding self-management and role of digital health tools were explored. We used visuals from the Manchester Digital Pain Manikin and potential pain visualisation ideas (annexure C) to stimulate discussions on digitally enabled pain assessment and management. The Manchester Digital Pain Manikin is a digital pain self-reporting tool, that allows users to track pain intensity and location on a smartphone interface, a feature that our previous research identified as an enabler for self-management (Ali et al., 2024; Ali, Lee, et al., 2023; Ali, Santisteban, et al., 2023). Prior to family interviews, participants were advised to provide comprehensive account of pain and pain management experiences, encouraging both convergent and divergent views about chronic pain management.

Data collection by guided by a principle of information saturation. Data collection, analysis and interpretation were led by a male researcher of South Asian heritage with expertise in public and digital health research involving ethnic minorities living in the UK. Data analysis was supported by a female health researcher of White ethnicity with expertise in family carer research. Prior to data collection or family interviews, the male researcher shared key information about general health research and explained purpose of conducting this study with families, including individuals with pain. This helped the researcher to improve participants’ understanding about research and build rapport with them. Interviews were audio-recorded, which were transcribed verbatim by a third-party transcription service. Three high-quality interviews were transcribed and translated into English, while the remaining interviews were transcribed into their original language, i.e., the language in which each interview was conducted. All transcripts were anonymised before analysis.

Data analysis

Quantitative demographic data were summarised descriptively in a tabular format. The interview transcripts were analysed using a reflective thematic analysis approach (Byrne, 2022), which acknowledges the active involvement of researcher’s positionality in interpreting data. Reflexive thematic analysis involves six iterative phases: (a) becoming familiar with the data; (b) coding; (c) generating initial themes; (d) reviewing and refining them; (e) defining and naming themes; and finally (f) producing the analytic report (Braun et al., 2022). Though we collected and analysed data simultaneously, the lead researcher maintained a reflexive journal to guide data collection for subsequent family interviews.

Two researchers conducted a line-by-line review of three English translated transcripts and coded it by using a combination of inductive and deductive approaches. Both researchers met to discuss coding and adjusted coding structure based on their understanding of the data. These discussions helped developing themes and shaping data interpretation and reporting. For data interpretation, we focused on the contrasts and overlaps between individuals and family members (Eisikovits & Koren, 2010). We organised data at three levels: taxonomy, themes and theory, as proposed by Bradley et al. (Bradley et al., 2007). The taxonomy of codes was developed based on code types, including conceptual, relational, perspective, and family characteristics. The codebook and code types were refined iteratively in Microsoft Excel through discussions with the research team. The final codebook was applied to all transcripts to ensure consistency and used to develop themes. We interpreted codes and themes to draw a set of general propositions, which helped explain and predict self-management practices and their outcomes.

Our data collection and reflexive thematic analysis approaches were guided by existing guidelines for ensuring methodological rigour (Braun & Clarke, 2024) and trustworthiness (Lincoln & Guba, 1985).

Findings

We interviewed ten families, consisting of ten individuals with chronic pain condition(s) and a total of 25 family members involved in their care (total n = 35). In the remainder of the manuscript, we have referred to individuals with chronic pain as ‘patients’ and the family members supporting their care as ‘family carers’. Interviews were conducted at patients’ residences (n = 6) or community venues (n = 4), with durations ranging from 33 to 62 minutes. Punjabi was the primary language used in interviews, followed by English and Urdu.

As described in Table 1, patients were predominantly female (n = 8), aged over 55 (n = 7), residents of highly deprived areas (n = 9), not employed (n = 10) and had lived in the UK for more than 10 years (n = 8). Notably, all patients lived with multiple long-term conditions, with 60% (n = 6) managing three or more comorbidities. Conversely, family carers were generally younger (64% under 44 years), more highly educated, and employed (n = 14) but 64% had at least one long term condition. Most of the households had multiple generations, suggesting diversity within a household in terms of languages spoken, digital and health literacy, and more broadly cultural practices.

Table 1: Participants characteristics (n=35)

Variables	Patients (n=10) Number (percentage)	Family carers (n=25) Number (percentage)
<i>Gender</i>		
Female	8 (80)	14 (56)
Male	2 (20)	11 (44)
<i>Age</i>		
18 – 34	Nil	9 (36)
35 – 44	Nil	7 (28)
45 – 54	3 (30)	4 (16)
55 – 64	4 (40)	4 (16)
65 and above	3 (30)	1 (4)
<i>Education</i>		
Nil	4 (40)	2 (8)
Primary	2 (20)	4 (16)
Secondary	1 (10)	6 (24)
Further education (e.g., A-level, BTEC)	1 (10)	3 (12)
College or University (post-graduate)	2 (20)	10 (40)
<i>Employed (part/full time)</i>		
No (e.g., student, retired, unemployed)	10 (10)	11 (44)
Yes	0	14 (56)
<i>Index of multiple deprivation decile</i>		
Most deprived (1 to 3)	9 (90)	-
Average (4 to 6)	1 (10)	-
Least deprived (7 to 10)	Nil	-
<i>Years lived in the UK</i>		
3 – 10 years	2 (20)	10 (40)
More than 10 years	7 (70)	8 (32)
Born in the UK	1 (10)	7 (28)
<i>Native language</i>		
English	2 (20)	5 (20)
Urdu	2 (20)	6 (24)
Punjabi	6 (60)	12 (48)
Other (Mirpuri, Italian)	Nil	2 (8)
<i>Relationship with individuals with pain</i>		
Spouse	-	8 (32)
Parents	-	4 (16)
Children	-	5 (20)
Grandchildren	-	1 (4)
Siblings	-	2 (8)
In-laws	-	5 (20)

Number of generations living in a same household		
One		
Two	1 (10)	-
Three	5 (50)	-
	4 (40)	-
Number of languages spoken in a family		
One		
Two	1 (10)	-
Three	5 (50)	-
	4 (40)	-

We developed three themes from the data: (a) family-led decision-making and implementation of pain self-management strategies; (b) variations in pain self-management strategies and outcome expectations due to socio-cultural and family circumstances; and (c) dissonance between two institutions: family and the healthcare system. We have illustrated these themes through participants' quotes, which informed the study's general theoretical propositions (presented in Table 2 as well as at the end of each theme).

Table 2
Themes and theoretical propositions

Theme	Summary	Theoretical proposition
Family-led decision-making and implementation of pain self-management strategies	South Asian families treat chronic pain management as a collective responsibility, combining traditional remedies with modern, consumer technologies. Younger family members often act as tech-gatekeepers for older members, who may also consult traditional healers and peers. To improve pain self-management, families expressed openness to digital pain self-reporting tools, provided they offer a shared, data-driven "family profile" approach for managing pain triggers.	Because pain self-management is multifaceted, involving affective and cognitive processes that shape treatment and management decisions, the effectiveness of prescribed pain treatments may remain limited when these underlying factors are not addressed adequately, reinforcing self-medication practices and reducing engagement with non-pharmacological treatment options.
Variations in pain self-management strategies and outcome expectations due to socio-cultural and family circumstances	Chronic pain self-management approaches of South Asians are influenced by living arrangements, with higher interdependence and support in multi-generational households. Level of interdependence is also reflected in preference between pain reduction and function improvement. Family carers play a crucial role: while it provides support and improves mood, high-stress situations may also arise from cultural expectations and the inability to function. However, digital tools may support learning from people with shared cultural backgrounds regarding how they are managing their chronic pain effectively.	Families with higher interdependence and cohesion, such as those in living joint family systems, are more likely to prioritise pain reduction over functional improvement, whereas families with lower interdependence tend to place greater emphasis on improvement in function. This highlights that success in pain management is not a universal metric but defined by the perceptions of the family unit.
Dissonance between two institutions: family and the healthcare system	There is a significant disconnect between South Asian families' expectations and the formal healthcare system. They feel that the NHS is unresponsive to their context, dismissive of their cultural practices, and focused on costs rather than care, leading them to seek relief through religion, tradition, and family-led strategies. Such perception and practices arise from wrongly perceived language or translator needs and advice (such as exercise, talking therapy) that feels irrelevant to their daily lives. However, families believe that digital tools to track and visualise pain could bridge this gap, helping doctors better understand their lived experiences.	When healthcare systems and professionals prioritise prescribed, and often standardised treatments over approaches that are responsive to people's socio-cultural contexts, individuals and families increasingly rely on alternate means to guide and adapt self-management strategies. Moreover, when individuals conceptualise pain treatment primarily in terms of medical and surgical interventions, they are less likely to assign value to non-pharmacological treatment options, such as physical and psychological therapies, potentially limiting their engagement with multimodal approaches to chronic pain management.

(a) Family-led decision-making and implementation of pain self-management strategies

Pain self-management was constructed not as an individual responsibility but as a collectively organised practice within a domestic sphere. Patients reported their lived experiences to be challenging, because it affected their daily function (e.g., mobility, quality of sleep) and general health and well-being.

Patients and their family carers adopted diverse strategies that mainly focused on pain reduction and guided by information received from digital and non-digital sources (i.e., family, peers, traditions). Broadly, these self-management practices ranged from old traditional remedies

(e.g., team with herbs and spices, turmeric, *punjari*) to contemporary approaches (e.g., hand massager, massaging chair). In addition, people used alternate treatments such as cupping, needling, herbal and homeopathic treatments. A few participants mentioned travelling to Pakistan to receive alternate treatments or seeking opinions on their treatment plans. For example, a family carer of an elderly patient mentioned:

To be honest with you, because she goes to Pakistan quite often. She goes to rural areas; there are herbalists and spiritual healers...She would ask them...and they would all say something...which she will then follow

(Family 6: daughter-in-law carer of a female first generation immigrant patient living in a tri-generational household)

Patients and their family carers adopted consumer pain management technologies, such as hand massager, massaging chair, for which social media acted as a source of information. Generally, younger family carers accessed such information (e.g., from TikTok, Instagram, Facebook) and made these technologies available to help patients. A son caring for his mother described:

We've got a lot of gadgets at home. A massage chair, message gun, heat packs...they give her comfort for pain and aches. Her eyes get very tired, so we've got an eye mask as well

(Family 6: son carer of a female first generation immigrant patient living in a tri-generational household)

Older patients and family carers mainly used YouTube to access information about pain management. Intergenerational exchange of information was common, which guided self-management decisions. However, family carers also recognised the issues of credible and misinformation, for which one family carer described their approach:

Before buying anything outside the GP prescription, like herbal medicines, we research it. We go to Holland & Barrett and get turmeric and black pepper. We read online reviews whether it's got a positive or negative effect, or have people actually benefited

(Family 8: daughter of a female first generation immigrant patient living in a tri-generational household)

The focus on pain reduction and lack of clarity regarding appropriate medication practice fuelled self-medication practices such as increasing doses during flareups or skipping medications due to (fear of) side effects. In these instances, family carers saw the person with chronic pain as the authority via their own embodied experience. For example, a family carer described:

'I sometime notice that she is uncomfortable on bed in middle of the night...I ask her that taking double dose is not helpful, but then I think only the person knows better about her needs because she thinks taking double dose might help her'

(Family 5: husband of a female first generation immigrant patient living in a uni-generational household)

'My mother-in-law was fed-up with taking a particular medicine... I think she was going through a phase where she just didn't want to take that medicines...She would just take one of them mostly. Once I found that tablet in waste bin...and I didn't realize that she wasn't taking it.'

(Family 6: Daughter-in-law of a female first generation immigrant patient living in a tri-generational household)

Moreover, all patients and their family carers mentioned the use of diet as a way to manage their pain. Among all self-management strategies, diet seemed to contribute significantly to their day-to-day management. However, changes in dietary practices were mostly caused by the seasonal/weather context, peers' advice and social media. One family carer described this as:

'Bone broth is good in the winter. We make another one where we...crush almonds and nuts (punjari). They [referring to people] say in the winter you should have all these, and to be honest, it helps her'.

(Family 8: Daughter of a female first-generation immigrant patient living in a tri-generational household)

Regarding the future use of digital pain self-reporting tools, many patients and family carers supported manikin-based tools to keep track of their pain. However, patients (generally older) expressed their lack of motivation to learn and use these tools themselves, rather preferred their family carers to use these technologies and help them in managing pain. One family carer said:

'it [digital pain self-reporting tool] is good for older people, like me, to describe their pain...such as what is the problem...where is the pain...how intense it is...it is be very helpful...but older people might not be able to use such tools [digital pain self-reporting tools], whereas carer can be very helpful in that regard'.

(Family 8: Female first-generation immigrant patient living in a tri-generational household)

For future pain management related decisions, family carers anticipated the use of pain self-reporting tools to track their pain and related factors longitudinally and use that information to change their routine practices as one carer mentioned:

'...if you use this [pain self-reporting tool] regularly... after 30 days you can see yourself, what you're eating for example...even for mum [as carer and patient] as well, if she can see ...she can be like...after 30 days I cooked something specific and it's not coincidence that those days were bad days for him (referring to patient)...that maybe a trigger...then she [mother] can adapt her cooking'.

(Family 7: Daughter of a male second-generation immigrant patient living in bi-generational household)

Proactive approaches towards pain self-management were also seen as a potential benefit of using digital pain self-reporting tools as one patient said:

...the visuals [referring to example pain visualisations], I think that might make me understand. If I have all the evidence in front of me saying which day was really bad for me, why it was bad for me... what did I eat or anything...I think that would improve things...because then it gives you a pattern as well, doesn't it?

(Family 7: Male second-generation immigrant patient living in bi-generational household)

Moreover, for such collaborative decisions, family carers recommended having access to this information as proxy users. This would help them to learn whether and to what extent the family-led decisions are effective for pain management. One of the family carers drew an analogy and explained and rationalise the proxy access as:

...my wife looks after my mum and her mum so she needs an app, where could put multiple people on that...so, maybe she could know what's going on with her own mother, what's happening with my mum, or somebody else in the family who's not well or who's got pain and aches...she could have access to multiple people...like Netflix where [there are] multiple people...lets say patient A, B, or C, and then all the information will come for that person, and then for the other person...so logging into one will have access to all of them, and all the notifications come up in different colours.

(Family 6: Son of a female first generation immigrant patient living in a tri-generational household)

In summary, we found that because pain self-management is multifaceted, involving affective and cognitive processes that shape treatment and management decisions, the effectiveness of prescribed pain treatments may remain limited when these underlying factors are not addressed adequately, reinforcing self-medication practices and reducing engagement with non-pharmacological treatment options.

(b) Variations in pain self-management strategies and outcome expectations due to socio-cultural and family circumstances

Family support was found to be consistently shaping pain self-management practices across all ten families. However, the availability of family support was depending upon number of generations living in a household, i.e., the level of interdependence was higher among trigenerational households. In uni-generational or bi-generational households, regular family support from younger generations was available but less frequently and for specific times, such as in evenings or weekends.

Over the years of pain management experience, people had varying self-management beliefs and practices, which were shaped by their living arrangements and level of family support available. In a multi-generational household, the level of support available was higher, reflecting a collectivistic model of care. For example, a family carer described:

...we all live together. We're an extended family. And somebody will always be, whether it's myself, my husband, my brother-in-law or my children, somebody will always be out to look after her, for Mum...Wherever we go, whatever we do, her needs come first.

(Family 6: Daughter-in-law of a female first generation immigrant patient living in a tri-generational household)

Family carers had significant role in providing support, whatever and whenever it is needed. There was huge influence of family carers and digital health information related to pain-self management on their decision-making processes and decisions. Depending on social and living arrangements, individuals adopted both socialisation and isolation as a strategy to self-manage their conditions, and particularly their moods. These situations are described as below:

It helps when my husband or my friends take me out...I walk and breathe out....my environment changes so as my mood....My husband helps my daughter cooking food, he serves and feeds me as well

(Family 3: Female first-generation immigrant patient living in a tri-generational household)

'He stays most of the time upstairs in his bed, so he just locks himself upstairs...When he just don't want to talk to anybody, he just tell everybody to go away and just leave me alone in one dark room'.

(Family 7: Wife of a male second-generation immigrant patient living in bi-generational household)

Grandchildren are like my medicine...If I'm feeling really down, angry with everybody, sometimes someone comes into my room I tell them, don't bother me, go away...grandkids come in they will jump on my bed...all of a sudden I forget about my pain. My mood swings, they completely change.

(Family 7: Male second-generation immigrant patient living in bi-generational household)

Living arrangements and level of family support also shaped people's expectation of treatments. Treatment expectations varied from improving either pain or daily function alone to improving both pain and daily function. In multigenerational households with small family sizes, where patients also had household responsibilities (such as cooking for the entire household), they prioritised function improvement over reducing pain. One participant described it as:

at the moment, my left hand is bothering too much, because I am left-handed. If my function is back, I can tolerate pain in right hand

(Family 10: female first-generation immigrant patient living in a bi-generational household)

In multigenerational households, younger generation had developed empathy and recognition of the problem and provided emotional support to individuals living with pain. A young participant described his day-to-day engagements with her mother as:

I feel her pain because I'm part of her. I see her arm shaking and things like that... and I don't really want to do anything that might upset her. So I mostly just talk to her. If talking isn't a good idea, then maybe pointing things out or offering quiet help can be better

(Family 10: son of a female first-generation immigrant patient living in a bi-generational household)

Stress was found to be a factor that was both intrinsic and extrinsic in nature, shaping overall pain experience in a social context. Most of the participants described how their inability to manage pain effectively triggered fear and stress in them. One of the participants described it as:

I keep thinking what happens if I develop any disability and get confined to bed and chair...then what will happen to me...I have this fear constantly in my head

(Family 5: female second-generation immigrant patient living in a uni-generational household)

Another participant described a situation that triggered stress due to not conforming to the societal expectation of being a man and a father:

Despite he is receiving social benefits, he is worried that he is not working and his situation is worsening too. He also thinks that instead of spending on kids, he is depending on them...he wants to earn and do something for kids

(Family 9: wife of a second-generation immigrant patient living in a bi-generational household)

In addition to person's own situation, cultural values and practices also triggered stress, which in turn triggered pain. One of the participants highlighted that cultural aspect as:

Stress caused by family issues keeps happening all the time...my wife and I—we're cousins ...So we're all very closely interconnected...my mother and my wife's mother are both sisters. So whatever happens in that family, because my mum is the eldest, will come to my mom and then it is my mom's duty...to solve everything

(Family 6: son carer of a female first generation immigrant patient living in a tri-generational household)

In addition, patients and family carers recognised that pain self-management strategies varied across South Asian households. Family carers wanted access to information on these strategies and their effectiveness. For this purpose, family carers supported simple graphic visualisations of patients' pain (self-)reports (i.e., pain story visualisations in annex). Comparing their own summaries with those of others living with chronic pain in similar circumstances was seen as a way to reinforce learning and promote better self-management. Both patients and family carers particularly valued evidence drawn directly from people with similar ethnic and cultural backgrounds.

'We want to know for mom is what kind of help is out there, what we can do to make her life a lot more comfortable and pain-free... so she is not only stressing...and helping her switching things...explaining to her the medication role, about what is going on, or telling her what food is good for her and what food is bad for you'.

(Family 6: son carer of a female first generation immigrant patient living in a tri-generational household)

In summary, families with higher interdependence and cohesion, such as those in living joint family systems, are more likely to prioritise pain reduction over functional improvement, whereas families with lower interdependence tend to place greater emphasis on improvement in

function. This highlights that success in pain management is not a universal metric but defined by the perceptions of the family unit.

(c) Dissonance between two institutions: Family and the healthcare system

Across all families, we identified a disconnect between a family (as an institute) and the formal healthcare system. We found patients to be dissatisfied with prescribed treatments and their outcomes as they perceived the healthcare system to be non-responsive to their needs. Though patients acknowledged that clinicians tried to help them by trying different treatments, but we found them fixated with negative treatment outcomes. One participant shared the views about her upcoming talking therapy appointment:

When I went to physiotherapist.....mostly they would do talking...if they gave any physiotherapy session then its benefit could only sustain for 30 mins...now they have referred me for a talking therapy....I don't know what is it....and honestly, I don't think it's going to be helpful...I am fed up now [with pain]. It has gone worse day by day and I think pain is not going to go away

(Family 10: female first-generation immigrant patient living in a bi-generational household)

Patients also perceived that the NHS is prioritising finances over patient wellbeing, thereby resulting in a class divide, where treatment is inaccessible and only available to those who could afford private healthcare. One participant expressed his experience and feeling as:

'when I went to see my specialist a couple of weeks ago, he mentioned that there is some kind of treatment out there for my condition but it's too expensive...you can't try that on the NHS...if you got the money, you can go to private and pay for it, that would improve your condition. So that's more frustrating, not being able to take that kind of treatment. Knowing that the treatment is out there but it's hard to reach'.

(Family 7: male second-generation immigrant patient living in bi-generational household)

Patients and family carers mentioned that clinicians often suggested non-pharmacological treatments (such as physiotherapy and psychological strategies) or advised physical activity, dietary changes and regular exercise. However, participants often rejected the utility of non-pharmacological treatments and general advice because these were not aligned with their treatment expectations and social realities. That is why, clinicians were perceived culturally misaligned, and often dismissive of patients' cultural practices, resulting in less open and transparent clinical consultations and patients feeling alienated. One participant described it as:

'So when you go to the doctor, you tell him any herbals doctors...they don't really believe in that kind of stuff. They want you out of that room quick. So it's in and out'.

(Family 6: daughter-in-law carer of a female first generation immigrant patient living in a tri-generational household)

Due to healthcare professionals' lack of understanding of the social context, patients felt that they were not fully understood, which resulted in treatments being less responsive, and hence not trusted. One family carer described it as:

Not many people know, what we need to do to manage our condition...Sometimes they [elders] listen to others rather than the professionals. When my grandma goes to the GP. He'll tell her you need to do this. Two minutes later, when she walks out, she's like he doesn't know anything...

(Family 8: Grandson of a female first generation immigrant patient living in a tri-generational household)

Clinical consultations were often undermined by a lack of cultural nuance. For example, the use of interpreters who might be linguistically matched but culturally/religiously mismatched which stifled engagement:

I remember with aunty (patient) she had an appointment, and they got an interpreter. They asked which language, we said Punjabi, and it ended up being a Sikh guy...so no one could understand anything, and he was speaking Punjabi.

(Family 6: daughter-in-law carer of a female first generation immigrant patient living in a tri-generational household)

Patients and family carers had a perception that 'good treatment' meant pain reduction rather than strategies to reduce the impact of pain, which seemed to stem from their limited awareness that chronic pain often does not fully resolve. Many patients described repeated consultations with no or little meaningful improvement, which often led to therapeutic interventions shifting from the clinic to their homes. In this setting, family carers and social networks became central to the interventions, drawing on their own cultural understandings of pain management. For example, this conversation among family members highlighted the challenge as:

Brother-in-law: I advise him to control his weight to manage pain

Patient: How can I control my weight, if I cannot walk

Wife: People say control weight or do this or that, but he can't walk, so how can he do that

Patient: Still, I try to do a bit of walk because only I have to do what needs to be done

Brother-in-law: I understand he cannot walk, but he can control his diet

(Family 9: second-generation immigrant patient living in a bi-generational household)

In the face of dissonance with healthcare systems, patients' and family carers' belief in religion and engagement with cultural practices were described as fostering hope and a more positive mood, which, in turn, appeared to support a more proactive approach to pain management. In particular, religion and spirituality were constructed as an ultimate source of relief, especially in situations where other strategies had failed:

What can we do....if doctor is not helping to manage pain then God will help....for that we will pray, recite Quran and offer prayer

(Family 9: wife of a second-generation immigrant patient living in a bi-generational household)

While the role of family members remained very critical in adoption of self-management strategies, one of the participants reflected on the role of extended family members and peers, which was constructed as fostering lack of engagement with one's activity levels:

If I or people around just ask him to take rest because you are unwell. Instead of encouraging him, we tend to show sympathies by saying don't stand, don't do this, don't do that.....this way he will be discouraged to take any action...because then we let disease overpower us

(Family 9: wife of a second-generation immigrant patient living in a bi-generational household)

We found cultural agency to be multifaceted and moderated by several factors, including intergenerational differences in cultural values, e.g., listening to and helping others. Despite this, patients and family carers described how digital health technologies or information brought together older generations with younger generations. One of the participants mentioned:

Ammi [Urdu term referring to mother-in-law] would take Joshanda [old traditional herbal tea]...we now have tried Joshanda for my daughter...when she was unwell and I saw it online somebody having Joshanda. I gave it to her and it did make a difference. Before that, I didn't believe it...It's true, they [younger generations] are picking it from social media and they do work.

(Family 6: daughter-in-law of a female first generation immigrant patient living in a tri-generational household)

Lastly, participants also mentioned the opportunity of bridging the gap between family and healthcare system as two institutes, and one patient mentioned:

'...we can have that [pain visuals] as evidence saying, for past 20 or 30 days, I've got my pain in this region of my body...and obviously they [clinicians] can then target that area, and they could change the way they give medicines'.

(Family 7: male second-generation immigrant patient living in bi-generational household)

In summary, we found that when healthcare systems and professionals prioritise prescribed, and often standardised treatments over approaches that are responsive to people's socio-cultural contexts, individuals and families increasingly rely on alternate means to guide and adapt self-management strategies. Moreover, when individuals conceptualise pain treatment primarily in terms of medical and surgical interventions, they are less likely to assign value to non-pharmacological treatment options, such as physical and psychological therapies, potentially limiting their engagement with multimodal approaches to chronic pain management.

Discussion

This study explored how South Asian individuals with pain and their families in the United Kingdom experienced and managed chronic musculoskeletal pain within their social and cultural contexts. The findings demonstrated that pain self-management is not an individual endeavour instead, it is a family affair, shaped by cultural values, living arrangements, and experiences with the healthcare system. We found that pain management decisions were largely family-led, drawing information from clinicians, social networks and online sources. Participants preferred delivery of non-pharmacological treatments (e.g., physical therapy) at home and access to digital information regarding how others are managing their conditions. While pain self-management strategies were diverse, variations in the practices and treatment expectations were influenced by socio-cultural and family circumstances, particularly on the level of interdependence within households. Participants found clinical advice insufficiently responsive to their social realities (i.e., physical capability, cultural practices and beliefs). This discrepancy shaped

their perception about treatment, where they assigned more value and hope with pharmacological treatments and not adopting non-pharmacological approaches to pain management (e.g., physical and mental therapies).

We found differences in treatment expectations between healthcare professionals and people living with chronic pain. Our findings reinforce that patients' expectations are shaped by their social context (Dhatt et al., 2012) and aligning care with expectations may result in patient satisfaction and trust (Calpin et al., 2017; Thompson et al., 2024). Across cultures families play a role in supporting self-management. However, the key distinction lies in the collectivism. In collectivist cultural context, individuals' identities are often closely aligned to their group identity than their own individual autonomy (Cho et al., 2022). For example in Asian cultures, interdependence often takes precedence over individual independence (Booth et al., 2024). Indeed, while all participants valued independence in physical functioning, the extent to which was dependent upon their living arrangements and family size, i.e., higher independence in smaller families and vice versa. This was reflected in participants treatment expectations, where individuals prioritised pain reduction over improvement in physical function, which is in contradiction with the recent policy shift, i.e., increasing focus on functional improvement than reducing pain (National Institute for Health and Care Excellence, 2024).

While positive treatment expectations is a predictor of positive treatment outcome (Maß et al., 2026), our findings suggest that such expectations are shaped by individuals' treatment perceptions, which are shaped by their social and cultural contexts. Despite participants reported receiving both pharmacological (e.g., medication) and non-pharmacological (e.g., lifestyle-related) advice, their understandings of pain management were characterised by a tendency to prioritise pharmacological interventions over non-pharmacological components of care. Paradoxically, evidence suggests low adherence to pain medications owing to people's negative beliefs about them (Kumar et al., 2015). In addition, treatment beliefs also varied significantly across generations within South Asians communities (Patel et al., 2008), as we found common in multigenerational households. Within these settings, exchange of information among family members played a central role in shaping people's perception of pain and influencing their decision related to management (Kimmitt et al., 2025; Strain et al., 2024). These findings suggest that treatment advice that is not responsive to individuals' social and cultural context may be less ineffective (Hwang, 2011), which we also found in our study.

A key strength of this study was inclusion of family perspectives, which enabled a more nuanced understanding of pain management in unique social and cultural contexts. This methodological approach and consideration to social contexts added value to our findings. However, interviewing additional families with diversity in their social contexts, particularly those with varying level of engagement with healthcare system, could add further value. Moreover, interviewing individuals with better pain management outcomes could help us build a holistic view of pain self-management practices (i.e., helpful and not helpful) in a broader South Asian context.

Future work should explore these pain self-management experiences within the context of the NHS 10-year health plan, whereby focus is on preventive efforts within communities. Our findings provided insights into how development of future digitally enabled and carer supported pain management intervention could support better pain management outcomes. Furthermore, pain management guidelines may benefit from reframing treatment outcomes to reflect individuals' needs and preferences, rather than assuming a universal preference for improvement in function. Better alignment between clinical recommendations and people's lived realities has the potential to improve access and outcomes and promote equity in pain management.

Conclusion

The study highlights that chronic pain self-management among South Asian individuals living in the United Kingdom is shaped by social, cultural and family contexts. Pain self-management is not solely an individual's responsibility, but a collective, family-oriented process shaped by cultural values, interdependence, and shared decision-making. These factors also shaped individuals' treatment expectations and management strategies, with a tendency to prioritise pharmacological interventions. Differences in living arrangements are reflected in prioritisation between pain reduction and function improvement. Therefore, future research should focus on developing digitally enabled and carer supported self-management interventions to deliver more personalised and culturally responsive care to South Asians living with chronic pain in the United Kingdom.

Declarations

Human ethics and consent to participate

The study received ethics approval from the University of Manchester' Research Ethics Committee # 2 (ref: 2025-24095-44063). All study participants provided informed written consent, including individuals with pain and their family members. The study was conducted in accordance with the Declaration of Helsinki. Interviews were conducted at a private place and data was processed and stored according to the University's governance and data protection guidelines.

Consent for publication

All the authors provided consent for publication.

Clinical trial number

Not applicable

Authors contribution

SMA conceived the idea of this study and drafted the protocol, which was reviewed and improved by SNvdV and DD. SMA drafted the topic guide, which was reviewed and improved by SNvdV, DD, CRM, and AR. SMA conducted interviews. SMA and CRM conducted analysis and CRM, SNvdV, DD, AR, MC supported SMA in data interpretation. SMA prepared the first draft and CRM, SNvdV, DD, AR, MC reviewed and approved the final draft of the manuscript.

Data availability

Data will not be available to other researchers owing to the lack of participants' consent.

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Conflict of interest

None of the authors has to declare any potential conflicts of interest with respect to the research, authorship, and/or publication of this article

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