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HER BODY GRIEVES HER UNSUNG PAIN: TRAUMATIC LIFE EXPERIENCES OF WOMEN LIVING WITH MEDICALLY UNEXPLAINED PAIN

Sreevidhya Kottarapat Srinivas[1] and Shalini Anant[2]

ABSTRACT

The present research with women diagnosed with medically unexplained pain explores the nature of their lived traumatic experiences; causative factors and consequences of medically unexplained pain as understood by them; coping mechanisms they used; their help seeking behavior and experiences with health professionals. This was carried out through individual in-depth interviews with eight women purposively selected from health care settings. Data was transcribed and coded. Thematic analysis of the data indicated that the participants had undergone significant stressors right from early childhood and continuing through adulthood. Childhood trauma was reported in terms of experiences like unfavorable discrimination between the siblings, not having a voice, consistently harsh parenting styles, having to take up excessive responsibilities and unexpected death of loved ones. During adulthood they reported experiences like gender-based discrimination at home, workplaces and elsewhere in the form of role strain, sexual harassment, and oppression. Several effects of the pain were reported in the areas of their sleep, diet, energy, interpersonal relationships, and their sexual relationship with their partners. Participants largely reported consulting medical professionals and most of them reported having negative perceptions of them. None of the participants reported consulted mental health professionals. Participants reported coping with the help of support from family and friends, medicines, ayurveda and yoga. The findings further emphasized that medically unexplained pain is a physical manifestation of psychological trauma endured by women. The study has implications for medical and mental health professionals to build awareness about the history of psychologically traumatic experiences amongst survivors of medically unexplained pain and the need to treat the psychological trauma at the core of chronic physical pain.

Key Words: *Women, Traumatic Life Experiences, Medically Unexplained Pain*

INTRODUCTION

The biomedical model posits that biological determinants have a key role in explaining illness as a condition caused by external pathogens or the internal functioning of the organs in the body. The biomedical model has been dismissive of the impact of psychological and social factors on the individual's health (Havelka et al., 2009). In situations where the medical field is unable to find the organic cause of a symptom, it is difficult to treat the illness medically (Kanaan et al., 2011). Due to the lack of a clear diagnosis, patients feel deprived of the social legitimacy as people with '*real*' illnesses. They often describe that the pain is real despite the absence of a medical finding (Louise, 2014). The distress experienced from their pain is real, regardless of whether or not a physical explanation can be found. And the distress from symptoms can be debilitating (Goodman, 2022).

Often subsumed under medically unexplained symptoms is medically unexplained pain (Williams et al., 2011). According to Henningsen et al., (2007) medically unexplained pain refers to any persistent complaints concerning the body which do not have a sufficiently explanatory structural or other specified pathology despite adequate examination. According to Burton et al., (2020) in the ICD-10 medically unexplained symptoms either multiple and across organ systems, or single and related to one organ system are coded as somatoform or dissociative neurological disorders within the mental disorders chapter. The main criteria involved "*repeated presentation of physical symptoms… in spite of repeated negative findings and reassurances by doctors that the symptoms have no physical basis*" Burton et al., (2020).

Estimates on the prevalence of chronic, unexplained pain have a wide range from 2 to 40% (Kerssens et al., 2002). The prevalence is known to be especially high in Asian countries (Patel, & Sumathipala, 2006). In India, almost a quarter (24.6%) of the 976 participants were found to have a diagnosis of medically unexplained pain and an additional 20.6% met the criteria of persistent medically unexplained pain (Bhatia et al, 2019). While only about

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[1] Tata Institute of Social Sciences, Mumbai
[2] Tata Institute of Social Sciences, Mumbai

one-third of the referrals in hospitals are provided a diagnosis (Maiden et al., 2003). Thus, indicating that individuals who are formally diagnosed are only a small fraction of the reality (Stone et al., 2009).

The prevalence of medically unexplained symptoms is seen to be much higher in women compared to men internationally (e.g., Herman, 2017) as well as in India (e,g, Bhatia et al., 2019). The World Health Organization report (2013) acknowledges that women still continue to face socio-economic disadvantage, gender-based violence, low or subordinate social status which contribute to their psychological distress, all of which can amount to traumatic lifetime experiences.

It was found from the famous Adverse Childhood Experiences study that life experiences in childhood which have been 'forgotten' over time and are further protected by shame and other social taboos play out powerfully and proportionately as late as half a century later, in terms of emotional state, biomedical disease, and even life expectancy (Felitti, 1998). The relation between traumatic experiences and somatization has been noted by several researchers (e.g., Heim and colleagues, 2006).

METHOD

For the present study, an in-depth interview guide was designed by the authors to explore how the pain impacted the daily routines of the participants, their experiences with health professionals, traumatic life experiences, feminist perspective, support systems and coping systems. The interview was prepared and carried out individually with the selected participants. The duration of the interviews ranged from an hour to two hours. The participants were women between the age range of 26 and 68 years. The sample was collected from the state of Kerala, in two cities Thrissur and Kochi over a period of one month from mid-April to mid-May, 2019. After interviewing 8 participants, saturation of themes was noticed and thus the data collection was stopped after that. A follow-up was conducted with five participants during the months of June and July, 2019.

Inclusion criteria was women above 25 years of age, fluent in English or Malayalam, those experiencing pain for more than 6 months, whose causes of the pain were medically not known despite having undergone diagnostic tests and those who have been under treatment for their pain for 3 months or more. People with any diagnosed pain disorder, psychiatric disorder, any speech or hearing deficit and physical disabilities were excluded.

The exploratory design helped gain a deeper understanding of factors that have received little attention in the research literature. Later, codes were generated, and a thematic analysis (Braun & Clarke, 2006) was carried out in an attempt to develop an understanding of the medically unexplained pain, related issues, contributing factors and some of the factors which are helpful in coping.

DISCUSSION

The nature and form of the traumatic experiences were elaborated upon by the participants in depth. The themes of traumatic life experiences that emerged were childhood trauma such as receiving consistently unfavorable discrimination in comparison with the siblings, especially male siblings. For instance, one participant reported crying with frustration, "*my mother's love towards my brother was a little more and she had a different kind of attitude towards me. Only for the one difference that he was a son, and I was a daughter*".

The participants often felt that they did not have a voice but even if they did muster up the courage to speak up they reported not feeling heard. For example, one participant reported that she belonged to an orthodox family with strict values and upbringing *"so when it's like that we lose our freedom in some sense. I feel like we only change as people. We don't have that space at all... the space to open up and talk or just talk".*

The participants also reported growing up with consistently harsh parenting styles. For instance, a participant reported about her experience of being parented by a rather autocratic father. She said "*that was that (sigh)... I had no say for anything in the house or in support. Everything was according to their wishes because my father was a very angry man and I could not talk to him or against him*".

Many participants also reported having faced, during childhood and after growing up, untimely death of a loved one. A participant said that her older brother passed away when she was in 10th standard and recalls it as a tragedy for their family. Another participant who is 68 years old, recalled the unexpected and sudden death of her son who was 39 years old to be an unpleasant memory and reported having felt like she had lost everything in her life.

All the women spoke about various factors such as restrictions at home. A participant recalled an incident when she was in college and had stayed back for an hour after the class. She said this was the most embarrassing experience *"my cousin came to pick me up and by the time I reached home my father got angry. He was like where were you until now. He shouted telling me that I don't have the right to even enter the house, he also said if you don't listen to what I have to say you don't have to live here. That day I felt really hurt. Ever since then, whenever I go out I would go with the fear that I have to be back by the time".* Later, her friends got to know about the incident which left her feeling ashamed.

Having had to take up excessive domestic responsibilities was another factor. A participant broke down as she reported that her father passed away when she was just three years old. Then, when she was merely 22, her husband passed away within a year after they were married, and she was left alone with her infant son. She recalls these two as her most tragic memories.

Most of the participants felt oppressed at their workplace. A participant spoke about the gender disparity she noticed during the campus placement. She said that "*the company felt like the men were more of an investment as the women would get married and leave work anyway".*

Being discriminated against at home only because they were the "girl child" and the role strain that they experienced due to their multiplicity of roles. One participant said that after the death of her father she is being the eldest daughter, had to give up her studies and take up all the responsibilities in her house and also did all the work of the house like a boy. Another participant said she had to take up the role of a single mother at the young age of 22 while also working to earn for herself, her son and her parents-in-law as her husband passed away just a year after their marriage and her family of origin refused to support her or accept her back. She recalled having to struggle alone to raise her son and earn their bread. This often led her to feel as though she did not have any time for herself as she was so occupied with her responsibilities which she had to fulfil for years together.

Instances of harassment and sexual abuse were also reported by the participants which often led them to feel unsafe and scared. One participant recalled a bus incident when the conductor misbehaved with her. She reported having felt "scared" the moment the abuse happened as it was unexpected. Her inability to react due to the fear of being judged made her feel angry and helpless. This often led her to avoid travelling by the bus in the future. Perhaps the anger that she suppressed in the moment lingered on and contributed to her physical symptoms. Some of them spoke about instances where men misbehaved with them in public spaces such as temples, buses or functions. One participant mentioned an instance in which she felt violated at her workplace. She asserted that she was not comfortable talking about it but said that it was related to a promotion. Her noticeable discomfort in talking about it indicated that she was still deeply affected by it after years.

As noted above, the participants reported several traumatic experiences right from their childhood and continuing throughout adulthood. Some of these traumatic experiences had not been shared by them with anyone else. While reporting many of them their facial expressions, tone of voice, body language and so on indicated that while they were leading their day to day lives in a seemingly normal way; these experiences had had a lasting impact and were most likely manifesting in the form of physical pain.

The participants had also been asked about what they believed was the cause of their pain. To this, they responded with various reasons. Some acknowledged the role of emotional distress, e.g., *"I felt that the pain started after I was not feeling well emotionally. I didn't feel so sad when my husband passed away, but it was after my son passed away that I felt affected by it both emotionally and mentally*."

Problems in adapting to new settings was another factor identified as leading to the pain. A participant crunched her eyebrows and looked angry as she said "*All of that comfortable lifestyle, after my marriage, when you live with your husband. When you leave that nice lifestyle and move into a joint family, how would that be? Those were the kind of problems that I have had*".

Another factor was their posture and how it affected their pain. A participant reported "*I mean my posture wouldn't be correct to feed [my son], like you know I might sit without back support. My only concern would be how to feed him and how to make him drink, so I give my comfort the least importance. So that is also an issue*".

The physical absence of their near and dear ones was also seen as causing the pain. For example, a participant reported *"now the place that I am staying is isolated. I feel like that. I think if it was a place with my family... I could have been a little better."* Another participant broke down into tears as she said *"It's becoming the 8th year since my son passed away. For the past 7 years my daughter-in-law, and grandson who is now 14-15 years... they stayed with us for so long and now at this time only they said they want to leave and left*". This often led them to experience feelings of loneliness and lack of support as they felt they had no one to empathize with them.

In response to another question, about the impact of medically unexplained pain on their lives, decreased energy to function was reported commonly. One participant looked disappointed as she said *"now I find it difficult to even make chapatis or cut mangoes with my hand. It's like I can't with my hands*". Another participant said that when she had guests over, she was unable to do tasks with the same speed that she had before the pain had started.

Disturbance in daily routine was another aspect which was reported. A participant said that she could not complete household chores alone the way she previously used to.

Disrupted sleep cycles were another factor which was affected due to the pain. One participant mentioned *"one or two months I felt like my condition became serious where I couldn't sleep at night*". Another participant looked distressed as she said *"So, yes when I came back at the time, I was really tired, and I had real back pain and I didn't want to take the painkiller. And yes, through the night... I kept waking up because of the pain. It was difficult to sleep.*"

In terms of the ways to cope with the symptoms, the participants reported using different techniques. Some of them spoke about resorting to yoga and meditation as a means which helped them to cope. A participant reported that *"when I used to do yoga, I used to feel very happy and energetic*". Another said that "*I try yoga and some breathing exercises to calm me down or whatever so yeah I do regular yoga and now and yeah I try taking a walk and listening to pleasant music*".

Ayurvedic treatment was used by some of the participants. One of them mentioned that she had resorted to ayurvedic treatment and that she was finding it helpful. Another said that there was a temporary relief that she would experience. She mentioned "*yes, because it is when I do it that there is a sense of relief so that's while I'm still doing it.*"

Distracting themselves by engaging in work was another method the participants used to divert their attention from the pain. A participant said that "*Whenever I am working, I indulge in it completely and I don't feel anything".*

Some of them used an emotion focused approach. A participant who mentioned that though her pain developed due to her posture and constantly carrying her child joyously said, "*I don't mind having more babies because... just the smile* [of the children]". The joy of seeing their children happy was a factor which helped them cope. A participant mentioned *"you know you get the energy for the whole day"* another participant said that engaging in her daughter's work gave her the motivation to work and helped her cope.

As noted from the above, participants used different techniques in order to cope. While some of them resorted to an emotion focused approach others would engage in yoga, meditation, ayurveda or work. However, it was heartening to note that most of them hoped to get rid of their pain someday.

Negative impacts on their interpersonal relationships with their parents-in-laws and partners were also reported by the participants when they were asked about how the symptoms affected their relationship dynamics. Some participants reported how their mothers could empathise more with them when compared to their mothers-in-law with regards to their feelings, they expressed emotions like frustration, sadness, helplessness, and anger because with the pain they were no longer able to continue doing activities which they earlier enjoyed, such as travelling, cooking, and completing tasks with the same speed.

Participants shared that in the beginning when their pain started, their partners as well as families and friends were supportive and understanding. However, as time progressed and the pain stayed, the support from their parents-in-law, and in some cases from the partner continued to decrease. The pain was seen to be an excuse they were "*making up"* to avoid participating in household chores. This was due to the absence of a clear diagnosis and the lack of a reliable treatment plan.

This often led them to even question the validity of their own experiences of the pain while also feeling the pain. It could be inferred that people with medically unexplained pain tend to internalize the stigma and invalidate their own pain. Previous research (Waugh et al., 2014) has also shown that about 40% of people experience stigmatizing social interactions and adopt those stigmatizing attitudes toward themselves, which is, in turn, negatively associated with self-esteem and pain self-efficacy.

When asked about their experiences with medical professionals most of the participants had visited multiple health professionals in the hope to make sense of and treat the pain that they were experiencing. One participant said that after two months of consulting the doctor they conducted scans such as endoscopy. However, they were unable to diagnose her with any specific condition. The same test was repeated two more times and similar results were found. The doctors then concluded that *"it's not that big of a problem*". Additionally, the participants' narratives suggested that the lack of support, inconclusive medical reports, combined with the experience of pain and its uncertainty are likely to have increased their distress levels. A participant said that the doctors had conducted scans for her chest but were unable to identify what was the cause of the pain. Another participant looked angry as she said that the doctors made her feel like she was wasting their time when they could not identify the reason behind the pain.

Overall, most of the participants expressed negative perceptions about their medical professionals: they felt that the doctors could not empathise with them, what they were trying to say or provide a solution to their problem. This, in turn, led to the participants feeling sad, frustrated, and angry. A participant said *"the difficulty of them not being able to understand what I was trying to tell them and... [I was] also a little angry"*. Another said "*to be honest, I felt sad as the doctor was not able to catch what I was trying to say. So, I felt like what I was* *facing was not getting solved... God!... and for me, I couldn't take the pain. It was a confusing stage at that time mostly*". The invalidation experienced by the survivors of medically unexplained pain was manifold. Not only were they unable to make sense of the pain due to the lack of a diagnosis; most of the time there was a dismissal of their experience and lack of empathy on the part of medical professionals.

However, two of the participants reported having positive experiences with the medical professionals due to factors such as the comfort of familiarity with the doctors and empathy which was expressed by doctors. In consonance to what a participant had mentioned, *"the medicines that doctor provides us with does not affect my body much. But it is helping me feel better"*.

INTERPRETATION AND IMPLICATIONS

The present research aims to contribute to Indian research literature in the field of lived traumatic experiences of women diagnosed with medically unexplained pain. The study can be used in bringing awareness about the existence of psychological trauma amongst survivors of medically unexplained pain. The findings indicate a strong need for being genuinely empathetic towards people living with chronic physical pain. Chronic pain is known to respond well to trauma focused psychotherapies, even though the primary symptoms are physical in nature, and a bottom-up approach is found to be more effective than a top down (like CBT) approach such as that given by Shapiro F. (2014) and Taguchi et al., (2021).

CONTROVERSIES

Data on lived experiences of people undergoing medically unexplained pain is collected through only in-depth interviews in the present research. No standardized tools on pain were included which could have helped quantify pain intensity and various other psychological factors related to pain. Secondly, clear causative links are difficult to draw in this exploratory study. It was a qualitative study with only 8 participants living in the state of Kerala with medically unexplained pain. It is likely that the sample is not representative of the population. The study explored only women participants, and traumatic life experiences of people of other genders have not been explored here.

FUTURE DIRECTIONS

Future research to explore the lived experiences of people with medically unexplained pain could include people of all genders and living in different parts of the country and could also explore the experiences and perspectives of health professionals including mental health professionals using a mixed methods approach. There is an immense need for mental health professionals to be empowered with treating chronic, especially medically unexplained pain with trauma therapy which can benefit a larger population in the longer run.

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