Experiences of Caribbean and South Asian women on the topic of living with long term pain

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agency

Introduction

This small- scale enquiry was funded by NHS England via the Diverse Research Engagement Network of Bristol, North Somerset and South Glos (BNSSG).

It could not have happened without the open-hearted women who stepped forward to share their health stories with honesty and grace. This report is a thank you to them.

The objective was to gain some understanding of the experiences of Caribbean and South Asian women on the topic of living with long term pain, including hearing about their interactions with primary health care, and how they talked about their pain with others. Nilaari Agency employed a Community Researcher for a day/week on a short-term contract to carry out the work. Nilaari Agency is a Black-led voluntary sector organisation based in Bristol that supports visibly minority ethnic (VME) people through the provision of free one-to-one counselling and emotional wellbeing activities/groups. It also provides training placements for VME students of counselling and other similar studies.

The focus of the enquiry was on long term (aka chronic pain) experiences of Caribbean and South Asian women, a qualitative study through one-to-one interviews carried out between November 2023 and January 2024. Pain was the shared health characteristic rather than a specific health condition such as fibromyalgia or arthritis. Consequently, some data is provided below on disabled people; people with a long- term health condition; and people with an impairment affecting daily functioning.

Hauser and Jones cite prevalence rates of ‘chronic widespread pain’ CWP in the UK population was estimated between 1.4% and 20.44%.

Obviously, this is a wide range but understandable due to being based on CWP being reported to healthcare professionals, taken seriously and duly recorded. It seems fair to argue that people with a long-term health condition (LTHC), and/or ‘functional impairments’, and/or registered as disabled are likely to live with pain, from frequently to chronically. Chronic pain is the term used for pain that continues for over 3 months, with or without an obvious cause. In contrast, acute pain may result from an injury, or after an operation or illness, for example but usually clears up by 12 weeks with or without treatment. Acute pain can sometimes lead to chronic/long term pain.

The latest estimates from the *Department for Work and Pensions* indicate that 16.0 million people in the UK had a disability in the 2021/22 financial year. This represents 24% of the total population.

The House of Commons’ Library resource on disability statistics tells us:

“The proportion of the population reporting a disability has risen by 6 percentage points since 2002/03, up from 18%. Most of this increase has been observed over the past decade, with disability prevalence up by 5 percentage points from 19% in 2010/11.

The prevalence of disability rises with age: in 2021/22 around 11% of children in the UK were disabled, compared to 23% of working-age adults and 45% of adults over State Pension age. Most people aged 80 and over reported a disability (58%).

Using age-standardised proportions, disabled adults of different ethnicities in UK- proportion of the total UK population of disabled adults- has been calculated thus (citing here only the ethnicities considered in this enquiry):

30% are of mixed heritage/ethnicities

26% are white

23% are Black African/ Caribbean/ British

21% are South Asian.”

In a UK Parliament report, we are provided with figures split by sex but not by ethnicity.

“From the age of 15 years, there are more disabled women than disabled men in the UK population. E.g. of the UK population aged 25 to 44 years, 19% are disabled women and 14% are disabled men. In the age range of 44 to 65 years of the UK population, 30% are disabled women compared to 25% being disabled men.”

People can be living with pain due to a long- term health condition. In a *Review of UK epidemiological evidence*, data is provided on people living with a long term health condition:

Per 100 of population, LTHC limiting work (both sexes, whole working age span):

11 white British; 13 Caribbean; 12 South Asian.

“An overview of this data could suggest that there is value in collecting disaggregated details based not only on sex but further broken down by ethnicity. It is well established that women experience greater functional disability throughout the life course than men (19); however, it is unclear why South Asian women, and to a lesser extent, African Caribbean women would be predisposed to functional limitations compared with White women. What is clear is that these findings highlight the service implications of addressing women’s health needs, as well as demonstrating the importance of considering the intersectionality of ethnicity and age in the planning and delivery of women’s health care services.”

Williams, Cox and Cooper share the following figures:

Percentage of the population in various age bands with a functional impairment affecting daily living tasks (not necessarily registered disabled).

	White British	South Asian	Caribbean
Women 18–34yrs	15.1	20.2	14.9
35–49yrs	23.3	39.2*	27.5*
50–59yrs	35.8	59.0*	43.2*
60+ yrs	57.2	79.9*	74.5*

The range of data above gives a sense of the national picture of how many people- split into demographic categories- live with long term pain or live with health conditions that are likely to involve regular, ongoing pain.

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Methodology

- A short summary information sheet was produced to explain what the enquiry was about, how to contribute if interested and also gave contact details for the Community Health Researcher. It was an important feature of accessibility to explain what the medical term ‘chronic pain’ actually means in every- day lives. From previous experience of health conditions such as dementia, many people from groups under-represented in health research as well as a health service provision discount themselves from the start if a term is unfamiliar, not fully understood or has a lot of stigma surrounding it.
- The information sheet was shared with colleagues, allies and known networks including via What’s App, printed copies handed out, via email.
- 12 women expressed interest. 9 were interviewed plus a white British female GP working in a health centre with a high ethnic diversity of patients.
- Regarding the women who expressed interest but did not progress to be interviewed- their availability and ability to commit to an interview day and time was affected by their health conditions, pain flare ups, managing family life alongside paid work and other commitments.
- It is worth noting that enquiries for contributors through networks of people of Indian ethnicity did not lead to any women of Indian ethnicity. Influencing factors might be that there is greater reluctance to talk about health conditions including pain experiences among this demographic. Equally, as the data shows from people with ethnic heritages from the Indian subcontinent/ South Asia, there are more disabled people, people with long term health conditions, people with functional impairments who are Bangladeshi and Pakistani than Indian.
- Time period of interviews: early Nov to early Jan. All participants preferred to be interviewed over the telephone as this fitted most conveniently with their personal and working lives, as well as managing their health conditions. Consent was taken over the telephone. Many of the women wanted an initial telephone call to hear more about the enquiry before agreeing to arrange an interview day and time. This indicates the time and effort that should always be factored in when carrying out qualitative research. The participants did not just want an information sheet and consent form to be sent to them via email, prior to agreeing to be interviewed.
- Topic Guide followed. Developed after reading some relevant research, taking account of the questions asked by other researchers in this area. Shared with Nilaari colleagues for input.
- Very small-scale look at academic research and other articles on this topic.

Case Study Tasneem (pseudonym used)

Background: A British Pakistani women aged in her 50s. She reported having mental health issues and persisting knee pain: a result of a "bad job by the NHS". Many years ago, she had slipped in snow, tearing a ligament and fracturing knee cap. Following this, she has had 2 operations on her knee.

In contrast to most of the other interviewees, Tasneem did not have to wait several years for a diagnosis as her persisting pain due to an injury and the impact of subsequent operations on her knee which she felt had not been carried out properly. However, it took time and perseverance to be given thorough information regarding how menopause was affecting her physical health.

"You know, the person who does my massage told me about it (HRT). So much of my hair was falling out. She said: 'You need testosterone. Your muscles are weak'.

My GP said my testosterone was fine. But then I saw a gynae who actually did tests… and my testosterone levels were low. The GP was useless. They don't want to do tests because they don't want to then have to spend money, to prescribe to you."

Tasneem observed the impact of caring responsibilities for family members on her pain. More than half the interviewees described giving care to their children and parents, putting others' needs first. Managing pain was often talked about within the framework of being able to continue to give care within the family.

"My father died in 2013. I think after that, it (knee) got worse.

My father got ill and I looked after him. I think I did not look after myself. […] I was with him when he died, he died in my arms….the impact of that…I could not get over it."

Tasneem also demonstrated a proactive attitude, motivation and persistence in seeking her own non-medical remedies to improve her physical and mental health, particularly mentioning the value of traditional knowledge of practitioners in the local South Asian communities. In addition to helpful advice from the massage therapist:

"Best advice has been from me, myself. From people who motivated me, like **** (a long-standing Yoga teacher, well known in local South Asian communities, who teaches in a holistic way- including Pranayama breathing, diet etc). Not the medical centre of things."

On the other hand, Tasneem described a lack of openness among most women in her Pakistani community. This differs from the Caribbean women interviewed who all described candour and open communications about the menopause with their peers.

"South Asian women are very private. They don't talk about the menopause…

Like taking HRT, they don't talk about it. I tell them that I am taking HRT……it is really helping me."

As described above, Tasneem seemed motivated to support her own health- particularly through the menopause and the effects of ageing- and to manage her pain. As well as traditional remedies, using castor oil, having massage, Tasneem does include regular physical activity in her life. A barrier is cost, despite still carrying out paid work. When asked what her recommendations were for the future of ‘pain management’ in Bristol:

“More physical activities, wellbeing activities. Free or low cost.

Sometimes you can’t afford to do anything. If I can do things 3 times a week….”

From Tasneem, we hear of the intertwined relationship between mental health and pain. Low mental health often causing pain to worsen. Persistent pain a likely cause for mental health difficulties.

“A few weeks ago, I was in a dark, horrible place. I did not get out of bed. [….]

When you are in a dark place, you feel the pain more, obviously.”

Tasneem reached out for medical support at this time, calling for a GP appointment, and was told the earliest one was 3 months away. She turns to her faith as a support:

“I think when my health gets bad, God helps me.

I am a Muslim. I’m not like a …what you see as a Muslim. I am open- minded. I don’t pray five times a day. I am a good person.”

The conflict between how to present oneself to the wider world in relation to health issues and living with pain was evident- the binary choice between being a victim or enduringly strong- came across:

“I work hard, put on a strong front.

You know, for me, to show weakness…..why would I show my weakness, my old age to people? [….]

I don’t want to rely on anyone as I get older.”

Case study Charleen (pseudonym used)

Background: Black British Caribbean woman aged 56.

Charleen has lived with persistent pain for 14 years, since pregnant with her daughter. Her ongoing pain after giving birth were put down to hormonal changes, posture during breastfeeding and fact that she was an older mother. Blood tests were carried out; she was advised to rest. Her arthritis diagnosis was made around 6 years later as a result of a 'happy chance': she happened to see a locum doctor who referred her for different tests.

“Maybe he was thinking outside the box compared to the other GPs (at her usual health centre).”

Her fibromyalgia diagnosis came later than that, after she was already seeing a rheumatologist once a month for quite a few months. This seems common with fibromyalgia diagnoses: as shared by other interviewees as well as anecdotally by other Caribbean and South Asian women who now have this formal diagnosis.

In that 6–7-year period leading up to her diagnoses, she continued looking after the family, managing the home and working as a Health Care Assistant.

“Now I look back, it was too long-winded. Maybe I should have pushed more. There was not a lot of enthusiasm (from health professionals) to look into it.”

Charleen was prescribed strong pain killers but made the decision to wean herself off them. They were causing her to become forgetful; there was 'brain fog'. She was given no advice or support from medical professionals to come off them, nor signposted to any other alternatives such as exercise sessions.

As with other interviewees, Charleen gave many examples that demonstrated how motivated she was and continues to be- to research alternative, non pharmaceutical based remedies to help her manage her pain.

“I started looking into other options. CBD capsules, arnica, turmeric, ginger- take these. I spoke with friends, work colleagues and a neighbour who also has pain. Not necessarily people with fibromyalgia.”

She is pragmatic, accepting that these remedies often are helpful, but they do not 'cure' the pain they do not always prevent flare-ups. Yet, she is resilient and works at it.

I find it hard to sleep- around 5 hours a night usually. I find the more active I am, the more I can sleep- sometimes 6 hours. Walking gives me exercise. Uplifts me because I am out in fresh air. A chance to socialise, I always see people. I deliberately take longer routes.”

As with the other interviewees, Charleen saves and spends money carefully, when she can, on alternative remedies that she has found of benefit.

“Every 3 months- I do a collagen course. It’s expensive but I did research on what the majority of people found helpful, and collagen came up.

Mentally, I am definitely better than I was, than being on the pain killers. It (alternative therapies) doesn’t always manage the pain.”

Half of the interviewees cited the menopause as either seeming to be pivotal period that was a catalyst for their health condition and ongoing pain; or the menopause making their symptoms worse, for those who already had a diagnosis. This is Charleen’s experience:

“The menopause has made my arthritis and fibro worse. Or there are worse menopause symptoms due to my health conditions.”

Another shared experience with half the interviewees is Charleen’’s decision to change her former job as a Health Care Assistant to better manage her health conditions and pain:

“I don’t want to be carried, that is the reason I left the job. It was not a caring environment towards staff. We gave care, did not receive care.”

You don’t want to be seen as a victim. You also want understanding from those around you.”

Charleen described the importance of being able to be open with her daughter when she was in pain and needed help. It was clear she also felt there was genuine support from family and friends:

“Having my family and friends in my corner, is the main thing.”

Simultaneously, she commented on a particular culture among ‘black and brown people on the topic of health conditions and living with pain. As with some of the other Caribbean/Black British interviewees, the tone set by mothers seems to have lasting impact and influence.

“I don’t think there is a middle ground for women- either keep quiet and get on with it or be a victim. I think of my mother who had lots of health problems. Never asked for anything until at the end when she was terminal. I saw that. Maybe that’s part of it. That’s the way I am supposed to be. I don’t know whether it is a background thing. A cultural way. A learned thing.”

[…] My mother grew us up. [….] My mum was the influence: independent, hard- working, get on with it no matter what the pain threshold is.”

“[…] Other black and brown people around me- seeing them around me, not realising what they are dealing with. Only after they die, and you go to their funerals- you learn that they had health issues. You see them in the shops, on the streets- getting on with things.”

Whereas many other interviewees were more precise about what they would like ‘more of’, with higher hopes of what kind of support, medication, treatment and other services they would ideally have wanted as their health issues arose, Charleen talked of wanting more understanding of people living with pain; a better awareness that some disabilities are invisible; and an informal support group for Women of Colour living with pain, particularly those in the menopause period of their lives.

Key learning from contributors

Contributors' brief details (pseudonyms used)

Name	Ethnicity, age range *	Diagnosis
Charlene	Black British Caribbean, over 55	Arthritis, fibromyalgia
Janine	Black woman, descendant of Africa. Aged 60	Diagnosed with Crohn's Disease 2 years ago after years of stomach issues and pain. High BP. Awaiting tests for type 2 diabetes. Menopause
Pearl	Black Caribbean, 55 to 65yrs	High BP; fibromyalgia; had hysterectomy; various eye conditions. Beta thalassemia
Rachel	African Caribbean, early 50s	Arthritis; recent hip replacement
Ayesha	Bangladeshi, over 50	4 Car accidents; 2 knee replacements; shoulder injury; various surgeries due to injuries
Laila	Bangladeshi, over 55	Thyroid, obesity
Savita	*Asian Indian, over 45*	*NA- interviewed in relation to her role in health services*
Sonia	Pakistani, over 50	Did not disclose; long term health condition
Tasneem	British Pakistani, over 50	Knee injury- torn ligament, fractured knee cap and subsequent operations. Mental health issues

*Note: contributors were asked to describe their ethnicity rather than given defined categories to tick; they were also asked to state which decade their age was in.

Theme: diagnosis

For all the contributors, diagnosis of their health conditions took at least 3 years. There was repeated reference to how much effort and persistence were needed to achieve this.

Charlene: Now I look back, it was too long-winded. Maybe I should have pushed more. There was not a lot of enthusiasm (from health professionals) to look into it.

Rachel: If it hadn't been for me pushing it, I would not have got hip replacement. If I hadn't pushed it for me, no one would have pushed it for me.

While this experience may not be unique to visibly minority ethnic women, from the start of interactions with health professionals, many contributors alluded to the impact of their ethnicity on patient care:

Janine: Racism undermines our self-confidence, sense of agency. Structural racism; overt racism; biases.

Pearl: When you go to the GP for example….with Black women, I suppose we have a certain standard of how we look, how we dress….

Because of our skin shade and how we dress, the GPs cannot see the amount of pain you are in.

Sonia: I write things down for (GP) appointments because my memory is affected. But when I take the paper out, the GP assumes it's too long a list for a 10 minute appointment. Sometimes it feels a Power Balance is there. […..] Definitely there's a barrier regarding talking about pain for those who speak languages other than English.

A question was asked as part of the interview with a local GP working from a central Bristol health centre:

Do you think sex and ethnicity affects how primary care colleagues respond to female VME patients coming in with long term pain?

The response: Yes. […] For example: a black woman comes in talking of fatigue. After learning she has 5 children and doesn't do exercise: the immediate thought is of fibromyalgia and chronic pain.

In some instances, making health appointments for their pain or other health related issues was a delayed action due to prioritising the needs of those around them:

Pearl: My mother had dementia, passed away 6 years ago. We looked after her at home. The four of us [siblings] looked after her. We stayed over, took turns. For 4 years. We did not want her in a home. She never went into a home.

On a number of occasions, I had pain flare ups. I just had to downloads of pain relief and carry on.

It really impacted on my health after my mum died. My body totally caved in. You don't realise you are putting in all this work until afterwards. You are running on adrenaline. ….I got shingles and all sorts.

Laila: It was not affecting life such the housework, looking after the children, cooking, paid work. I just kept going.

This chimes with the recent Nurofen report on *Pain and Sex* which showed that in medical appointments discussing pain management, women (and those identifying as women) were more likely to be asked questions on how the pain was affecting 'daily activities' such as caring for children or other family members, carrying out housework and cooking. In contrast, men were mainly asked the effects of the pain on their capacity in paid work roles.

Theme: treatment and therapies post diagnosis

Contrary to perceptions- shared via informal conversations with health professionals- that people living with long term pain are principally seeking pharmaceutical pain relief in their health appointments, the interviews of this study showed considerable and consistent motivation to seek non pharmaceutical ways to live with pain better. These avenues/options not provided by health professionals- for the main part- but through conversations with friends, internet and other research, alternative health practitioners, and a self-developed way of trying and testing.

Rachel: A friend recommended Capsaisin cream. The GP had not suggested this. I went to the GP asking for this on prescription which the GP did. The cream really helps.

Tasneem: Best advice has been from me, myself. From people who motivated me, like ### [a long-standing yoga teacher in local central/east Bristol community, of Indian ethnicity] who teaches in a holistic way- including breathing, diet. Not the medical centre of things.

There were many instances that such treatments and therapies were self-funded, with contributors saving as much as they could to have them whenever possible.

Janine: I had a fall and could not wee. I was diagnosed with corda equina. They (health professionals) wanted to put in a catheter. I refused and went to my chiropractor. It solved the issue. My chiropractor said- it's a trapped nerve.

Pearl: A lot of the funds for having, …you know like acupuncture, is limited. Certain services are only for a short period of time. For example: acupuncture free for 8 sessions [through NHS referral]. Then not able to access further free sessions for 2 years. The Fibromyalgia NHS clinic shut down now. Acupuncture has been most helpful. £90 per month for chiropractic treatment. That was possible, just about affordable when I was working but not now as I have left work [due to pain and health issues].

Charlene: Every 3 months, I do a collagen course. It's expensive but I did research on what the majority of people found helpful.

Theme: Relationship with Health professionals- both sides of the coin.

The balance regarding relationships and advice/treatment from health professionals was weighted towards negative experiences. Comments revealed contributors experienced:

- frustration.
- not feeling listened to.
- not being enabled to be active partners in their own health,
- repeat appointments for the same issues
- delays in referrals to more specialist health services despite these repeated appointments
- no mental health type support/referral offered when a diagnosis was finally made.

Tasneem: I am taking HRT……it is really helping me. Physically I am stronger.

[…] You know, the person who does my massage told me [about HRT]. So much of my hair was falling out. She said- you need testosterone. Your muscles are weak.

My GP said my testosterone was fine. […] The GP was useless. They don't want to do tests because they don't want to then have to spend money, prescribe to you.

Rachel: [referred to a consultant by her Physiotherapist whom she saw privately]

Later, I saw a consultant who said if he had seen that Xray- he would have sent me for a hip replacement immediately. My GP was not the one who referred me to the consultant.

There were also positive experiences and meaningful support:

Pearl: I finally found a fantastic GP. He referred me to a pain management group which covered MH too. That is a big part of your pain.

Janine: I go to them [GPs] first to hear what they have to say. Then I make my mind up of what I listen to. My mum and my aunt were more wary of GPs; the generation above them thought they were gods. Best advice is a little bit from the GP; I research; I question; then I go back to my doctor and question my doctor. […]

The first doctor after my Crohn's diagnosis was excellent: prescribed acupuncture and talked about different diets.

Acknowledgement needs to be given to GPs and others working in front-line primary care roles, that there is frequently not enough information, resources and budgets available to them to support patients. The GP interviewed cited acupuncture at the top of her wish list of alternative therapies to be available in her practice in the future. She actively seeks out information of acupuncture and other alternative options such as exercise classes in the local area for patients; and disseminates this information to colleagues.

She also shared feelings of empathy for patients living with long term pain and/or a long term health condition with few affective, ongoing, affordable treatment options:

The idea that you are then cast adrift to do it for yourself is hard.

Theme: loss

Many examples were given of giving up paid work or changing the nature of paid work.

Laila: I do not have the health- physical and mental health – to work full time. And that goes back to the pain, and health issues. I don't want to put myself back in the situation of being disabled again.

Charlene: I don't want to be carried, that is the reason I left the job. It was not a caring environment towards staff. We gave care, we did not receive care.[…]

I rethought my job- was a health care assistant. Found better work for my health: based at home, not face- to- face work. It's a Call Centre role.

Pearl: I worked in the NHS and left the job due to pain and health conditions. Such as- the stairs became too painful to manage. I worked for 14.5 years in a GP practice. Previously I also worked in a pharmacy.

Around half the contributors talked of giving up other activities, or interests, or friendships. Although in none of the interviews were the words 'isolation' or 'loneliness' used, it would be easy to imagine finding oneself socially isolated and lonely as a result of giving up paid work and other aspects of life and identities. The mental health impacts on physical health of social isolation and loneliness are now well-researched and documented.

Pearl: I used to love walking. Walking outdoors; I used to walk for miles.

[…] I love gardening. I know my limit. I will go outside, and I will maybe do 15 minutes, half an hour. Then I come back in. I used to do hours.

I try to do little pocket of things I enjoy doing. I love reading and sewing but can only do small amounts.

Ayesha: I wanted to study more. When the children were young, I could not study, I had family responsibilities. I got involved with my husband's business more [rather than starting to study] because I can do that, I can fit it in [around health issues, fluctuating pain etc].

My garden has been empty. I could have done so much in the garden.

My daughter asks, "How come every other household has Bangladeshi vegetables growing but we don't?". I can't sit down to plant them, look after them.

Sonia: I started avoiding family gatherings because people would ask: what are you doing now?" Before, when I was working, I kept in touch with work colleagues. Then it took a lot of effort to meet up with them; they would not understand that I could not stay too long. Gave up- it was too much effort.

Theme: role of friends

The contributors of Caribbean and Black British ethnicities were the warmest and most effusive of the importance of their friends- to be able to be fully honest with, for peer support, for informal advice etc.

Rachel: I can meet with friends my age now and most of our topics are our ailments and pain. We laugh. Most of my friends have pain issues as well. We are motivated to talk about it; share ways of coping with pain.

Janine: Menopause and Black women- we do talk about it. Share experiences about doctors' advice.

Charlene: I find it hard to sleep. […]. I find the more active I am, the more I can sleep- sometimes 6 hours. Walking gives me exercise. Uplifts me because I am out in fresh air. A chance to socialise, I always see people. I deliberately take longer routes.

It seems noteworthy that none of the contributors of South Asian ethnicities talked in the same terms of the positive role of friends in their lives with specific reference to sharing support and/or advice on health issues.

Tasneem: South Asian women are very private. They don't talk about the menopause…

Like taking HRT, they don't talk about it. I tell them that I am taking HRT……

Ayesha: (on topic of pain in wider community of Bangladeshi women)

People just hide it; feel it is embarrassing.

There are other ladies in the group [with pain]. Sometimes you ask them, they tell you, and they say not to talk to anyone else. You notice that they are not well, in pain, not doing certain things [during group activities]. They are still doing the housework and everything, but it is damaging them. Other family members will say, 'why you are talking about this?'

Savita: Our dark skin….I have just found out I am vitamin D deficient. I think South Asian people don't realise that the lack of sun does these things [cause pain] to your body. Then they struggle and don't know how to ask for help.

Sonia was the only contributor of South Asian ethnicity who drew attention to the importance of peer support for managing her long-term pain, mental and physical health issues. This was through other mothers of various ethnicities at a 'Stay and Play' group when her offspring were very young; they then evolved into a 'Time out group for Mums' (see quotation below).

Theme: Role of family

Whilst friends were key in support for the Caribbean and Black British contributors in particular, it is not always so straight forward with family members- for the full range of ethnicities of contributors to this study.

Ayesha: If I could have been helped to lose the weight, this would have helped more. […]

In 2016, I did a diet plan with the Dietician my GP sent me to. I did those diet pills, but this wasn't for me. So, I left it. I was referred to Slimming World, but this did not help.

I was referred to *Future Diet* before Covid and this helped. I lost 3 stone. It was a *Keto* diet.

My children were worried for my future health- how it [the Keto diet] would affect my cholesterol and heart. They did not want me to continue the Keto diet. I have now put on 2 stone again.

I tried with *BeeZee Bodies* [healthy weight programme funded by Public Health/Bristol City Council] but it was always full. I did not have a chance.

Pain and weight is my concern. Pain and weight issues are together. Pain has become so bad in past weeks. I could not understand why. […]

The GP wants me to do Keto diet again, but my family don't want me to do it.

Rachel: With family, I am less open about my pain. In comparison with a male family member- he was in agony, had double hip replacement. My family could not believe it was that bad for me.

Sonia: Being open with others….it took a while for the family to understand. Not understanding that my pain dictates my routine I started avoiding family gatherings because people would ask: "what are you doing now?" [….] I started spending more time with others who also lived with pain; we met through a local community centre where I went to *Stay and Play* with my daughter, and *Time Out Group* for Mums. We were all struggling- mental health, anxiety, or physical health. Peer support, empathy, understanding was shared.

Tasneem: My parents would say: God is punishing you for living a bad life.

[…] I used to be feisty when I was younger. You know, Asians, they don't always like that.

Others are strengthened by family:

Charlene: Having my family and friends in my corner, is the main thing.

Pearl: My husband and daughter are very supportive. I am a very open person with how I communicate with friends. I do communicate a fair bit. You need to listen to other people.

Only one South Asian woman who was part of this enquiry talked of being able to be open and seek advice from family members- just her sisters:

Laila: I kind of moaned [….] mainly to my sisters. It was not often, we all have busy lives. […] on my Dad's side, there are heart problems. Mainly the men. It is a genetic thing. Talking to my sisters, turns out that women can also get it but 15 years after men do.

Theme: Menopause

Several of the comments cited above illustrate different attitudes towards the menopause, specifically the capacity to be open about with others in the family, with friends, in the wider community. It was evident that Black British and Caribbean contributors felt able to be frank about the menopause, whereas this seems out of bounds for the majority of South Asian women, from the testimonies of the Bangladeshi and Pakistani women in this enquiry.

As a health issue in itself, for those who already had a diagnosed health condition, it seemed to worsen when these women entered menopause. For others, their long term health condition seemed to be triggered by the onset of menopause. None of the contributors talk of useful advice, support or treatment for the many symptoms of menopause from health professionals.

Janine: The long list of menopause symptoms- are just not known about by women but also GPs. For example: dry mouth.

All the contributors were asked what they would want in an ideal world, regarding living with their long term pain and health conditions. One request was:

Charlene: An informal support group of other Women of Colour living with pain, particularly menopause also. Sharing tips. Being open with each other.

Theme: ethnic heritages, 'home culture'

Comments during interviews provided insights into the effect on the full range of health that differing ethnic heritages and home cultures that are not white British can cause.

Rachel: Arthritis is quite a big thing in African Caribbean communities so I thought it was inevitable that I would get it. I feel it is part of my ethnic identity. I think I managed it [the pain] because I found a way to manage it better….

Pearl: A lot of the doctors, they try to explain things to patients of a different ethnicity, and they are not explaining things the way they should do, for patients to understand. West Indian patients- they come in, for example, "I have got sugar." GPs don't understand this means type 2 diabetes. […] They don't understand the foods that we eat as well.

Laila: I am healthier in Bangladesh; don't eat the snack food. I have breakfast, lunch and dinner properly. I eat three times a day but here- snack, don't eat at proper, regular mealtimes.

Janine: I came back from Gambia feeling so well. Food was fresh and beautiful. But I was still under the radar of the hospital who said I still had issues. They gave me antibiotics; they ripped my guts to pieces. They wanted to give me more antibiotics and I said ‘no way’. I went to my Kinesiologist.

With Black people, growing up, we have always had decent food. Caribbean food, health tonics and bitters. Now all the bitter foods have gone.

Tasneem: I am a Muslim. I’m not like a …what you see as a Muslim. I am open- minded. I don’t pray five times a day. I am a good person. […]

When you do good things for other people, good things come back to you.

There is a Supreme Being.

Published academic research and other articles on Chronic Pain experiences of women, particularly visibly minority ethnic women, such as of African American and South Asian ethnicity

Having worked in the field of Chronic Pain in 2019-including seeking out academic research on the topic- it felt noteworthy that little had improved in the availability of academic research that specifically considered women, visibly minority ethnic (VME) women in particular. The reasons for this may be that little research is carried out- and funded- for this demographic; and/or that any research carried out does not proceed to publish its findings in academic journals. This is a competitive and detailed process.

Published research available- using free resources such as PubMed- were all based in the USA, with a weighting towards African American/ Black American women. Whilst it is of great value that a demographic of VME women were considered distinctly from ‘all women’, it also serves to highlight the experiences of other VME women not just in USA but in other countries where they live as a minority community.

Never-the-less, the findings in these published research articles provided added insights, guidance and evidence for this small scale ‘enquiry’.

“Pain is never the sole creation of our anatomy and physiology. It emerges only at the intersection of bodies, minds and cultures.” (Cousin et al).

This article- based on a qualitative research study- included some similar comments shared with interviewees of this Nilaari study: the choice between either being a victim or a ‘Strong Black Woman’. For Black American women, there seems also the even more negative identity ‘option’ of “Uppity Black Woman” or “Angry Black Woman”.

One contributor stated that “As African American women, we keep it to ourselves and are expected to be strong.”

[…]

“Thus, our participants had to demonstrate their vulnerability and physical pain through outward behaviours, such as crying. It was not easy for women to show “weakness”, but this was an intentional and real behaviour to receive basic healthcare and pain management. […]

One participant unashamedly displayed her emotions when she visited a local primary care clinic:

‘I literally had to go in there the same way. In tears.’ (Cousin et al)

This resulted in an Xray carried out on her and medication given.

“There is no universal language for pain. Pain is a personal and idiosyncratic experience, and people often use metaphors. Pain metaphors and pain descriptors often have different meanings depending on culture and experience.

[….] This miscommunication can result in a pain assessment that focuses on understanding the description of pain rather than the impact of pain." (Bostick et al)

This resonates with the experience of a contributor to this enquiry, of attending a 'pain management course' which included a reference to a pale pallor as a possible sign of being in pain.

Not showing a pale skin tone, and appearing neatly dressed, with cared-for hairstyles or smooth headwraps/hijabs and thus possibly not seeming to be living with daily pain levels by medical professionals/ colleagues etc. can result in reticence and vulnerability to talk about pain, and to avoid seeking help and advice for managing it.

"When you go to the GP for example….with Black women, I suppose we have a certain standard of how we look, how we dress….

Because of our skin shade and how we dress, the GPs cannot see the amount of pain you are in."

There exists a large volume of evidence of an increased risk of long-term health conditions, living with disabilities from a younger age than the white British population, effects of ageing starting younger in many VME communities. E.g. functional ability article.

This equates to a higher probability of living for longer, from younger than average age compared to the white British population, with regular/long term pain- as illustrated by over half the participants. The impact is worsened by support/advice in pain management often not meeting needs.

"…chronic pain cannot be understood, and therefore effectively managed, without regard to its social and cultural aspects, such as the role of the family, social structures, and religious beliefs. People from culturally and linguistically diverse (CALD) communities have higher levels of pain, disability, and psychological distress when they live in a Western environment. These adverse outcomes are in part due to the less-than-adequate pain treatment that they receive." (Bostick et al)

It seems of value to draw attention to the fact that none of the contributors to this study reported being offered any psychological support/talking therapy for their ongoing pain, nor at the point of their long-awaited for diagnosis. Only one contributor was able to secure some talking therapy support at a much later stage, as part of a trial *Rethinking Pain* service in her local area (see Best Practice case study in Recommendations). She found this of significant benefit, as well as the peer support group and low cost/free physical activity available through this service.

As a contrast, emotional wellbeing support is considered an important element of the NHS Diabetes Prevention Programme: one of the sessions in the free, community based 12 week learning programme people were supposed to be routinely offered by primary care professionals before the Covid19 pandemic arrived in 2020. However, it seems persuasive that psychological therapies may be more effective and sought by people living with ongoing pain as a 'first resort' rather than pharmaceutical prescriptions. As noted by Hauser and Jones:

> Psychological factors such as adverse childhood experiences, traumatic life events, interpersonal conflicts and psychological distress play an important role in the predisposition, onset and severity of chronic widespread pain (CWP)
>
> […]

A reason for this could be that in contrast to pharmaceutical 'remedies', based on well-funded clinical trials, often by the pharmaceutical companies themselves.

> There are no systematic reviews, and indeed, there are few randomised controlled trials (RCTs) of psychological therapies for CWP. (Hauser and Jones)

This same article cites: prevalence rates of CWP range from 1.4% to 20.44%

Given the paucity of published academic research on long term pain/ chronic pain/ chronic widespread pain specifically focussed on women, and women of colour in particular, a small search was carried out of 'grey literature', articles published outside the field of academic journals. This proved invaluable, leading to articles which related to a reference to 'Bibi syndrome' described by a contributor to this enquiry. A July 2020 *Huffington Post* article details it thus:

> South Asian women, in particular, have been known to complain about being dismissed by doctors who claim they are suffering from the so-called "Mrs Bibi syndrome", also known as "Begum syndrome".
> Derived after the common south Asian surnames "Bibi" and "Begum", it refers to an imagined condition where south Asian women are said to exaggerate their health complaints despite showing few objective signs of ill health.
> This "medical racism" can make patients reluctant to open up to doctors and lead to neglect of health conditions.

An article in Kinesis magazine cited this experience:

> One such example was a doctor who said she first heard the term 'Mrs Bibi' being used as a medical student. Ten years later, as a foundation year doctor, the term was used by her colleague to diagnose a patient who was due to be seen in the Emergency Department. The colleague went as far as to call the patient's surname "the crucial diagnostic clue".

A reference is made to an outcome of this bias:

> Aside from the obvious racial insensitivities, it serves to alienate other patients from ethnic minorities. They may delay seeking treatment as they believe their conditions will not be taken seriously and to avoid being diagnosed with 'Bibi-itis'.

The two tropes or stereotypes of Black women and South Asian women- the former often being seen as the 'Strong Black women' who look too well presented to be in ill-health or in pain; the latter being seen as prone to over-exaggeration of ill-health or pain- are examples, albeit negative examples, as regarding all VME women as a homogenous group is false, misleading and unhelpful. It does not adequately convey the experiences in daily life of women from different visibly minority ethnic communities.

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Recommendations

- First response from health professionals in consultations to be 'prescription' to free or low cost physical activities and alternative therapies (holistic therapies). Acupuncture cited most frequently by contributors. This to be the standard approach rather than pharmaceutical prescription.
- Trying to initiate and embed continuity of care in primary care centres.
- More effective and timely pathway for referral to specialists.
- Informal peer support. E.g. monthly- peer support groups specifically for women, perhaps also more specifically for Women of Colour on topic of living with pain is worth trialling.
- Improvements needed regarding Menopause, starting with knowledge, sensitivity and more holistic provision from primary care level. E.g. anti-depressants not necessarily suggested so readily; more explanation/information given on the wide range of symptoms of menopause and reasons why they may be experienced; information on how to manage these in a more person-centred, whole-health way such as through diet, exercise.
- Best Practice Case Study: Bradford based ***Rethinking Pain Service***

  Rethinking Pain | Community-Based Pain support

  Testimony from SB, Pakistani woman:

  A few months ago, I was referred to *the Rethinking Pain* service. This Included some physio, and a Social Prescribing (SP) worker. The SP worker referred me to swimming in a special warm therapy pool- free for 16 sessions. This is very beneficial. The good thing about this- no waiting list. The hydrotherapy pool via a previous NHS Physio referral had a long waiting list.

  The SP worker also referred me for counselling. This was the first time since my diagnosis that counselling has been offered. Whole life, whole person support is offered. A social drop in also for peer support. This is really good. There are Rethinking Pain outreach workers going out into communities, running sessions in community centres, faith led centres etc. There are exercise classes for those with pain. The exercise sessions such as Pilates in my local leisure centre- I observed some and knew I could not do them. The Pilates at Rethinking Pain service is accessible.
  It's (Rethinking Pain) a joined-up service.

  The ***Rethinking Pain*** service was originally a trial service consulted by the local Clinical Commissioning Group, covering Bradford and Keighley. Its outcomes proved its needs and return on investment, so it has continued with support from NHS funds as well as other partners. It is based on GP referral but there are also community ‘outreach’ workers who go out to local community venues including faith- based organisations, to raise awareness of the service as well as explain the concept of pain and ways to manage it better. There are various language skills within this outreach team.

Peer support groups are offered at various community- based venues across the service’s area. There are Social Prescribing link workers on the team who signpost to accessible free/low-cost physical activities and emotional wellbeing sessions. Both one-to-one and group support are available.

The website hosts a range of resources including videos explaining pain in languages other than English, exercise videos and guided meditations. Working as a Social Prescribing Link Worker with a ‘case load’ particularly of GP patients living with long term pain, I was frequently asked for such resources by patients and health service colleagues.

Information shared by Ruth Brady, Senior Health & Wellbeing Coach with Rethinking Pain:

Since the service launched in Nov 2022, we have had a total of 2388 people referred in. Some people have gone through the service and have now been discharged and we are currently working with 1604. We get on average around 35 new referrals per week.

Between April 23 and March 24, we had 1693 referrals.

We have recently had a paper published by Leeds Beckett University, please see link below.

http://journal.frontiersin.org/article/10.3389/fpain.2024.1299027/full?&utm_source=Email_to_authors_&utm_medium=Email&utm_content=T1_11.5e1_author&utm_campaign=Email_publication&field=&journalName=Frontiers_in_Pain_Research&id=1299027

This report would not have happened without the open-hearted women who stepped forward to share their health stories with honesty and grace; hoping to set change in motion, to improve the experiences of other women living with long term pain.

This report is a thank you to them.

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