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# Chronic pain experiences of immigrant Indian women in Canada: A photovoice exploration

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## ABSTRACT

**Background:** Over the past two decades, the prevalence of chronic pain has significantly increased globally, with approximately 20% of the world's population living with pain. Although quantitative measures are useful in identifying pain prevalence and severity, qualitative methods, and especially arts-based ones, are now receiving attention as a valuable means to understand lived experiences of pain. Photovoice is one such method that utilizes individuals' own photography to document their lived experiences.

**Aims:** The current study utilized an arts-based method to explore immigrant Indian women's chronic pain experiences in Canada and aimed to enhance the understanding of those experiences by creating a visual opportunity for them to share their stories.

**Methods:** Twelve immigrant Indian women captured photographs and participated in one-on-one interviews exploring daily experiences of chronic pain.

**Results:** Women's photographs, and description of these photographs, provided a visual entry into their lives and pain experiences. Three themes emerged from our analysis: (1) bodies in pain, (2) traversing spaces including immigration, and (3) pain management methods. Findings revealed that women's representations of pain were shaped by a clash between culturally shaped gender role expectations and changing gender norms due to immigration processes. The use of photovoice visually contextualized and represented pain experiences, proving to be a valuable tool for self-reflection.

**Conclusions:** This research uncovers the multifaceted nature of chronic pain and identifies the influence of immigration, gender, and social relations on the exacerbation of pain in immigrant Indian women.

## RÉSUMÉ

**Contexte** : Au cours des deux dernières décennies, la prévalence de la douleur chronique a considérablement augmenté au niveau mondial, alors qu'environ 20 % de la population mondiale vit désormais avec la douleur. Bien que les mesures quantitatives soient utiles pour déterminer la prévalence et la sévérité de la douleur, les méthodes qualitatives, en particulier celles basées sur les arts, sont désormais considérées comme un moyen précieux de comprendre les expériences vécues de la douleur. La méthode Photovoice, qui utilise les photographies prises par les individus pour documenter leurs expériences vécues, est l'une de ces méthodes.

**Objectifs :** Cette étude a utilisé une méthode basée sur les arts pour explorer les expériences de douleur chronique vécues par des femmes immigrantes d'origine indienne au Canada. Elle visait à améliorer la compréhension de ces expériences en leur donnant l'occasion de partager leurs histoires.

**Méthodes :** Douze femmes immigrantes d'origine indienne ont pris des photos et ont participé à des entrevues individuelles portant sur leur expérience quotidienne de la douleur chronique.

**Résultats :** Les photographies des femmes, ainsi que la description de ces photographies, ont permis d'entrer visuellement dans leur vie et leur expérience de la douleur. Trois thèmes ont émergé de notre analyse : (1) les corps en souffrance, (2) la traversée des espaces, y compris l'immigration, et (3) les méthodes de prise en charge de la douleur. Les résultats ont révélé que les représentations de la douleur chez les femmes étaient façonnées par un conflit entre les attentes culturelles en matière de rôle de genre et l'évolution des normes de genre due aux processus d'immigration. L'utilisation de la méthode Photovoice a permis de contextualiser et de représenter visuellement les expériences de la douleur, ce qui s'est avéré un outil précieux pour l'autoréflexion.

**Conclusions :** Cette recherche met en lumière la nature multifacette de la douleur chronique et révèle l'influence de l'immigration, du genre et des relations sociales sur l'exacerbation de la douleur chez les femmes immigrantes d'origine indienne.

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## Introduction

> *Bearing witness to pain and suffering by capturing the lived experiences that caused these conditions represents one of the noblest goals of research, and arts-based qualitative research offers the greatest potential for this to occur.*[1]

Over the past two decades, the prevalence of chronic pain has significantly increased globally, with approximately 20% of the world's population living with pain.[2,3] The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."[4] Although there are many definitions of chronic pain, it is defined by the International Association for the Study of Pain as pain persisting for more than 3 months.[4] Chronic pain is associated with increased physical, psychological, and emotional suffering.[5,6] In Canada, chronic pain is a growing health concern because one in ten individuals between the ages of 12 and 44 have chronic pain, with the number of those affected increasing with age.[7]

### The lived experience of chronic pain

Chronic pain is often studied with quantitative methods that assess pain prevalence and severity through self-administered questionnaires, such as numeric rating scales, visual analog scales, and the Short Form McGill Pain Questionnaire.[8] Although these measures are helpful in quantifying the types and intensity of pain,[9] they do not fully tap into the contextualized, subjective experience of pain: the cultural, social, and familial aspects.[10] Quantitative questionnaires may also not be as immediately understandable to immigrant populations as well as those living elsewhere than North America and Europe due to culturally specific styles of describing and reporting pain.[11,12]

Qualitative research, on the other hand, can deepen the exploration of the subjective dimensions of pain by placing it in the context of individuals' everyday lives. Qualitative methodologies are increasingly recognized for their value in pain research because they tap into differences among individuals' experiences, gendered influences, and the multidimensional and subjective nature of pain.[10,13] Exploring these differences and their contexts is important for identifying what exacerbates the pain as well as individual challenges and barriers to pain management. Although quantitative studies have brought these differences to light,[14–17] there is need for qualitative research exploring the lived experiences of women's chronic pain to gain a deeper understanding of it in the context of their lives.

### Approaching the lived experience with photovoice

Research exploring lived experiences has its roots in the qualitative methodology of interpretive phenomenology. This methodology focuses on the individual's experience and context in which it occurs, therefore acknowledging the expertise of the individual in their cultural lifeworld as well as the influence of the social context.[18,19] An interpretive phenomenological approach to examine the lived experiences of chronic low back pain among older adults in the United States revealed that chronic pain is physically, spatially, relationally, and temporally lived and felt.[20]

Photovoice is an elicitation method and an arts-based methodological approach utilizing visual imagery to document individuals' experiences, and, in doing so, it enhances the understanding of these experiences through sharing of stories behind those visual representations.[21] Since its inception in the 1990s, photovoice has been used to enhance the voices of marginalized and often underrepresented individuals.[22] During the photovoice process, participants take pictures of what is most meaningful to them in relation to the phenomenon under study. Their pictures then become a platform for discussion of the experience and, in doing so, often enables critical reflections on the experiences with the ultimate goal of promoting action and change.[23,24] The photographs, then, represent only the "tip of the iceberg"[1]; they uncover and provide the occasion to voice often hidden or overlooked experiences moving the individual toward change. For a phenomenon with so many indescribable qualities like pain, photovoice can be a useful tool for gaining access to an individual's often muted responses. It can also elucidate the cultural context in which experiences take shape.[25–27] Photovoice has been used with a wide range of underrepresented populations to examine social, political, and health issues, particularly among women. For example, photovoice has been used to explore rural Chinese women's experiences of reproductive health, as well as the social and cultural experiences of women who have emigrated to various parts of the globe.[21,28] This has led to an enhanced understanding of these women's main concerns and needs locally and in diasporic contexts and in a visual medium that health care professionals and policymakers can easily comprehend.[21] Thus, this method provides recognition of the significance of women's subjective experiences.[29]

Photovoice has been used in previous research to elicit phenomenological data and to capture lived experiences of phenomena through visual representation.[18,30,31] The photovoice method can promote the authenticity of phenomenological inquiry by creating opportunity for those in the study to capture what is most meaningful to them,

rather than being guided solely in an interview setting. Van Manen[32] also highlighted the importance of other forms of data collection outside the interview in phenomenological work; for example, through literary and artistic methods. These other means of tapping into lived experiences can provide an understanding of aspects within human experience that words cannot always express.[18] Although photovoice has a strong social justice and emancipatory perspective because it finds its roots in the critical paradigm of qualitative work, it complements phenomenological inquiry well with its emphasis on individual experiences, as well as the influence of social and contextual factors. This can deepen our understanding and contextualizing of individuals' lifeworlds to better understand their experiences, as well as identifying how they would like to see their condition improved. The "combined use of interpretive phenomenological methodology and the photovoice method [can therefore] employ an innovative approach to data collection."[18]

## Photovoice methods to explore chronic pain

Pain is often resistant to language and at times best described outside the constraints of words; for example, through silence, moans, or cries.[33] Different cultures have different meanings of pain that can also blur both the interviewer's and participant's meanings of pain.[34–36] Pain reports are influenced by context and culture.[11,12] As Zborowski[12] described in his landmark study exploring pain experiences in Jewish, Italian, and Old American hospital patients, the expression and reporting of pain are learned experiences through cultural systems, particularly early childhood socialization by family and friends. Young children observe and internalize how those around them behave and respond to pain and begin to imitate such patterns. Social learning and comparison therefore shape an individual's attitudes toward pain. This, in turn, influences the attention a person pays to pain stimuli, as well as their pain response.[11] Thus, though qualitative interviews are a key method to explore lived experiences of chronic pain,[37,38] nonverbal methods may be helpful in capturing a more situated, culturally competent understanding of the pain experience, enabling one to go beneath the "verbal layer of communication, externalize difficulties and address the psychosocial impact of chronic physical illnesses"[39] as well as its meaning and particularities for the individual in pain. As a visual arts-based methodology, photovoice, in particular, has emerged as a useful approach for exploring multidimensional lived experiences and to further elicit and represent phenomenological data.[18]

The use of photovoice specifically to explore chronic pain experiences is a relatively newer area of research. However, studies using this method highlight how it reveals the physical, social, and emotional aspects of pain, making it invaluable for a deeper understanding of chronic pain.[40,41] For example, photovoice enabled black and Caucasian men and women living with chronic pain to reflect on the physical, social, and emotional aspects of their pain experiences as well as to bring these experiences to life. In that study, participants were asked to (1) take photographs of their life with pain, (2) take photographs of what they would like their lives to be like without pain, and (3) share their experiences in an exit interview. While choosing which photos to display, participants reflected on their needs and coping mechanisms as well as how to communicate them.[40] Another study using photovoice asked participants to take photographs of the challenges and solutions of living with rheumatoid arthritis as well as to participate in an interview and group discussion sharing their photographs. The findings revealed that a reduced sense of agency and difficulty coping with visible and invisible aspects of illness were key challenges of living with chronic pain.[42] Thus, the use of photovoice was both informative and therapeutic for those in the study and valuable for health care providers in understanding the challenges of living with chronic pain.[41]

Photographs encapsulating chronic pain experiences, as well as reflections on these images, can therefore provide nuanced understandings of pain that might otherwise remain unseen or unspoken. In general, photovoice may work particularly well to understand the pain experience in people from immigrant communities, who often have greater difficulty in communicating pain experiences due to language and cultural differences in expression and pain beliefs.[34,43] In addition, patients' different understandings of what pain is and how badly it affects them is a known issue in the clinic, creating a barrier to adequate pain assessment and treatment.[44] Photovoice used as part of a clinical evaluation of pain might more deeply inform health care providers' understandings of how pain happens for an individual as well as their preferred pain management practices, helping providers to also include more traditional remedies.[44]

## Indian women and chronic pain

Epidemiological studies conducted across various geographic locations have found that women report pain more frequently than men.[45] Multiple studies have shown that musculoskeletal pain, including joint pain caused by arthritis, migraine headaches, and pain-related disabilities, affects women significantly more than men.[46] Chronic pain, particularly, is more frequent

in women, and women report more intense pain at multiple pain sites.[47] In fact, research has shown that women are more likely than men to report recurrent and widespread pain in *most* body regions.[48] Based on these findings, many believe that the "greater burden of pain may lie with women" compared to men.[49]

The Indian community is the fastest growing immigrant group in Canada and many other parts of the world.[50,51] Although it is unknown whether chronic pain is greater among immigrant Indian women than Indian men in Canada, research conducted in India revealed that chronic pain is more prevalent and severe among Indian women than among Indian men of all age groups.[52] The most common pain experienced by Indian women is musculoskeletal pain, specifically in the knees, joints, and legs. Studies conducted with Indian women who have emigrated to other countries, such as Malaysia and the United Kingdom, have also found a similar pattern of greater chronic pain prevalence and severity compared to Indian men.[15,16] In fact, Indian women reported chronic pain with greater severity than women of other ethnic, cultural, and immigrant backgrounds,[14] suggesting that especially as this population steadily increases, it is an important group to study.

### Objectives of current study

This research was part of a larger study that employed both qualitative interviews and photovoice methods. We initially explored the lived experience of chronic pain in Indian immigrant women using conventional qualitative interviews and learned that experiences of pain were shaped by gender roles and expectations enforced through culture. Immigrating to Canada exacerbated pain because women had to balance traditional household responsibilities with employment outside the home.[53] We then used photovoice to help reveal important contexts to women's verbal accounts of chronic pain that might not have been conveyed through language. For example, we hoped that photovoice might help situate the pain within specific cultural dimensions. It might also help participants for whom English was not their first language to depict their pain; in using photovoice, participants would control the images they showed, which would provide a window into their world. Nondiscursive language adds to phenomenological inquiry by providing another lens to the first-person perspective of the phenomenon.[18] Therefore, given the growing number of Indian immigrants with chronic pain, the cultural nuances of pain, and the value of photovoice as a tool to examine women's health experiences, especially in relation to pain,[40,41] we explored the chronic pain experiences of Indian immigrant women in Canada using photovoice. By doing so, we hoped to better understand the real toll of pain on this population as well as provide a deeper understanding of their health needs to improve research approaches, programs, and practice.[37,54] Only findings from the photovoice methods are presented here.

## Methods

### Participants and recruitment

This study expands on previous work exploring the lived experiences of immigrant Indian women's chronic, noncancer pain.[53] All aspects of the study received University of Toronto Ethics approval (Approval No. 35563), and participants gave explicit permission for their photographs to be used in any publication. Women were recruited from the Greater Toronto Area through community organizations that were tailored specifically to culturally diverse women (i.e., welcome centers, immigrant service organizations). The lead researcher (N.M.) contacted organization directors to determine suitability of the study for women they served. Once identified, the organizations posted recruitment flyers, as well as personally informed women who met the study's inclusion criteria. If these women showed interest and gave permission, the lead researcher then contacted them with further questions and details about the study. Participants were provided with digital cameras and interviewed about their printed photos in a place of their choosing: at one of the community agencies or at home. Recruitment was nonprobabilistic, purposeful sampling, including snowball sampling methods (via women who participated in the study).

Inclusion criteria were as follows: (1) chronic musculoskeletal pain for longer 3 three months; (2) 30 to 60 years of age; (3) first-generation immigrant from India to Canada; (4) immigration within the past 10 years; (5) clear communication in English, Hindi, or Urdu; (6) self-identifies as a woman; and (7) able to participate in taking photographs (cannot be blind or partially sighted).

We selected women with musculoskeletal pain because it is the most common type of pain experienced by Indian women, with age increasing prevalence.[55] Studies also show that Indian women have a higher percentage of musculoskeletal pain when compared to Indian men, as well as when compared to women of other cultural groups.[14,15] The age range for participants was selected because research shows that for Indian women, the prevalence of musculoskeletal pain increases during these years.[16,52] The inclusion criterion of having immigrated to Canada

within the last 10 years was to capture the recent influence of Indian culture on these women's experiences of chronic pain; however, we did include one participant who was eager to participate despite having lived in Canada for 13 years. Also, Statistics Canada[56] shows a significant increase in immigration of individuals from India to Canada within the past 10 years as compared to individuals migrating from other countries (i.e., Pakistan, China). Lastly, participants who could communicate in English, Hindi, or Urdu were selected because these are languages spoken and understood by the research team.

Exclusion criteria included (1) language other than English, Hindi, or Urdu; (2) no complaints of musculoskeletal pain; and (3) previous/current pain stemming from cancer or treatments for cancer. Research shows that individuals attach different meanings to pain if the pain they experience is associated with cancer.[57] Cancer pain, for example, occurs in the context of a highly threatening disease and is associated with heightened psychological stress, anxiety, fears of death, and stigma.[58] Therefore, the meanings, interpretations, and management of pain may be different for individuals who have, or have had, cancer. Therefore, those who have pain in association with cancer have different and unique experiences compared to those who have non-cancer pain and thus they were excluded from the current study.

After study completion, each participant was given an honorarium of $50. To ensure confidentiality, participants were assigned pseudonyms. Privacy and ethical issues related to the use of cameras were explicitly addressed with participants. They were instructed to avoid taking photos of identifiable markers if they chose to have their photographs released for research publication. They were also given detailed instructions on how to be fully aware of their surroundings, including identifying potential dangers that may exist in their surroundings while using the camera.

## Data collection

Photovoice approaches typically employ an initial camera orientation session, an individual interview, and a focus group discussion of photographs using an interview guide (i.e., SHOWeD or PHOTO).[59] We followed a similar approach utilizing six steps of photovoice data collection: (1) welcome, consent, and camera orientation session; (2) follow-up phone call and check in; (3) collection of cameras and logbooks, initial review, and analysis; (4) individual interviews; (5) individual photo sharing session using the guide PHOTO (described below); and (6) optional photo sharing in group discussion.[18] We chose to include the additional phone call and check-in to offer help and ensure that participants were not having difficulty with the photography task. We also made the group discussion of photographs optional, because our participants told us that they were not comfortable sharing their photos in a larger group.

### Welcome, consent, and camera orientation session

The initial welcome and camera orientation session was carried out by N.M. either at a local community agency or in women's homes. Participants were welcomed to the study and thanked for participating. We explained the study's purpose and methods in detail, sharing that the research was to understand their experiences of chronic pain, as well as the context in which their pain experiences evolved. Participants were also given consent forms to review and sign. Consent was obtained using a three consent form process specifically designed for photovoice,[60] which included obtaining (1) participants' written informed consent, (2) written informed consent from those not in the study whose images were captured in the photographs, and (3) consent to release photographs for research purposes. Participants were also given a detailed photography orientation session about the responsibilities and risks of including others in their photographs.

Fujifilm QuickSnap Waterproof Disposable Cameras were dispensed with instructions. The camera had 27 exposures for participants to take as many photographs as they wished; however, we asked them to take at least 5 to 10 photographs to capture their chronic pain experiences. They were also asked to create a title for each photograph (prior to handing over the cameras for development) and to keep a logbook to record additional information about their insights while taking photographs. A take-home package also included detailed instructions. Participants had 2 weeks to complete the photography.

### Follow-up phone call and check-in

One week after the welcome and camera orientation session, N.M. called participants to check on their progress and answer any questions. Troubleshooting help was offered if needed, but no difficulties were reported. Women were again reminded of the instructions and that they had one more week to complete their photography.

### Collection of cameras and logbooks, initial review, and analysis

One week after the follow-up phone call, N.M. collected cameras and logbooks. An interview time was set up at a place of the participant's choice. In the meantime, we

developed the photographs and transcribed the logbooks with NVivo. Field notes based on the researcher's (N.M.) initial thoughts and interpretations were also typed out.

### Individual interviews

The sessions were conducted in person by N.M. in the participant's home or another location of their choice in a language that was most comfortable (English, Hindi, or Urdu) and audio-recorded in full. The first part of the session was an individual interview in which women were asked about their lived experiences of chronic pain.[53]

### Individual photo sharing

The second part of the session was a discussion of the photographs themselves, with participants choosing three to five of the photographs that best represented their pain experiences. These were discussed especially with respect to how the images related to their chronic pain. As a guide to discussing their images, we asked the following questions[61]:

**P**: Describe your **p**hoto?

**H**: What is **h**appening in your picture?

**O**: Why did you take a picture **o**f this?

**T**: What does this picture **t**ell us about your life?

**O**: How can this picture provide **o**pportunities for us to improve life/chronic pain? What would you like to change, if possible?

These questions were used only as prompts to stimulate discussion; thus, discussions took shape around what each participant identified as most important in their photographs.

### Optional photo sharing in group discussion

At the end of this session, we invited all 12 participants to an optional group discussion in which they would have the opportunity to share their photographs with others in the study. None of the 12 participants accepted the invitation because they said they did not feel comfortable sharing their photographs and experiences of pain with a group.

### Photograph analysis

N.M. is a critical qualitative researcher who has extensive knowledge of photovoice through graduate-level coursework and additional training via workshops on the photovoice methodology. N.M. led the analysis of photographs; however, themes were identified by the entire research team through regular meetings and discussions. The four-part layered approach was used to analyze the photographs: previewing, reviewing, cross-photo comparing, and theorizing.[18,62,63] In the *preview* phase, each photograph was viewed alongside the participant's description of the photo. This provided the intended representation and meaning of the photograph. In the *review* phase, we looked to see whether the participant's descriptions went beyond the photo, itself. To do this, participants' descriptions were combined with the researcher's perspectives. For example, if there was a photograph of a staircase, we would look to see whether descriptions were of the staircase alone or whether they encompassed aspects of the participant's life, such as financial difficulties that might dictate living in a space that required one to climb steep staircases. In the *cross-photo comparison* phase, the entire collection of photographs from all women were examined to discern any emerging visual themes. In particular, van Manen's[19] guidelines for phenomenological reflection and thematic analysis were utilized. Phenomenological reflection is a process that aims to uncover deep meanings by reflecting on lived experience and by analyzing thematic aspects of the experience. Thematic analysis is the "process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work."[19] We conducted this process by using van Manen's selective approach, asking questions such as, What images seem particularly meaningful or revealing about the pain experience? Are there any objects/images that stand out? In what ways is culture represented in the photographs? Lastly, in the *theorizing* phase, photographs were organized further into phenomenological themes, which supported the findings from the interview data.[53] Particularly, van Manen's[19] four thematic guides were reflected on to provide insight on the women's experience of pain: lived space, lived body, lived time, and lived human relation.

The lead researcher (N.M.) shares a similar cultural background and immigration history with women in the study, which proved valuable during interviews because it created comfort for participants and, thereby, space for open dialogue. During data collection and analysis, N.M. used a self-reflection tool (social identity map) to position herself within the research and consider her own experiences in relation to participants.[64] By reflecting on her own identity as an immigrant Indian woman, living through the settlement process, and dealing with challenges that minority women encounter, N. M. identified as an "insider"[65] and was able to have deep discussions with participants about this particular

history as they were describing their photos. The self-reflection tool also allowed N.M. to identify differences between her own experiences and those of the participants (i.e., age, marital status, living with pain), which gave her the opportunity to ask deeper questions and give space to women to describe these experiences in detail. N.M. also met with participants multiple times prior to the photo sharing interview, which helped form a relationship and allowed N.M. to better understand the cultural context shaping women's photographs.

## Results

Twelve women participated in this photovoice study. Most had emigrated to Canada 10 years prior, with an average of 8 years. Their ages ranged from 34 to 60. Participants came from diverse regions of India from the north (Kashmir) to the south (Kerala). They identified with various religious groups, including Christianity, Hinduism, and Islam. When asked to rate their overall health, the majority of women indicated "fair" or "good." All reported chronic noncancer musculoskeletal pain, primarily in the knees, legs, and hands; the average length of their pain was 7 years, with five women reporting pain for more than 10 years. Most said this was the first time they had been asked to reflect on their pain. Participants captured between 4 and 17 photos (Table 1). Those who took more photos often had duplicates, capturing the same subjects from slightly different angles, focus, or zoom.

The photograph analysis revealed three emergent themes: (1) bodies in pain, (2) traversing spaces including immigration, and (3) pain management methods.

### *Bodies in pain*

Body parts were often the subject of the photos, with feet, hands, and knees the most represented. In discussing the photos, participants said these were the sites of the greatest pain further weakened by housework and employment.

### *Pain and work*

Women attributed the pain in their feet, hands, and knees to aspects of work, both inside (dish washing, laundry) and outside (standing on their feet for long periods) the home. They noted that their work at home intensified the pain caused by their outside employment. For example, in describing a photograph of her feet (Figure 1), Veda spoke about the pain she felt after a long day at her job that was further intensified by caring for her two little children once she returned home. Reflecting on the photograph of her feet, she described how they would swell at the end of the day, causing pain in her legs. In general, when discussing painful body parts, participants talked about how they had little help with household chores, which they described as putting more of a toll on their own bodies than on those of other family members, particularly their husbands.

### *Pain impeding movement*

Pain in the feet and knees impeded movement, such as walking, exercising, or simply getting up and sitting back down. Those with chronic knee pain often mentioned that the pain had weakened their bodies to the point that they no longer were able to get out of bed in the

**Figure 1.** "Swollen feet at the end of the day" (Veda).

**Table 1.** Participant demographics.

| Pseudonym | Age | Marital status | Years in Canada | Duration of pain | Location of pain | Number of photographs captured |
|---|---|---|---|---|---|---|
| Diya | 49 | Married | 13 | 4–5 years | Knees, joints | 12 |
| Ayesha | 42 | Married | 10 | 2+ years | Neck, shoulders, arms | 8 |
| Meera | 48 | Married | 10 | 5 months | Shoulder, head | 15 |
| Aditi | 55 | Married | 10 | 4 years | Back, shoulder | 13 |
| Isha | 40 | Married | 2 | 3 years | Lower limbs, head | 14 |
| Shreya | 34 | Married | 3 | 6 years | Back | 7 |
| Veda | 48 | Married | 9 | 7 years | Hands and fingers | 6 |
| Nisha | 60 | Divorced | 10 | 10+ years | Widespread body pain | 12 |
| Naira | 54 | Divorced | 10 | 10 years | Widespread body pain | 4 |
| Darsha | 36 | Married | 1 | 18 years | Legs, shoulders | 17 |
| Maryum | 59 | Married | 10 | 10 years | Right hand | 11 |
| Sophia | 50 | Married | 10 | 10+ years | Neck, shoulders, lower back, hands, knees | 16 |

morning. Nisha captured this in her photograph titled "pain while getting up" (Figure 2), and she described getting up as laborious, difficult, and painful, linking that pain to weakening of knees and joints.

Ayesha described her photograph of weights as a symbol of her chronic pain "weighing [her] down" (Figure 3). She elaborated saying that she did not have the energy and bodily strength that she had prior to the pain. She explained that moving her body in ways she once enjoyed, such as lifting weights, was no longer possible. In describing her pain as "weighing her down," Ayesha was expressing that she still wished to carry out her hobbies and yearned to be able to move with ease. However, the chronic pain in her life made her feel weak, restricting what she could do. Her description is one of both despair and resilience. She stated:

> Sometimes I try lifting five pounds weight but [the pain] flares up . . . like hell. So sometimes I try to do at least three pounds in both hands. . . . That's why I took the picture [to show that] one day I'll able to lift two ten pounds [of weights].

**Figure 2.** "Pain while getting up" (Nisha).

**Figure 3.** "[Pain] weighing me down" (Ayesha).

### *Traversing spaces*

Participants photographed the spaces in which they experienced pain: spaces of employment as well as home. Also described were spaces that once gave women pleasure but did no longer due to their association with pain.

### *Immigration*

Immigration itself is a traversing of space and played a major role in how women experienced pain. Participants spoke about how their lives postimmigration had changed. In India, they had help from maids with household tasks; however, in Canada, no one helped. Not having anyone to help with housework exacerbated this pain. These changes in living space and loss of domestic help intensified their pain. The gendered expectation that housework was women's work entangled immigration and gender norms.

Participants also compared the relative impact on their pain of employment spaces in India and Canada. In Canada, they worked long hours—in some cases, 12-h shifts—washing dishes and standing on their feet, whereas in India they either did not have outside employment or, if they did, it was an office job with fewer hours. Employment outside the home as well as the types of jobs requiring long hours of standing resulting from immigration became sources of pain.

### *Employment spaces*

Work outside the home, in factories or warehouses, and its resulting exhaustion figured in participants' descriptions of their photographs. Part of this exhaustion was due to commute time getting to work. In Canada, their workplace sometimes required hours of travel to reach, and this was seen as exacerbating their pain. Meera, for example, described working very far from her home and identified this as a challenge, especially in times of pain:

> Five years I went to Markham from here and two years I went to Waterloo every single day . . . 185 km . . . because of some personal issues, I [then] chose to work from home.

Taken together, these descriptions portray immigration as well as travel to work that came from immigration as presenting them with pain-filled spaces in which to spend their days.

Even working from home was painful. It required sitting for long periods of time, which was described as aggravating existing pain. Sophia's picture of pain was of

her at-home work desk (Figure 4). In describing the photograph, she explained that there was pain just sitting and typing for long hours.

> I do this [keyboarding for] 12 hours. . . . I am constantly sitting [and] am using my hands . . . the same hands, the same set of muscles. . . . The other option is quit your job but . . . I cannot afford to quit my job. (Sophia).

### *Living spaces*

Their new Canadian homes were also described generally as either triggering or intensifying pain. Home-induced pain included apartment buildings that required walking up and down stairs. For example, Maryum took a photograph of a laundry machine (Figure 5) and discussed how carrying heavy baskets of laundry up and down the stairs aggravated her knee and leg pain.

> The thing with the laundry is that I have to climb steps to get there, I have to put the clothes in the bucket, then climb the stairs then take it out and . . . put it in the dryer. Then from the dryer I have to put it back and climb the steps back down to the apartment. (Maryum)

**Figure 4.** "Sitting: Working and in pain" (Sophia).

**Figure 5.** "Laundry: Responsibility of washing everybody's clothes" (Maryum).

Some women spoke of living downstairs in basement apartments to save financially for their new life in Canada. They pointed out that this cost saving came with the additional challenge of climbing steep stairs to get in and out of their homes, which not only triggered their pain but also added to its chronicity. Isha took a picture of a staircase (Figure 6) and called it "the height of pain," marking the very place she lived as the cause of her pain. She said,

> Whenever I have acute leg pain these stairs are actually [the] worst for me. . . . I can't even climb them up . . . and being South Asian and being very new immigrant and not having a proper place to live at . . . we have to live [in] such kind of conditions and, you know, to face all these challenges . . . in a basement where I have to climb up to reach the road.

Therefore, their new home became associated with and entwined with the causes of their pain. Women mentioned that basements were a new part of their life since coming to Canada, suggesting that their immigration was literally a step downward.

## *Pain management methods*

### *Traditional remedies*

Pain management methods, particularly traditional remedies, were also photographed. Photos of massage oils for painful body parts and cloths to apply pressure for easing pain spoke to the need for pain relief as well as to harkening back to Indian customs as the source of that relief. Darsha photographed herself performing a yoga breathing exercise and titled the image "Buddhist chanting to defeat the pain and bring out a stronger me" (Figure 7). In describing this photo, Darsha spoke about praying and having a deep belief

**Figure 6.** "The height of pain" (Isha).

**Figure 7.** "Buddhist chanting to defeat the pain and bring out a stronger me" (Darsha).

in a higher power, which got her through the toughest pain days.

Traditional remedies were valued over allopathic treatments. Although women went for allopathic care and were prescribed Western medicines to relieve pain, these went unused unless the pain was unbearable; even then, participants preferred remedies based on their cultural traditions. Isha photographed a bottle of turmeric and a glass of milk (Figure 8), titling it "Health benefits of turmeric." Of the image she said, "I generally take a cup of milk at night with turmeric just to have some internal cure for my pain." She learned this technique from her mother before immigration and talked about how she preferred this rather than getting pain relief from medications the doctors prescribed.

### *Household support*

Household support was viewed as a possible remedy for their pain. When discussing photos of household chores, some said they thought household help would remedy their pain. They believed that this kind of support would help them manage their pain by giving them time to relax and rest. They hoped that their children would help with cleaning and laundry, and they would have appreciated their husbands helping with daily chores such as cooking, but this was not the case. Shreya explained this when she said,

> We don't have help in terms of husbands helping us, or everybody sharing the workload. . . . I hope this changes [and women receive support].

They did not want to have a continuous line from their outside work to their housework; they longed to be able to take time for a massage, rubbing oils on affected areas, or meditation and yoga. However, this would require household support that they were not receiving.

### *Rest*

Ayesha's photo of a pillow and a blanket (Figure 9) was titled "Resting and dreaming a pain-free life." She described the photo of how she hardly had time to rest because of her busy day but knew that resting was very much needed to relieve the intensity of her pain. As she looked at her photo she said,

> I am always on the go. I am [a] productive person. . . . I hate myself when wasting half a day not doing anything, but now my body requires it. My body requires to take things one at a time.

Darsha photographed herself sitting on her balcony, looking out at the neighborhood, relaxing with a hot drink (Figure 10). She titled her photo "My hot drink to drown my pain in." She said that the intensity of pain seemed to lessen when she had the chance to rest. Although her current schedule did not permit time to take care of herself, self-care was something she wished to prioritize to manage

**Figure 8.** "Health benefits of turmeric" (Isha).

**Figure 9.** "Resting and dreaming a pain-free life" (Ayesha).

Figure 10. "My hot drink to drown my pain in" (Darsha).

her chronic leg pain. Thus, even photographs of relaxation highlighted the lack of time and support for self-care.

## Discussion

This is the first report globally of the use of photovoice, an arts-based method that utilizes visual imagery, to document immigrant Indian women's experiences of chronic pain. Photovoice supported as well as extended the findings from our qualitative interviews, delineating immigrant Indian women's chronic pain as physically, spatially, and relationally experienced.[53] The pictures and participants' comments on the pictures provided a rich and witty chronicle of their pain experience within their lived lives. The photos revealed three themes: (1) bodies in pain, (2) traversing spaces including immigration, and (3) pain management methods.

### *Bodies in pain*

#### *Traditional gender roles*

In traditional Indian culture, women's bodies are often viewed as vehicles to carry out expected duties and responsibilities[66,67] such as reproduction, motherhood, and wifely duties.[68] Their bodies are vehicles of cultural values and gender norms, used for carrying out household chores and responsibilities that require long hours of physical labor, such as cooking and cleaning for the family.[69] With scant financial resources, in India, they can use other women's bodies such as extended family and paid domestic help to decrease the burden. When this help is lost due to immigration, it is only their own bodies that carry out this tremendous workload. In our study, for example, women took photographs of domestic tasks related to fulfilling their gendered role of taking care of the household—laundry and dishes needing washing. This suggests that their now unshared physical duties placed them in conflict with their bodily health because fulfilling these gender norms inflicted noticeable pain.

#### *The influence of pain on women's relationships*

The photographs and their descriptions emphasized the meaning and importance of the pain experience in relation to their bodies and family.

*Relations with body.* Participants described the relationship they had with their bodies. There was dissonance in their descriptions—both depersonalization and love. For example, painful, swollen hands, knees, and feet were described in a negative and objective way, as if they did not belong to the rest of their bodies. In the photos, hands, feet, and legs were disembodied. However, when women spoke about the importance of resting and managing pain, they described their body in a more compassionate and whole way as a full entity that needed to be cared for and respected.

*Relations with family.* Family relationships intensified pain. Photographs and their descriptions spoke to years spent fulfilling these obligations, linking them intimately with pain. In talking about their photos, participants described their family work as an obligation and a form of obedience, which took the focus away from self-care and their pain. Family members were described as demanding time and not taking on a share of the domestic work; husbands, children, parents, and in-laws were all our participants' responsibility. Participants expressed the concern that their bodies were "weakening" under the strain. Thus, family—their demands and lack of help—was intertwined with participants' pain. Home was a place filled with painful stimuli: stairs, washing machines, unwashed dishes.

### *Traversing spaces*

#### *Immigration and pain*

It was apparent from every photo and description that the greatest space traversed, that from India to Canada, played a role in their pain. Immigration came with less domestic support; women were expected to work long hours as well as complete household work such as laundry and cleaning without help. They also had longer commutes and were employed in jobs with demanding physical labor. The Canadian living space was apartment buildings and, often, basements, both of which came with exacerbation of pain due to the use of stairs. The differences between their Canadian and Indian living spaces suggest a significant change in class status,[70,71] not just the result of a simple traversing of space. This downward social mobility and likely changing class status exacerbated their experiences of chronic pain; the lost availability of domestic help placed them as the sole worker in their homes, with domestic chores commonly symbolizing their pain. Previous research has shown

that these changes in housing and working conditions have a negative impact on chronic pain experiences.[72]

### Gender roles and pain

Intertwined with immigration was the maintenance of some traditional gender roles with the addition of others. This double load exacerbated their pain. Descriptions of the photos highlighted how traditional gender roles caused, increased, and kept participants from remedying their pain. Indian women are primarily responsible for maintaining harmonious relationships, cohesion, and honor within the family.[73] They are taught to place family members' needs above their own, often leading to self-neglect.[68] The Indian culture's prioritization of group over individual goals emphasizes interconnectedness and cohesion among individuals, especially within the household.[73] In the domestic domain, this responsibility falls to women, increasing gendered pressures on Indian women who immigrate.

The new additional role of working outside the home conflicted with traditionally prescribed gender roles: taking care of the home and care for those who dwell within.[74] Therefore, even if a woman worked outside the home, it remained her duty to take care of the family upon return, exacerbating her pain. Although women understood that self-care would be an important part of pain management, scarce social and economic resources as well as a dearth of family support made them unable to prioritize their pain relief.[67] The juxtaposition of family duty and earning a living created a challenging relationship between fulfilling their gender roles and their new economic roles, which, taken together, created and exacerbated their pain.

### Relations with living and working spaces

Both domestic and workspaces were associated with pain. In photos, pain was linked with housework. Home was a place filled with painful stimuli: stairs, washing machines, unwashed dishes. The Canadian home space tended to be contrasted with the Indian home space. The former was photographed and described as full of pain-inducing chores, whereas the latter was described as restful and encouraging ease.

The Canadian work environment was also described as one of unremitting pain. Employers required 8 to 12 hours a day of work requiring long hours of standing. Participants were warehouse, factory, and foodservice workers—jobs they would have never done if they had stayed in India. These spaces were associated not only with physical demands but also with a drop in class status and the taking on of a role contrary to their gender, intertwining immigration, gender, and pain.

The relationship one has with surrounding space can either promote or discourage health.[75] With respect to workspaces, immigrant populations in Canada, and immigrant women in particular, often face precarious working conditions.[70] Due to occupation downgrading and the sex-segregated labor market, they often find themselves in service- or care-oriented work, with low wages, minimum benefits, and long and unstable working hours.[70] With respect to home spaces, due to financial difficulties, immigrants often live in homes that are not well constructed or meant to be lived in[70] and that may pose accessibility issues.[76] In line with this for Indian women in Canada, in particular, the domestic environment is one of the main sites in which health promotion is either fostered or neglected.[77] Thus, living and working spaces had a negative impact on health-promoting behaviors for these women and conspired to relegate them to living with chronic pain.

## Pain management methods

### Traditional methods

In concert with our qualitative interviews in which women described not taking medicine prescribed by their doctors,[53] traditional methods of pain relief were pictured, whereas prescription medicine was not. Traditional methods were linked with time they did not have; rest on satin pillows and turmeric drinks were photographed as the pain relief they had no time to use. These traditional methods intersected negatively with traditional gender roles. Their pain itself kept them from engaging in healing activities like gardening.

Gendered family relationships decreased their ability for self-care. In talking about their photos, participants described their family work as an obligation and a form of obedience, which took the focus away from self-care and their pain. Family members were described as demanding time and not taking on a share of the domestic work; husbands, children, parents, and in-laws were all our participants' responsibility. Participants expressed the concern that their bodies were "weakening" under the strain. Thus, family—their demands and lack of help—was intertwined with participants' pain and their inability to take care of themselves.

### Visual wit

However, even in their pain, participants demonstrated humor and insight about their situation, suggesting that these might be a coping mechanism for their pain. Many of the photos were visually witty, with the image punning on the photo's title. Isha titled her photo representing the exacerbation of pain due to staircases "The height of pain" (Figure 6). Ayesha, in talking about her

inability to lift heavy weights as she used to before her chronic pain condition, titled her photo "[Pain] weighing me down" (Figure 3), and her photo of silk pillows on a chair evoked a fantasy life that would be pain free. Women also talked about how basements were a new part of their life since moving to Canada, linking living in basements as literally "a step downward." This use of puns and visual wit might be considered a source of resilience and pain mitigation because the use of humor has been linked to reductions in anxiety and catastrophizing in people with chronic pain.[78]

### *Did photovoice help them manage their pain?*

The choice of what to photograph as well as the descriptions of the photos clarified the conditions of their pain to participants. Images revealed particular places or objects that triggered or reinforced their pain (i.e., the keyboard at work; the staircase at home). However, this also led to in-depth discussions of lack of social support, pain management techniques, and aspirations for better self-care—signs of hope and resilience. Photovoice therefore enabled women to critically reflect on their own pain experiences, giving them a platform to share how they would like their experiences to be improved and pain reduced: easier jobs, rest, and help with household tasks. Photovoice allowed us to uniquely identify the relational aspect of chronic pain and, through that, how immigration and gender conspired to exacerbate their pain.

Participants said that the photographic process enabled them to visually understand the range of places in which their pain occurred, was triggered, and was alleviated in their day-to-day lives. Until trying to capture their pain on camera, they did not realize how, and to what degree, chronic pain had affected their lives. Through this activity, they identified their lack of time for self-care and, specifically, for pain management as well as their family's lack of prioritization for their care. Thus, in addition to providing an important perspective on their chronic pain, photovoice allowed them a chance to critically reflect on the circumstances causing pain and feelings about those circumstances.

Photovoice also enabled imagining activities and solutions that might promote their health; in describing their photos, women noted aspects of their lives that, if changed, would help them manage their chronic pain. In some cases, this change was identified as internal through prioritizing themselves. Thus, as in previous work, photovoice had the added advantage in that in affording visualization of the problem, it fostered critical self-reflection, empowering the participants to imagine specific life changes that would improve their self-care and make their health a priority.[21,79,80]

Photovoice also showcased participants' resilience; their photos and titles were witty, and in discussing their photographs they expressed hope about managing their pain despite their role as women immigrants with family and work demands. Our participants also identified management techniques aligned with their own personal and cultural practices, further highlighting their resilience; they hoped to manage their pain regardless of new and traditional challenges to prioritizing their health. These findings support those of other qualitative research showing that South Asian immigrant women with chronic pain state their ability to control it and are hopeful that there will be effective treatments congruent with their cultural traditions, practices, and beliefs.[43] New to our study is the demonstrated wit and punning shown by our participants' photographs and titles, showcasing humor and wit as a source of resilience in the face of chronic pain.

## Future directions

The prescribed questions one asks of the pictures might be helpful adjuncts to a clinical pain interview, asking about what the pain means for the person in pain as well as the context of their pain. Photovoice might help create educational tools for doctors, nurses, and other health care providers to enhance communication about pain experiences during patient–provider interactions as well as enable patients to come to a deeper understanding of their pain. All of these aspects of photovoice could strengthen patient–provider communication about chronic pain, which might help to transcend language barriers, cultural meanings, and the inherent ineffable aspects of the pain experience. Future research should explore such benefits of the photovoice method as a tool to communicate chronic pain experiences within the clinical setting.

Future work should also delve deeper into the context of photographs taken (i.e., Who is taking the photographs? Are participants arranging themselves or their settings in a particular way? Are participants comfortable showing their face in the photograph?). For example, in our study, most women took the photographs themselves; however, two participants had another person take photographs of them. We did not ask the reason for this because it was beyond the scope of the study; however, it would be interesting to understand why this was the case—perhaps these women required further support because of their chronic pain or because they were more recent immigrants and had difficulty using the cameras. Age may have also played a role in comfort level using the cameras. Future studies should gauge the contextual nuances of the photography task to further uncover particular aspects of women's lives.

## Limitations

The use of photovoice to explore chronic pain experiences is a relatively new method in public health research and in pain studies.[40,41] Therefore, it is difficult to support the findings from the current study with other scholarship that has also used photovoice to examine chronic pain experiences. However, because this is one of few studies to use the method in pain research with an immigrant population, the findings showed that photovoice is beneficial to explore women's experiences of pain; it enables them to identify triggers and challenges associated with their pain, as well as their own management techniques. Examining pain experiences using semistructured interviews yields answers to questions that are posed by the researcher; however, giving individuals cameras and asking them to critically think about their pain provides a new dimension to the experience. For example, during the photo sharing session, discussions are centered around what those suffering want to discuss, rather than what researchers want to know. Aptly put by Harper,[29] rather than "representing a view from the outside looking in," photovoice provides "a view from the inside looking out." This is beneficial, especially when exploring pain among women of diverse backgrounds, because it enables them to visually show contextual aspects of their stories, which further paints a culturally sensitive picture of their lived experiences. Further, only married women participated in this study. Their experiences of chronic noncancer pain may not be representative of that of unmarried women and of the broader population. Future work should delve deeper into the complexities of marital status itself and its impacts on women's chronic pain experiences.

The photovoice method in this study was modified from its original protocol to take into consideration women's personal preferences and comfort levels. For example, the final component of this study was to be a focus group in which women would come together and share their photographs with each other to engage in further discussion of their pain experiences. However, none of the 12 women agreed to participate in a focus group, because they only felt comfortable sharing their pain stories on an individual basis. Thus, there was no photovoice group discussion.

## Conclusion

With the higher pain prevalence among Indian women than among Indian men, as well as the increased immigration of Indians to Canada, it is important to understand the expression, nuances, and situatedness of chronic pain as well as how Indian women would like to manage their chronic pain experience. The use of an arts-based method, photovoice, to capture and elicit these aspects of pain provided a window through which to better understand Canadian-Indian women's pain experiences. We learned from women that immigration, gender, and social relations intertwined to exacerbate their chronic musculoskeletal pain conditions. Therefore, this study sparks new questions and inquiries into immigrant Indian women's lived experiences of chronic pain. A deeper exploration of pain in the gendered lives of women, their relationships and interactions with family members, their strategies to overcome pain, and lack of supports is needed. There are always more dimensions of the lived experience that need to be uncovered and understood, because understanding the true nature of a phenomenon can "never be completely fulfilled."[81]

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